# Allied health education for disability rights: A case study from the University of Sydney's Faculty of Health Sciences

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Thesis presented in partial fulfilment of the degree of Master of Occupational Therapy

> Discipline of Occupational Therapy Faculty of Health Sciences The University of Sydney Submitted 28 October, 2015

## Allied health education for disability rights HSBH5006 Research Elective Dissertation Statement of Authentication

I, Claire Bowley, hereby declare that this submission is my own work and that it contains no material previously published or written by another person. Nor does it contain any material that has been previously accepted for another degree.

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Signed: \_\_\_\_\_

Date: \_\_\_\_\_

I would like to personally thank my supervisor, Stephanie Short, and Ann-Mason Furmage, for their insight, support and encouragement in the completion of this thesis.

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I would also like to thank the many staff at the University who assisted me in countless ways in the completion of this thesis, including those individuals who participated in the study. **Thesis Abstract** 

**Introduction:** Persons with disabilities are vulnerable for rights violations when accessing healthcare. As allied health professionals play a significant role in the care of persons with disabilities, it is important that allied health professional competencies and education recognise the rights of persons with disabilities. However, a preliminary literature review indicated that the incorporation of disability rights within allied health professional competencies and education has not been researched. The University of Sydney's Faculty of Health Sciences offers health professional education to six allied health disciplines: Occupational Therapy, Rehabilitation Counselling, Speech Pathology, Physiotherapy, Diagnostic Radiography and Exercise Physiology.

**Aim:** This study aimed to investigate the nature and extent to which the competencies and education of these six allied health professions focus on disability rights, and to explore the supports, barriers and recommendations for the future incorporation of human rights within allied health professional education.

**Method:** This study used a mixed-mixed design involving quantitative keyword searches and qualitative content analyses of competency documents, education documents and transcripts of interviews conducted with coordinators of disability rights subjects. The United Nations Convention on the Rights of Persons with Disabilities (2006) was used as a theoretical framework during data analysis.

**Results:** An allied health continuum emerged from the results, suggesting the extent to which the professions focus on disability rights varies. Occupational Therapy, Rehabilitation Counselling and Speech Pathology had the strongest human rights focus. Conversely, disability rights were not recognised by Physiotherapy, Diagnostic Radiography or Exercise Physiology education. Interviews attributed this phenomenon to a biomedical rather than a rights-based approach to disability.

**Conclusion:** There is considerable scope for allied health professions to strengthen human rights-based education through ethical codes, competencies, and accreditation and registration requirements, with the aim of reducing rights violations experienced by persons with disabilities when accessing allied health care.

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# **Journal Article**

Thesis abstract word count = 296 Literature review word count = 4973

# SECTION 1: LITERATURE REVIEW

# Allied health education for disability rights: A case study from the University of Sydney's Faculty of Health Sciences

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# Allied health education for disability rights: A case study from the University of Sydney's Faculty of Health Sciences

## 1. Introduction

#### 1.1. The problem

It has been reported that "virtually every Australian with a disability encounters human rights violations...every day of their lives", and a large majority of these occur in healthcare settings (National People with Disabilities and Carer Council, 2009, p. 4). Despite this, it has been argued that health professional education does not typically recognise the rights of persons with disabilities (e.g., National Council on Disability, 2009; Scullion, 2000; Shakespeare, Lezzoni, & Groce, 2009). Therefore, health professionals may not enter practice equipped to work with persons with disabilities using a rights-based approach.

#### **1.2.** Allied health within the University of Sydney

The University of Sydney's Faculty of Health Sciences provides education to six allied health disciplines: Occupational Therapy, Rehabilitation Counselling, Speech Pathology, Physiotherapy, Diagnostic Radiography and Exercise Physiology (University of Sydney, 2014). Allied health professionals provide care that aims to improve and maintain client function, where many play a significant role in the care of persons with disabilities (Allied Health Professions Australia, n. d.; Australian Government, 2013). The Faculty of Health Sciences has demonstrated a commitment to ensuring their allied health professional graduates are equipped to work with persons with disabilities using a rights-based approach, as the 2011-2015 Strategic Plan is underpinned by the United Nations (UN) Convention on the Rights of Persons with Disabilities (University of Sydney, 2011).

#### 1.3. Multidisciplinary allied healthcare

Allied health professionals are also expected to be competent in areas specific to their profession (e.g., Occupational Therapy Australia, 2010), and able to work as part of multidisciplinary teams (e.g., Australian Medicare Local Alliance, 2013).

Multidisciplinary practice occurs when professionals from a range of disciplines work together to produce the best possible outcomes for their clients (Australian Government, 2012). If allied health professionals are to demonstrate a commitment to working with persons with disabilities using a rights-based approach, it is important that a rights-based approach be included in the competencies and education of all allied health professions. It is therefore considered appropriate that a Master of Occupational Therapy student conduct this study, which will explore the rights-based focus of the University of Sydney's six allied health disciplines.

### 2. Aim of literature review

This literature review provides a background to the human rights and disability rights movements, commencing with the creation of the UN General Assembly in 1948 (UN General Assembly, 1948) and with Disabled Peoples International holding its first World Assembly in 1981 (People with Disability, 2010), respectively. However, it is recognised that preceding historical events contributed to both movements (e.g., the Civil Rights movement).

The rights of persons with disabilities within the academic and grey literature of the six allied health disciplines will then be reviewed, including a review of international and national health professional competencies. The incorporation of human rights within health professional education will then be reviewed.

#### 3. Search strategy

Academic literature was sourced via a comprehensive search of four electronic databases (Table 1). Different combinations of search terms were applied to provide a wide literature source. However, this search strategy may not have uncovered all human rights literature, as a variety of additional terms are used when discussing human rights (e.g., participation, inclusion, accessibility). These terms were not included as it was beyond the scope of this literature review. Abstracts were screened and relevant articles retained. Articles were sourced via the University's online library system, and reference lists were reviewed for additional relevant publications. Studies were limited to those published in English and conducted with humans, and there were no predetermined time limitations.

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Table 1

Academic literature search strategy.

Databases	Medline (via Ovid SP); Educational Resource Information		
	Centre (ERIC; via Ovid SP); Cumulative Index of Nursing		
	and Allied Health (CINAHL; via EBSCO host); Web of		
	Science Core Collections.		
Search terms			
Human rights	human right*; social justice; patient right*; civil right*;		
	human dignity; disability right*; occupational right*.		
Disability	disabilit*; disabled person*; intellectual disabilit*;		
	international classification of functioning, disability and		
	health; disability evaluation; mild disabilit*; severe		
	disabilit*; developmental disabilit*; multiple disabilit*;		
	physical disabilit*; learning disorders.		
Health professional	curricul*; clinical competence; education; education,		
education	nursing; education, medical; education, allied health;		
	education, competency-based; education, health sciences;		
	health professional education; health education; students,		
	health education; schools, health occupations; schools,		
	allied health; students, health occupations; allied health		
	occupations education; allied health education; medical		
	education; course evaluation; program development;		
	curricul* development; integrated curricul*.		
Allied health	Occupational Therapy, Speech-Language Pathology;		
	Physical Therapy Modalities; Physical Therapy;		
	Physiotherapy; Exercise Therapy; Exercise Physiology;		
	Rehabilitation Counselling; Diagnostic Radiography;		
	Radiography.		

Grey literature was sourced via a comprehensive search of organisational websites (Table 2). Documents were retained if they focused on human rights, disability, health professional education and/or the competencies of the six allied health disciplines.

Table 2

Grey literature search strategy.

Organisational	Australian Government; Australian Human Rights	
websites	Commission; Australian Institute of Health and Welfare;	
	Australian Institute of Radiography; Australian	
	Physiotherapy Association; Australian Physiotherapy	
	Council; Centre for Disability Research and Policy;	
	Commonwealth of Australia; Disabled Peoples	
	International; Medical Radiation Practice Board of	
	Australia; National Council on Disability; National People	
	with Disabilities and Carer Council; Occupational Therapy	
	Australia; Occupational Therapy Board of Australia; Office	
	of the High Commissioner for Human Rights; People with	
	Disability; Physicians for Human Rights; Physiotherapy	
	Board of Australia; Rehabilitation Counseling Association	
	of Australasia; Speech Pathology Australia; United	
	Nations; University of Sydney; World Health Organization;	
	the World Confederation for Physical Therapy; WFOT.	

# 4. Theoretical framework

The current study is grounded in the view that human rights are universal rights that all human beings are equally entitled to (UN General Assembly, 1948), such as the right to health (UN General Assembly, 1948, 1966b). The current study understands the human rights for persons with disabilities in accordance to The UN Convention on the Rights of Persons with Disabilities (The Convention) (UN General Assembly, 2006), paying particular attention to the eight general principles (p. 4). Like The Convention, the current study views disability as "an evolving concept...that...results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society" (UN General Assembly, 2006, p. 1), where attitudes of healthcare professionals are considered as one of the largest barriers to accessing healthcare

(Byron & Dieppe, 2000; Carter & Markman, 2001; Tervo, Palmer, & Redinius, 2004).

As this understanding of disability is not clear-cut, the current study considers it important to understand disability from the perspective of persons with disabilities. Tom Shakespeare, a disability advocate and academic, views impairment as a difficulty in physical, mental or social functioning, and disability as the relationship between a person with an impairment and society (Shakespeare, 2013). Like The Convention, this perspective recognises the interaction between a person's impairment and their environment. In support for this conceptualisation, accounts written by persons with disabilities portray that it is more often the attitudes of others that are disabling rather than intrinsic effects of impairments themselves (e.g., Keith, 1994; Morris, 1989). However, persons with disabilities may internalise aspects of disability definitions (French, 1993), while many view themselves as having an impairment without adopting disability as an identity at all (Cameron, 2014; Shakespeare et al., 2009).

The current study strives to promote the perspective of persons with disabilities by conducting the study in collaboration with a disability advocate, Ann-Mason Furmage. Ann-Mason provided input throughout the study, particularly during data analysis and discussion phases, and has the following positions:

- Deputy Chair, Independent Living Centre NSW;
- Co-Chair, Sydney Local Health District Disability Action Plan Implementation Committee;
- Member Royal Prince Alfred Hospital Consumer Advisory Committee;
- Member Royal Prince Alfred Disability Action Plan Working Group;
- Member of the Occupational Therapy External Advisory Committee for the University of Sydney; and,
- Former President of the Physical Disability Council NSW, 2004-2012.

### 5. Human rights

#### 5.1. The human rights movement

The Universal Declaration of Human Rights (Universal Declaration) acts as a legal and moral foundation for international human rights legislation, recognising the

"equal and inalienable rights" of all human beings (UN General Assembly, 1948, p. 1). The Universal Declaration was developed in response to the atrocities of World War II (United Nations, n. d.-a), where physician involvement highlighted the risk for abuse of power by health professionals (Reis & Wald, 2009). The Universal Declaration (UN General Assembly, 1948), together with the International Covenant on Civil and Political Rights (UN General Assembly, 1966a) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) (UN General Assembly, 1966b), form the International Bill of Human Rights (Office of the High Commissioner for Human Rights, n. d.). The International Bill of Human Rights has been translated into legislation that aims to promote and protect the rights of all human beings (United Nations, n. d.-b). By becoming a party to and ratifying international human rights legislation, nations assume obligations to promote and protect human rights through the development of compatible domestic legislation (Office of the High Commissioner for Human Rights, 1996-2015).

#### 5.2. The right to health

The right health was first acknowledged in the 1946 Constitution of the World Health Organization (WHO), which defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease" (WHO, 1946, p. 1). The Universal Declaration proceeded to discuss health as part of "the right to an adequate standard of living" (UN General Assembly, 1948, p. 7), again recognised in the ICESCR (UN General Assembly, 1966b). As the Australian Government ratified the ICESCR in 1980 (Australian Government, 2009), the Australian Government has a legal responsibility to ensure all Australian citizens are able to experience a fulfilment of the right to health. Australia has demonstrated its commitment to the right to health though the Australian Charter of Healthcare Rights (Australian Commission on Safety and Quality in Health Care, 2008). This document describes the rights of Australian healthcare patients, including the right to accessible healthcare, respect and dignity, and participation and inclusion in treatment decisions (Australian Commission on Safety and Quality in Health Care, 2008).

#### 5.3. Upholding human rights

While the ultimate responsibility to ensure human rights are upheld lies with governments on behalf of their citizens, professionals who work with people at risk for rights violations have a responsibility to promote and protect the rights of their clients (Hunt, 2008; Mann, 1996; McIvor Joss, 1996; Office of the United Nations High Commissioner for Human Rights & WHO, 2013). Despite this, it is claimed that most health professionals have not heard of the right to health, and if they have, they are typically unsure of what it means conceptually and operationally (Hunt, 2008). As allied health professionals often work with persons with disabilities (Allied Health Professions Australia, n. d.; Australian Government, 2013), it is important that their education equips them to work with persons with disabilities using a rights-based approach.

#### 6. Rights of persons with disabilities

#### 6.1. The disability rights movement

Disabled Peoples International held its first World Assembly during the context of the 1981 International Year of Disabled Persons (People with Disability, 2010; UN General Assembly, 1980), emphasizing that the rehabilitation of persons with disabilities should employ a rights-based approach to ensure participation and equal opportunity (UN General Assembly, 1980). Consequently, disability started to be understood using a holistic framework rather than as a diagnosis to be treated by medical professionals (Short, 1981). This contributed to a shift away from the biomedical model towards a rights-based approach.

#### 6.2. Disability rights legislation

Australian federal legislation, primarily the Disability Services Act 1986 and the Disability Discrimination Act 1992, go part of the way in recognising the rights of persons with disabilities. The Disability Services Act was developed to enable community participation and integration through services promoting independence and employment opportunities (e.g., independent living training, open employment services) (Commonwealth of Australia, 1986). The Disability Discrimination Act

1992 was developed in an attempt to protect persons with disabilities from discrimination, underpinned by the notion that persons with disabilities have the same rights as other community members (Commonwealth of Australia, 1992). However, it has been argued that these legislative efforts are based on inadequate international legislation (Clear, 2000; Clear & Gleeson, 2002).

Disability was not explicitly mentioned as a protected category in the International Bill of Human Rights equality clauses, and until recently the Convention on the Rights of the Child was the only international legislation that referred explicitly to disability (UN General Assembly, 1989). This neglect has contributed to the history of rights violations experienced by persons with disabilities. It has been argued that violations were exacerbated by the development of non-binding disability instruments (Parker, 2006), such as the Declaration on the Rights of Mentally Retarded Persons (UN General Assembly, 1971). While such instruments were well intentioned, they have been criticized for being paternalistic and congruent with a biomedical model (Degener & Quinn, 2002; National Council on Disability, 2002; United Nations, 2004); thus increasing the segregation of persons with disabilities through specialised services and welfare (Kayess, 2004). These critiques led disability activists to petition for binding international legislation that provides a framework for the promotion and protection of the rights of persons with disabilities (e.g., Disabled Peoples International, 2003).

#### 6.3. The UN Convention on the Rights of Persons with Disabilities

The Convention is the first legally binding international instrument that applies human rights principles to persons with disabilities (United Nations, 2007). Adopted by the UN General Assembly in 2006 (UN General Assembly, 2006), and ratified by Australia in 2008 (Australian Human Rights Commission, n. d.), its purpose is to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities" (UN General Assembly, 2006, p. 3). Its development involved the input of persons with disabilities (Lang, 2009), instilling a paradigm shift towards a rights-based approach that delegitimises paternalistic treatment, biomedical models and segregated service

delivery (Kayess & French, 2008; Quinn & Degener, 2002). The Convention is based on eight general principles (Table 3) (UN General Assembly, 2006, p. 4).

## Table 3

The Convention's eight general principles (UN General Assembly, 2006, p. 4).

1	Respect for inherent dignity, individual autonomy, including the freedom to
	make one's own choices, and independence of persons
2	Non-discrimination
3	Full and effective participation and inclusion in society
4	Respect for difference and acceptance of persons with disabilities as part of
	human diversity and humanity
5	Equality of opportunity
6	Accessibility
7	Equality between men and women
8	Respect for the evolving capacities of children with disabilities and respect for
	the right of children with disabilities to preserve their identities

The Convention recognises that persons with disabilities have a right to health free from discrimination (UN General Assembly, 2006, pp. 15-16), imposing an obligation to develop rights-based approaches in the provision of healthcare for persons with disabilities (Palmer & Short, 2010; Weller, 2010). Despite this, recent reports have indicated that a large majority of rights violations for persons with disabilities occur when accessing healthcare (National People with Disabilities and Carer Council, 2009; WHO, 2014). These violations support the notion that health professional students should be educated about the rights of persons with disabilities, recommended in the World Report on Disability (The World Report) (WHO & The World Bank, 2011).

## 6.4. The World Report on Disability

WHO and the World Bank describe the current situation for persons with disabilities in The World Report, based on the best available scientific evidence and in reference to The Convention (WHO & The World Bank, 2011). They describe

human rights issues faced by persons with disabilities when attempting to access healthcare, including unequal treatment by healthcare professionals. In an aim to overcome inequalities faced by persons with disabilities when accessing healthcare, they recommend that universities "ensure professional training courses include adequate information about disability, based on human rights" (WHO & The World Bank, 2011, pp. 269). This recommendation acts as the springboard for the current study.

## 7. Rights of persons with disabilities within allied health

The extent to which disability rights are recognised within the grey and academic literature of the University of Sydney's six allied health professions will now be reviewed. We start with Occupational Therapy.

### 7.1. Occupational Therapy

Occupational Therapy is a client-centred profession concerned with promoting health and wellbeing through occupation (World Federation of Occupational Therapists, 2010), the purposeful and meaningful everyday activities that people need to, want to and are expected to do (World Federation of Occupational Therapists, 2011).

Within international grey literature, the World Federation of Occupational Therapists (WFOT) code of ethics asserts that Occupational Therapists ought to approach clients with respect and to "not discriminate against persons on the basis of...disability" (World Federation of Occupational Therapists, 2005, p. 1). WFOT also published a position statement on human rights, asserting that all humans have the right to participate in occupations that enable them to fulfill their potential and to experience satisfaction (World Federation of Occupational Therapists, 2006). At a national level, Occupational Therapy Australia's (2010) Minimum Competency Standards for New Graduate Occupational Therapists asserts that Occupational Therapists ought to facilitate occupational access and participation, show clients respect, demonstrate an acceptance of diversity and respect for human rights, and to not discriminate against clients on the basis of disability.

With academic literature, it has been further argued that Occupational Therapists should demonstrate a commitment to applying international human rights standards in practice; particularly when considering persons vulnerable to social exclusion (e.g., persons with disabilities) (Galheigo, 2011). Hammell, a rights-focused academic, proposes that Occupational Therapy should focus on the right for all people to participate in occupations that contribute positively to their wellbeing (i.e., their occupational rights) (Hammell, 2008). Hammell and colleagues assert that occupational rights provide a practice framework aligned with WFOTs position statement on human rights (Hammell, 2008, 2015; Hammell & Iwama, 2012), and bring practice in line with the belief that occupational engagement affects wellbeing (e.g., Law, Steinwender, & Leclair, 1998). Hammell has extended this thinking to consider persons with disabilities (Hammell, 2015).

Therefore, grey and academic Occupational Therapy literature clearly demonstrates an international and national commitment to healthcare that promotes the rights of persons with disabilities.

### 7.2. Rehabilitation Counselling

Rehabilitation Counsellors assist persons experiencing disability or disadvantage to live independently, to access community services, and to participate in employment or education (Australian Society of Rehabilitation Counsellors, 2011). The definition of Rehabilitation Counselling in itself implies that Rehabilitation Counsellors are committed to promoting the rights of persons with disabilities. The Rehabilitation Counseling Association of Australasia and the Australian Society of Rehabilitation Counsellors both recognise that Rehabilitation Counsellors ought to respect the rights of persons with disabilities, by facilitating independence and providing accessible and non-discriminatory services (Australian Society of Rehabilitation Counsellors, n.d.; Rehabilitation Counseling Association of Australasia, 2013).

Therefore, there exists a commitment for Rehabilitation Counsellors to use a rights-based approach when working with persons with disabilities within the grey literature. While this literature review did not find academic literature outlining the rights-based focus of Rehabilitation Counselling, the reviewed organisational

documents refer specifically to practice that promotes the rights of persons with disabilities.

### 7.3. Speech Pathology

Speech Pathologists assess and treat people who have communication disabilities and difficulties swallowing (Speech Pathology Australia, 2014). Within the grey literature, Speech Pathology Australia's (2011) Competency-Based Standards for Speech Pathologists stipulate that Speech Pathologists ought to recognise the rights of individuals for communication and swallowing, as these skills affect education, employment, social and community participation. Within the academic literature it is further acknowledged that Speech Pathologists ought to be concerned with human rights, as persons with communication and language impairments are at risk for losing their right to autonomy (Brady Wagner, 2004).

While this grey and academic literature does not refer specifically to persons with disabilities, it does suggest that Speech Pathology is cognisant of some human rights principles in relation to Speech Pathology practice.

#### 7.4. Physiotherapy

Physiotherapists assist individuals and populations to maximise their quality of life by developing, maintaining and restoring functional movement (World Confederation for Physical Therapy, 2011a). Within international grey literature, the World Confederation for Physical Therapy (WCPT) has published practice standards (World Confederation for Physical Therapy, 2011e), ethical principles (World Confederation for Physical Therapy, 2011e), ethical principles (World Confederation for Physical Therapy, 2011b, 2011c). These documents indicate that Physiotherapists ought to provide care that is accessible and respectful of their client's rights, dignity, integrity and self-determination. The WCPT has also endorsed The Convention, encouraging its member organisations to promote The Conventions implementation within practice (World Confederation for Physical Therapy, 2015a, 2015b). At a national level, the Australian Physiotherapy Association recognises that Physiotherapy can promote social inclusion and participation for persons with disabilities through equitable access to services and equipment (Australian

### Physiotherapy Association, 2006, 2010).

Therefore, Physiotherapy appears cognisant of some principles related to the rights of persons with disabilities within international and national grey literature. However, this literature review did not find academic literature outlining the extent to which a rights-based approach is incorporated within Physiotherapy practice.

### 7.5. Diagnostic Radiography

Diagnostic Radiography involves the production of high quality images to diagnose injury or disease, allowing the provision of appropriate treatment (Australian Institute of Radiography, n.d.). The Australian Institute of Radiography stipulates that Radiographers shall ensure their practice is not adversely affected by "religion, sex, race, nationality, party politics, social or economic status or the nature of a patient's condition" (Australian Institute of Radiography, 2007, p. 6), and that Diagnostic Radiographers shall treat clients with respect and dignity and uphold their rights (Australian Institute of Radiography, 2013). Therefore, it appears that Diagnostic Radiography is cognisant of some human rights principles in relation to health professional practice within national grey literature. However, it has been argued that the opportunity for clients to exercise their autonomy when accessing radiological services is not always present (Hofmann & Lysdahl, 2008). One possible explanation for violations of the right to autonomy is that Diagnostic Radiographers may use a biomedical rather than a rights-based approach to disability. This is problematic, as biomedical models have been argued to neglect the person and their context by conceiving disability as a condition that can somehow be treated and cured (Imrie, 1997).

## 7.6. Exercise Physiology

Exercise Physiologists use exercise-based interventions to prevent chronic disease or injury, and to assist in restoring optimal physical function (Exercise and Sports Science Australia, n. d.). Exercise Physiologists work with persons who have disabilities, including those with spinal cord injury, acquired brain injury, Parkinson's disease, multiple sclerosis and cerebral palsy (Exercise and Sports Science Australia, n. d.). Exercise Australia assert that Exercise Physiologists shall

abide by Anti-Discrimination Laws and deliver equitable and accessible healthcare (Exercise and Sports Science Australia, 2014). However, the extent to which Exercise Physiologists are expected to work with persons with disabilities using a rights-based approach is less clear; which is perhaps again representative of a biomedical rather than a rights-based approach to disability.

# 7.7. Comparing the professions

The above review suggests that the extent to which the six allied health professions recognise the rights of persons with disabilities varies (Table 4). Occupational Therapy and Rehabilitation Counselling appear to display the strongest commitment to disability rights, as demonstrated through international and national literature and through the definition of Rehabilitation Counselling itself. These professions are followed by Physiotherapy and Speech Pathology. While Speech Pathology does not refer specifically to disability, both professions recognise human rights within international and national literature. Diagnostic Radiography and Exercise Physiology appear to display the weakest commitment. While these professions recognise human rights in national grey literature, neither refer specifically to disability.

# Table 4.

The extent to which the six allied health professions recognise the rights of persons with disabilities.

Recognition	Discipline	Human rights	Disability
Strong	Occupational Therapy	Х	Х
	Rehabilitation Counselling	Х	Х
Medium	Physiotherapy	Х	Х
	Speech Pathology	Х	
Weak	Diagnostic Radiography	Х	
	Exercise Physiology	Х	

#### 8. Human rights within health professional education

Given that the six allied health professions recognise the importance of human rights to varying degrees, it is essential that Universities provide human rights education. It is of further importance that this education equips students to work with persons with disabilities using a rights-based approach, as persons with disabilities are vulnerable for rights violations when accessing healthcare (National People with Disabilities and Carer Council, 2009; WHO, 2014). Academic literature exploring the incorporation of human rights within health professional education will now be reviewed.

### 8.1. Review of human rights within health professional education

This literature review found five previous studies that have reviewed the incorporation of human rights within medical, nursing and public health curricula, primarily within the United States of America (USA) and the United Kingdom (UK).

Vincent and colleagues (1994) surveyed 156 medical students from 26 medical schools in the UK to investigate awareness of human rights within the curricula. While 57% of these students thought that human rights were important, only 20% indicated that human rights were included in their education. To gain an estimate of the incorporation of human rights in nursing curricula, Chamberlain (2001) surveyed 51 subject coordinators responsible for teaching ethics and law to UK nursing students. Only 10 of the 16 human rights issues listed on the survey were taught by the majority of respondents.

To determine the extent to which human rights was included within USA medical curricula, Sonis and colleagues (1996) surveyed 113 coordinators of compulsory bioethics subjects within USA medical schools. Using a similar survey to Chamberlain (2001), Sonis and colleagues reported that medical schools included approximately seven of the sixteen surveyed human rights issues. To determine the number and content of human rights subjects within the USA and selected countries worldwide, Brenner (1996) reviewed the curricula of 28 USA Schools of Public Health, 15 USA Masters of Public Health programs and 34 international Schools of Public Health for the incorporation of human rights within their curricula. Brenner's review identified eight subjects that incorporated human rights, six from the USA,

and one each from Mexico and Australia. The subject from Australia focused on human rights within the context of health. More recently, Cotter and colleagues (2009) explored the nature, extent and barriers to implementing human rights within the curricula of 108 Schools of Medicine and Public Health in the USA. Only 37% of the surveyed schools offered some level of human rights education during the past academic year, whereby time constraints (82%), lack of qualified instructors (41%) and lack of funding (34%) where perceived as barriers to incorporating human rights into curricula.

### 9. Issues arising from the literature review

The above results suggest that human rights are not always successfully incorporated into medical, nursing and public health curricula within the USA and UK. However, the incorporation of the rights of persons *with disabilities* within *allied health* professional education remains unresearched. This is significant, as persons with disabilities are vulnerable for rights violations when accessing healthcare (National People with Disabilities and Carer Council, 2009; WHO, 2014), and allied health professionals play a significant role in the care of persons with disabilities (Allied Health Professions Australia, n. d.; Australian Government, 2013). Further, the competencies of some allied health professions appear to have a greater focus on the rights of persons with disabilities than others, most notably Occupational Therapy and Rehabilitation Counselling. If allied health professionals are to demonstrate a commitment to working with persons with disabilities using a rights-based approach, it is essential that a rights-based approach be incorporated into the education and competencies of all allied health professions.

#### **10.** The current study

#### **10.1. Research problem**

The provision of allied health professional education about disability rights remains unresearched, and the competencies of some allied health professions appear to have a greater focus on the rights of persons with disabilities than others. As a

result, allied health professionals may not all enter practice equipped to work with persons with disabilities using a rights-based approach.

## 10.2. Research aims

- To investigate the nature and extent to which professional competencies expect allied health professionals to work with persons with disabilities using a rights-based approach.
- 2. To investigate the nature and extent to which allied health professional education focuses on the rights of persons with disabilities.
- 3. To explore the supports, barriers and recommendations for future incorporation of human rights within health professional education.

### **10.3. Research questions**

- 1. What is the nature and extent of the competencies about the rights of persons with disabilities expected by the Australian peak governing bodies of the six allied health disciplines?
- 2. What is the nature and extent of education about the rights of persons with disabilities provided by the University of Sydney's six allied health disciplines?
- 3. What are the perceived supports and barriers when attempting to incorporate human rights into health professional education?
- 4. How might the incorporation of human rights into health professional education be improved?

#### 10.4. Dissemination plan

Results from the current study will be submitted for publication in *Health and Human Rights*, adhering to their Submission Preparation Checklist, Author Guidelines and Editorial Style Guide (Appendices 1-3). This Harvard University-based, open access journal is committed to exploring how a rights-based approach to health can be incorporated into health professional practice. This is therefore a suitable publication option, which has published research cited in this literature review (i.e. Brenner,

1996; Cotter et al., 2009). Results will also be submitted for presentation at a relevant conference (e.g., the 11<sup>th</sup> National Allied Health Conference), and efforts will be made to present findings within the University and relevant disability organisations (e.g., Physical Disability Council of NSW). This dissemination plan aims to ensure that results reach a range of audiences, including human rights professionals, allied health professionals, University staff and students, and organisations/individuals who identify as having a disability.

# 11. Conclusion

This is the first study in the world to investigate the educational commitment of allied health to the rights of persons with disabilities. Results from this study have the potential to direct the future development of competencies and curricula that recognise the rights of persons with disabilities, particularly with respect to the approaching University of Sydney's Faculty of Health Sciences 2016-2020 Strategic Plan. Given that competencies and education shape the behaviour of health professionals, such changes would have the potential to reduce the rights violations experienced by persons with disabilities when accessing allied healthcare.

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## **SECTION 2: JOURNAL ARTICLE**

Education for disability rights: The allied health continuum

#### Allied health professional education for disability rights HSBH5006 Research Elective Dissertation Education for disability rights: The allied health continuum

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Competing interests: Claire Bowley is a student and Stephanie Short is a Professor of the Faculty of Health Sciences, University of Sydney. Ann-Mason Furmage is a Member of the Occupational Therapy External Advisory Committee for the University of Sydney and affiliated with organizations that may have interests in the subject matter of this research (for example, the Physical Disability Council of NSW).

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#### Allied health professional education for disability rights HSBH5006 Research Elective Dissertation **Abstract**

Background: Persons with disabilities are vulnerable for rights violations when accessing health care. However, the commitment of allied health to disability rights has not been researched. The University of Sydney offers six allied health qualifications: Occupational Therapy, Rehabilitation Counseling, Speech Pathology, Physiotherapy, Diagnostic Radiography and Exercise Physiology. This study aimed to investigate the nature and extent to which the competencies and education of these six professions focus on disability rights, and to explore supports, barriers and recommendations for future human rights education.

Methods: Quantitative keyword searches and qualitative content analyses of competency and education documents and transcripts of interviews conducted with coordinators of disability rights subjects.

Results: The allied health continuum that emerged from this study suggests the extent to which the professions focus on disability rights varies. Occupational Therapy, Rehabilitation Counseling and Speech Pathology had the strongest human rights focus. Conversely, disability rights were not recognized by Physiotherapy, Diagnostic Radiography or Exercise Physiology education. Interviewees attributed this to a biomedical rather than a rights-based approach to disability.

Conclusion: There is scope to strengthen rights-based allied health education through competencies and registration requirements, with the aim of reducing rights violations experienced by persons with disabilities when accessing allied health care.

#### Allied health professional education for disability rights HSBH5006 Research Elective Dissertation Introduction

#### Background

The UN Convention on the Rights of Persons with Disabilities (The Convention) asserts that persons with disabilities have the right to "equal enjoyment of all human rights " and to enjoy "the highest attainable standard of health".<sup>1</sup> This imposes an obligation to develop rights-based approaches in the provision of health care for persons with disabilities. As Australia ratified The Convention in 2008, the Australian Government is legally obliged to ensure all Australians with disabilities enjoy their human rights within the context of health care.<sup>2</sup>

From the perspectives of an allied health student, a disability advocate, and an allied health academic, we have conducted this study to hold our institutions to account in implementing their obligations; in this case, the University of Sydney's Faculty of Heath Sciences. The Faculty of Health Sciences provides education to six allied health disciplines: Occupational Therapy, Rehabilitation Counseling, Speech Pathology, Physiotherapy, Diagnostic Radiography and Exercise Physiology.<sup>3</sup> The Faculty of Health Sciences 2011-2015 Strategic Plan is underpinned by the "values embedded in the moral and legal framework of the United Nations Convention on the Rights of Persons with Disabilities (2006)", demonstrating a commitment to allied health care that promotes the rights of persons with disabilities.<sup>4</sup>

However, persons with disabilities have been reported to experience rights violations when accessing health care.<sup>5</sup> Consequently, WHO and The World Bank recommend in The World Report on Disability that universities: "ensure professional training courses include adequate information about disability, based on human rights".<sup>6</sup>

This recommendation is the springboard for this study. As a starting point, we reviewed literature exploring the nature and extent to which human rights are incorporated within allied health professional competencies and education.

#### Health professional competencies

We examine here the competencies of the six allied health professions under investigation. While competencies published by Australian peak governing bodies all recognize human rights, Occupational Therapy and Rehabilitation Counseling appear to display the greatest interest in human rights and the rights of persons with disabilities.<sup>7</sup> This claim is reviewed below, including an exploration of national and international competency documents and academic literature.

The World Federation of Occupational Therapists position statement on human rights asserts that all humans have the right to participate in occupations that enable them to fulfill their potential and experience satisfaction.<sup>8</sup> Occupational Therapists have also demonstrated an interest in the right for all persons to participate in occupations that enhance their wellbeing (that is, their occupational rights), which has been applied to persons with disabilities.<sup>9</sup> Rehabilitation Counseling competency documents assert that Rehabilitation Counselors ought to respect the rights of persons with disabilities, by facilitating independence and by providing accessible, non-discriminatory services.<sup>10</sup>

#### Allied health professional education for disability rights

#### HSBH5006 Research Elective Dissertation

Speech Pathology and Physiotherapy also recognize human rights, however the degree to which this extends to persons with disabilities is less clear.<sup>11</sup> And lastly, the extent to which Diagnostic Radiography and Exercise Physiology recognize the rights of persons with disabilities is least clear.<sup>12</sup>

To our knowledge, no previous research has investigated the rights-based focus of allied health professional competency documents.

#### Health professional education

Several studies conducted in the United Kingdom (UK) and the United States of America (USA) are relevant to this study.

Vincent and colleagues surveyed 156 medical students from 26 medical schools in the UK.<sup>13</sup> While 57% thought human rights issues were important, only 20% indicated that human rights were included in their education. Chamberlain surveyed 51 individuals who taught ethics and law to UK Nursing students.<sup>14</sup> The majority taught only 10 of the 16 surveyed human rights issues.

Sonis and colleagues surveyed 113 coordinators of compulsory bioethics subjects within USA medical schools.<sup>15</sup> Using a similar survey to Chamberlain, Sonis and colleagues found that medical schools only included approximately seven of the sixteen human rights issues. Additionally, Brenner reviewed the curricula of 28 USA Schools of Public Health and 15 USA Masters of Public Health programs and 34 international Schools of Public Health for the inclusion of human rights subjects, identifying only eight subjects that focused on human rights.<sup>16</sup> More recently, Cotter and colleagues surveyed the Deans from 108 USA Schools of Medicine and Public Health.<sup>17</sup> Only 37% of these schools offered human rights education during the past academic year, whereby time constraints (82%), lack of qualified instructors (41%) and lack of funding (34%) were perceived as barriers to teaching human rights.

The above findings suggest that human rights are not always successfully incorporated into medical, nursing and public health curricula. More importantly, the incorporation of disability rights within allied health professional education remains unresearched.

#### The current study

This study intends to rectify gaps identified in this literature review, by exploring whether the competencies and education of the University of Sydney's six allied health professions recognize disability rights.

The aims of the current study are to

- 1) investigate the nature and extent to which professional competencies expect allied health professionals to work with persons with disabilities using a rights-based approach;
- 2) investigate the nature and extent to which allied health professional education focuses on disability rights; and,
- 3) explore the supports, barriers and recommendations for future incorporation of human rights within allied health professional education.

Allied health professional education for disability rights HSBH5006 Research Elective Dissertation **Method** 

#### Data collection

Allied health professional competency and education documents were collected, and interviews with coordinators of subjects that focused on disability rights were conducted. Field notes were recorded before and after data collection.

Methods used to collect competency documents are outlined below.

Allied Health Professions Australia's (AHPA) website was reviewed to identify the Australian peak governing bodies for the six allied health professions, identifying the following.

- Occupational Therapy Australia;
- Speech Pathology Australia;
- Australian Physiotherapy Association; and,
- Exercise and Sports Science Australia.

As Rehabilitation Counseling and Diagnostic Radiography are not represented by AHPA, their peak governing bodies were identified through a Google search; listed below.

- Rehabilitation Counseling Association of Australasia; and,
- Australian Institute of Radiography.

Governing bodies websites were systematically searched for documents outlining the professions codes of ethics. In the case of no codes of ethics, codes of conduct were collected.

Methods used to collect education documents are outlined below.

*Subject summaries* of all subjects taught by the six allied health disciplines in 2014 were reviewed and subjects that referred to disability were identified. Subjects offered in 2014 were analyzed, as only semester 1 of 2015 had been taught at the time this study was conducted.

*Subject outlines* for subjects that referred to disability were obtained, through telephone and/or email contact with the 2014 subject coordinators and/or program directors. Subject outlines are documents that outline the learning aims, objectives and content of subjects.

Methods used to interview coordinators of subjects that focused on disability rights are outlined below.

Individuals who coordinated a 2014 subject that focused on disability rights were invited to participate in 30-minute semi-structured telephone interviews via email. Subjects were considered to have focused on disability rights if their subject outline included the following keywords.

- 1) Disability and human rights; or,
- 2) Disability and at least two keywords from The Conventions eight general principles (Table 1).<sup>18</sup>

If coordinators were not able to participate due to no longer working at the University, 2015 subject outlines were obtained and similarly reviewed. If 2015 subjects focused on disability rights and were taught during semester 1 of 2015, coordinators were invited to participate.

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Interviews were conducted using an interview guide, from a previous pilot study.<sup>19</sup> The interview guide included closed-ended and open-ended questions, divided into five sections.

- 1) Enrolment details;
- 2) Formal curriculum;
- 3) Informal curriculum;
- 4) Supports and barriers; and,
- 5) Comments and suggestions.

Questions aimed to explore the nature and extent to which education focused on disability rights, and the supports, barriers and recommendations for future human rights education. The interviewer recorded responses in writing on the interview guide, which were typed into an electronic interview guide post-interview. Typed interview guides were emailed to participants for member checking.<sup>20</sup>

#### Data analysis

A mixed-methods design using quantitative and qualitative approaches was used, as there are few studies reviewing human rights within health professional competencies and education and therefore no obvious agreement on the best approaches to use.<sup>21</sup> These approaches included a

- 1) quantitative keyword search; and,
- 2) qualitative content analysis.<sup>22</sup>

The quantitative method is outlined below.

Quantitative keyword searches of the competency and education documents were used to investigate the *extent* to which the six professions focus on disability rights.

Twelve keywords were used. These keywords included *disability* and *human rights*, as well as *10 keywords from The Conventions eight general principles* (Table 1).<sup>23</sup> The number of keywords referred to by each document was calculated. Keywords were only included if they referred to the expectations of health professionals when working with their clients and/or to the content taught within subjects.

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Table 1. Ten keywords derived from The Conventions eight general principles<sup>24</sup>

tions eight general principles
Keywords
1. Respect.
2. Dignity.
3. Autonomy.
4. Choice.
5.Independence.
6. Non-discrimination.
7. Participation.
8. Inclusion.
(1. Respect.)
9. Equality.
10.Accessibility.
(9. Equality)
(1. Respect)

The qualitative method is outlined below.

Competency documents, education documents, and interview transcripts were analyzed using a qualitative content analysis to investigate the *nature* of the competencies and education.

Documents and transcripts were read through multiple times to gain a sense of the whole. Content that referred specifically to the expectations of health professionals when working with their clients and/or to the content taught within subjects was analyzed. Using an inductive approach, content was divided into meaning units, condensed, and then abstracted and labeled with a code (Table 2). Codes that referred to human rights were sorted into sub-categories and categories, which were then arranged into an overarching human rights theme. Keywords from The Conventions eight general principles were used as a theoretical framework (Table 1).<sup>25</sup> An audit trail detailing decisions made during data analysis was recorded, and education documents and transcripts were de-identified to protect participant confidentiality.<sup>26</sup> HSBH5006 Research Elective Dissertation

 Table 2. Examples of meaning units, condensed meaning units and codes

Meaning Unit	Condensed Meaning Unit(s)	Code(s)
At all times we endeavor to ensure our	our services are accessible.	Accessibility
services are accessible and there is	there is equity of access to	(services)
equity of access to services for our	services.	Equitable access
clients; such equity being determined by	not compromised by	(services)
objective consideration of need and not	prejudice or favor.	Non-discrimination
compromised by prejudice or favor.		

#### Results

#### Allied health professional competencies

The following competency documents were collected for analysis.

- 1) Occupational Therapy Australia's Code of Ethics;<sup>27</sup>
- 2) Rehabilitation Counseling Association of Australasia's Code of Professional Ethics for Rehabilitation Counselors;<sup>28</sup>
- 3) Speech Pathology Australia's Code of Ethics;<sup>29</sup>
- 4) Australian Physiotherapy Associations' Code of Conduct;<sup>30</sup>
- 5) Australian Institute of Radiography's Code of Ethics;<sup>31</sup> and,
- 6) Exercise and Sports Science Australia's Code of Professional Conduct and Ethical Practice.<sup>32</sup>

Quantitative results are outlined in the below paragraph and Table 3.

Rehabilitation Counseling and Speech Pathology were the only disciplines to refer specifically to disability. Rehabilitation Counseling (10/12) and Speech Pathology (9/12) also included the most keywords; followed by Occupational Therapy (8/12), Physiotherapy (8/12), Diagnostic Radiography (7/12) and Exercise Physiology (6/12). All competency documents referred to human rights, dignity, choice, non-discrimination and accessibility. The majority referred to respect, autonomy and equality. Independence, participation and inclusion were the least referenced keywords.

#### Allied health professional education for disability rights

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Table 3. Results from quantitative keyword searches of competency documents.

KEYWORDS	Occupational	Rehabilitation	Speech	Physiotherapy	Diagnostic	Exercise	TOTAL
	Therapy	Counseling	Pathology		Radiography	Physiology	
Disability		Х	Х				2
Human rights	Х	Х	Х	Х	Х	Х	6
Respect	Х	Х	Х	Х	Х		5
Dignity	Х	Х	Х	Х	Х	Х	6
Autonomy	Х	Х	Х	Х			4
Choice	Х	Х	Х	Х	Х	Х	6
Independence		Х					1
Non-discrimination	Х	Х	Х	Х	Х	Х	6
Participation	Х	Х					2
Inclusion							0
Equality			Х	Х	Х	Х	4
Accessibility	Х	Х	Х	Х	Х	Х	6
TOTAL	8	10	9	8	7	6	

Notes. Total refers to the number of keywords included in the competency documents, within (vertical) and between (horizontal) documents. The white rows indicate the 10 keywords from The Conventions eight general principles.<sup>33</sup>

Allied health professional education for disability rights HSBH5006 Research Elective Dissertation Results from the qualitative content analysis of the competency documents are outlined

below. The 10 keywords from The Conventions eight general principles was used as a framework (Table 1).<sup>34</sup>

1) Respect. Respect is recognized in all competency documents, except Exercise Physiology. The documents that do refer to respect assert that health professionals are committed to practice that respects client's rights (for example, dignity), as well as their personal and contextual factors (for example, their health needs and culture). Speech Pathology Australia's Code of Ethics states that: re

...we respect the rights and dignity of our clients and we respect the context in which they live.

2) Dignity. Dignity is acknowledged within all competency documents, as all health professionals are expected to promote the dignity of their clients by adhering to procedures and legislation that protect privacy and confidentiality.

3) Autonomy. All competency documents assert that health professionals ought to promote their clients right to autonomy, except Diagnostic Radiography and Exercise Physiology. Occupational Therapy's document states that autonomy implies patients are "active participants in any decision regarding their involvement in services", and Rehabilitation Counselors are expected to advocate for their clients during situations where autonomy is reduced (for example, during involuntary admission to hospital).

4) Choice. The right to choice is recognized by all professions, as all health professionals are expected to ensure clients are able to make informed choices (for example, regarding likely benefits and risks of services). Health professionals are also expected to uphold their client's rights to withdraw from treatment, to seek a second opinion and to determine who will be provided with their personal information.

5) Independence. Independence was only acknowledged by Rehabilitation Counseling, where Rehabilitation Counselors are expected to support their clients: "efforts at self-advocacy both on an individual and an organizational level".

6) Non-discrimination. While all documents assert that health professionals shall provide nondiscriminatory services, Rehabilitation Counseling and Speech Pathology are the only professions to refer specifically to persons with disabilities. The Australian Institute of Radiography's Code of Ethics states that Radiographers shall:

...ensure the provision of non- discriminatory services to all people regardless of age, colour, gender, sexual orientation, religious affiliation, political allegiances, type of illness, ethnicity, race, and mental or physical status.

7) Participation. Participation is recognized by Occupational Therapy and Rehabilitation Counseling, where both professions ought to ensure clients are: "afforded the opportunity for full participation in their own treatment team".

8) Inclusion. Inclusion is not recognized by any document.

9) Equality. The right to equality is recognized in all competency documents, except Occupational Therapy and Rehabilitation Counseling. The competency documents that do

Claire Bowley

Allied health professional education for disability rights HSBH5006 Research Elective Dissertation refer to equality assert that health professionals ought to ensure equitable availability of health services and resources.

10) Accessibility. All health professionals are expected to ensure clients are able to access their personal information and services, including physical and attitudinal access. Exercise and Sports Science Australia's Code of Professional Conduct and Ethical Practice states that:

An Exercise and Sports Science Professional must... uphold the Client's right to gain access to the necessary level of healthcare.

#### Allied health professional education

The six allied health disciplines taught 295 subjects in 2014. Of these 295 subjects, 20 subject summaries referred to disability. Subject outlines for these 20 subjects were obtained. Of these 20 subject outlines, 12 focused on disability rights. Results from quantitative keyword searches of these 12 subject outlines are outlined in the below paragraph and Table 4.

The majority of subjects were taught by Rehabilitation Counseling (8/12), followed by Occupational Therapy (2/12) and Speech Pathology (2/12). Physiotherapy, Diagnostic Radiography and Exercise Physiology did not teach any subjects that focused on disability rights. Across all subject outlines, human rights, participation, inclusion and accessibility were the most frequently referenced keywords; followed by choice, independence, non-discrimination, and equality. Respect, dignity and autonomy were the least referenced keywords.

#### Allied health professional education for disability rights

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Table 4. Results from quantitative keyword searches of subject outlines that focused on disability rights.

	DISCIPLINES												
	Occup	Occupational Rehabilitation							Speech				
KEYWORDS						Couns	seling				Path	ology	TOTAL
	SUBJECT CODES												
	OT1*	OT2*	RC1*	RC2*	RC3	RC4	RC5*	RC6	RC7	RC8	SP1	SP2*	n = 12
Disability	Х	Х	Х	Х	Х	X	X	Х	Х	Х	Х	X	12
Human rights	Х	Х	Х					Х				X	5
Respect								Х					1
Dignity													0
Autonomy													0
Choice	Х	Х			Х		Х	Х					5
Independence	Х	Х		Х				Х					4
Non-discrimination								Х	Х	Х			3
Participation			Х		Х		Х	Х	Х		Х	Х	7
Inclusion	Х	Х	Х				Х	Х			Х	Х	7
Equality			Х			Х		Х		Х		Х	5
Accessibility	Х	Х		Х		Х	Х	Х			Х		7
TOTAL	6	6	5	3	3	3	5	10	3	3	4	5	

Notes. Total refers to the number of keywords referred to in the subject outlines, within (vertical) and between subjects (horizontal). The white rows indicate the 10 keywords from The Conventions eight general principles.<sup>35</sup> Subjects are referred to using de-identified subject codes to protect the confidentiality of subject coordinators. \* = Subjects whose coordinators participated in interviews.

Allied health professional education for disability rights HSBH5006 Research Elective Dissertation A qualitative content analysis was used to analyze the nature of the subjects whose

coordinators participated in interviews, which included interview transcripts and corresponding subject outlines.

Coordinators of six of the twelve subjects that focused on disability rights participated in interviews, indicated by an asterix next to their subject code in Table 4. As some subjects were taught in more than one discipline and/or level of study (that is, undergraduate and postgraduate), interviews with four subject coordinators were completed (Table 5). An interview was completed with the coordinator of the 2015 Occupational Therapy subjects, as the 2014 coordinator no longer worked for the University and the 2015 subjects also focused on disability rights.

Table 5. Interview summary table.

	Subject	Enrolment requirements	How human rights were	Subject learning aims
	codes		incorporated within subjects	
Subject 1	OT1	Elective	Integrated theme	To develop students' knowledge, skill and attitudes about
	OT2			people with intellectual disability, with a focus on
				participation and support needs.
Subject 2	RC1	RC1 – Compulsory	Integrated theme	To introduce students to definitions of
	SP2	SP2 – Elective		disability/disadvantage and rehabilitation in community
				settings, with a specific focus on individual and systemic
				factors that explain disability.
Subject 3	RC2	Compulsory	Integrated theme	To teach students the history and philosophy of
				rehabilitation as a human service, with a particularly
				focus on how movements such as eugenics, social
				Darwinism, independent living and the Disability
				Movement have changed and shaped attitudes to
				disability.
Subject 4	RC5	Compulsory	Integrated theme	To teach students key concepts and practices in
				rehabilitation and health assessment applicable to a range
				of settings, with a specific focus on employment.

Notes. Subject codes correspond to the subject codes used in Table 4.

# **Submission Preparation Checklist**

As part of the submission process, authors are required to check their submission's compliance with all of the following items. Submissions may be returned to authors that do not adhere to these guidelines. Please note that all citations must be formatted according to the Author Guidelines prior to submission.

1) The submission has not been previously published, nor is it before another journal for consideration.

2) The submission file is in Microsoft Word.

3) Where appropriate, URLs for the references are provided.

4) The text is single-spaced; uses a 12-point font; employs italics rather than underlining (except with URL addresses); and all illustrations, figures, and tables are placed within the text at the appropriate points, rather than at the end.

5) The text adheres to the stylistic and bibliographic requirements outlined in the<u>Author Guidelines</u>. It is of particular importance that references are formatted as endnotes that follow HHR style.

6) The submission includes author name(s), affiliations, and contact information.

7) Research involving human subjects, human material, or human data, must have been performed in accordance with the <u>Declaration of Helsinki</u> and must have been approved by an appropriate ethics committee. A statement detailing this, including the name of the ethics committee and the reference number where appropriate, must appear in all manuscripts reporting such research.

Please submit all manuscripts to the editors

at <u>HHRSubmissions@hsph.harvard.edu</u>.

# Author Guidelines

Health and Human Rights adopts author guidelines broadly similar to those of other publications that embrace an open access philosophy. Our guidelines have benefited notably from the previous work of our colleagues at Open Medicine and PLoS Medicine. In many instances, the following guidelines reflect language developed at Open Medicine. These general guidelines serve as a supplement to the journal's editorial style guide. Please refer to both documents in preparing your manuscript for submission.

HHR EDITORIAL STYLE GUIDE

# 1. General principles

As online publishing creates opportunities for adding detail, layering information, cross-linking, extracting portions of articles, and adding background material (e.g., research surveys, databases), authors are encouraged to work with our editors to use these features to their advantage.

## Open access

Health and Human Rights Journal (hereafter HHR) does not charge authors article processing fees unless authors can utilize an institutional open access publishing grant. Many institutions and research facilities have funding grants available to support publication in open access journals – some are listed in this <u>OA Directory</u>. If authors cannot access OA grants, article processing fees are waived by HHR. Authors are asked whether they can pay this fee only **after** a paper is accepted for publication, and inability to pay will not impact publication. If authors are able to use open access funds to cover article publishing fees, they will receive an invoice for US\$1800.

# 2. Criteria for authorship

An author is generally considered to be someone who has made substantive intellectual contributions to a study. Authorship credit is based on 1) substantial contributions to conception and design or acquisition of data, or analysis and interpretation of data; 2) the drafting

of the article or critical revision of same for important intellectual content; and 3) final approval of the version to be published. Authors should meet conditions 1, 2, and 3.

When a large, multi-center group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

When submitting a group author manuscript, the corresponding author should clearly indicate both the preferred citation and all individual authors as well as the group name. Other members of the group will be listed in the acknowledgments (see "other contributors" below). The National Library of Medicine indexes the group name and the names of individuals that the group has identified as being directly responsible for the manuscript.

## Additional considerations:

- All persons designated as authors should qualify for authorship, and all those who qualify should be listed.
- Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.
- Authorship should not be attributed solely on the basis of acquisition of funding, collection of data, or general supervision of the research group.
- A "guarantor" should be identified to take responsibility for the integrity of the work as a whole, from inception to published article. The name of this person will be published.
- The order of authorship on the by-line is a joint decision of the coauthors. Authors should be prepared to explain the order in which authors are listed.

# 3. Other contributors

All contributors who do not meet the criteria for authorship should be listed in an acknowledgments section, including those who provide:

• purely technical help or writing assistance

• general support, such as a department chair

• financial and material support, such as grants, equipment, or drugs. Other contributors may be listed under headings such as "clinical investigators" or "participating investigators," and their function or contribution should be described — for example, "served as scientific advisors," or "critically reviewed the study proposal."

# 4. Competing interests

All authors will need to complete Competing Interest statements regarding potential conflict of interests related to author commitments and project support. Authors should read the <u>Competing Interest</u> <u>Policy</u> prior to submitting their manuscripts and provide all relevant information at the time of submission.

# 5. Word count

Please include a word count for the text only (excluding abstract, acknowledgments, figure legends, and references) as well as a separate word count for the abstract. Please see journal guidelines on the website for suggested word length. **Submitted manuscripts must not exceed 7,000 words, inclusive of abstract and references.** Book Reviews must not exceed 1,000 words. Letters to the Editor must not exceed 2,000 words.

# 6. Abstract

All original research articles submitted for peer review must include an abstract. The abstract should reflect the content and findings of the article and emphasize new and important aspects of or observations related to the study. In general, it should include information on the background or context of the study as well as the purpose(s), methods, results, and conclusions of the study. Abstracts must not exceed 200 words.

## 7. Figures and tables

• Please state the number of figures, tables, and illustrations accompanying your submission so that editorial staff and reviewers can verify their receipt.

- Supply figures in a format that can be edited so that we can regularize and edit spelling, the font and size of labels and legends, and the content and presentation of captions.
- Illustrations must be of publishable quality as we do not have a dedicated graphics department.
- Please include your data spreadsheet with figures prepared as charts and graphs.
- If you are submitting a figure as an image file (e.g., PNG or JPG), do not include the caption as part of the figure; instead, provide the captions with the Word file of the main text of your article.

# 8. Title of article

We recommend short, effective titles that contain necessary and relevant information required for accurate electronic retrieval of the work. Please also keep the following in mind:

- The title should be comprehensible to readers outside your field.
- Avoid specialist abbreviations if possible.

# 9. Style

Please refer to the <u>HHR style guide</u> when preparing your document for submission. In preparing manuscript for submission, authors may refer to the *Chicago Manual of Style* for questions that are not answered by HHR editorial guidelines.

# 10. References

HHR reviews manuscripts with references formatted as endnotes. Please follow the references section in the style guide to ensure correct style and formatting. References must be formatted in HHR style prior to document submission. Note that endnotes are for citations only; HHR does not accept contextual footnotes.

# 11. Ethics approval

Research involving human subjects, human material, or human data, must have been performed in accordance with the <u>Declaration of</u> <u>Helsinki</u> and must have been approved by an appropriate ethics committee. A statement detailing this, including the name of the ethics

committee and the reference number where appropriate, must appear in

all manuscripts reporting such research.

## Please submit manuscripts to the editors

at HHRSubmissions@hsph.harvard.edu.

# Health and Human Rights Journal

**Editorial Style Guide** 

Last updated: March 26, 2015

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This document is an extensive guide to journal style for *Health and Human Rights Journal*. It includes specific editorial guidelines for our in-house copyeditors and proofreaders, and will also be useful to authors as they prepare manuscripts for submission. These guidelines are based on the journal's 1994–2006 editorial guidelines but address many new style questions and recommended revisions that were discussed during the online and print development of volume 10, the first issue published under the editorship of Dr. Paul Farmer. The aim for this guide is clarity and consistency.

This guide is open to further correction and emendation. Please address any suggestions to the journal's editorial office at: hhrjournal@hsph.harvard.edu.

#### 2015

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Health and Human Rights Journal François-Xavier Bagnoud Center for Health and Human Rights Harvard T.H. Chan School of Public Health FXB Building, 7<sup>th</sup> Floor 651 Huntington Ave. Boston, MA 02115

#### Health and Human Rights Journal

#### **Editorial Style Guide**

This document provides extensive guidelines on style and formatting that have been developed to address most issues related to the editorial phase of journal layout as they specifically relate to *Health and Human Rights: An International Journal*. While the development of this style guide was structured conceptually on the latest edition of *The Chicago Manual of Style* (CMS) as a reference standard, *HHR* style differs from CMS on many details. For questions not answered here, users should refer to the CMS.

#### I. GENERAL SPELLING AND USAGE GUIDELINES FOR TEXT

#### A

**abbreviations:** In general, do not use abbreviations, but do for names of states in endnotes and for academic degrees (but do not use periods or spaces) — e.g., BA, MA, PhD, JD; US, UN, CT, MA. Do not abbreviate journal names in references; do not use periods for abbreviation of "editors" (eds) or "editor" (ed); *do* add periods after initials in bibliography (see citation format) — e.g., A. B. Smith. **acknowledgments:** Do not spell with an *e*.

**acronyms:** 1) If using an acronym, always spell out at first use and put acronym in parentheses; use acronyms, however, only if they are going to be referred to (as stand-alone item) more than once in subsequent text. If clarity invites using the full name again later on in the article, it is fine to use the full name, but don't define the acronym again. 2) Depending on the context and the item in question, it is sometimes preferable not to use an acronym at all, even if one exists for the organization or concept in question.

ad hoc: Do not italicize.

advisor

age: Hyphenate, as in four-year-old girl; five- to eight-year-old children.

Alma-Ata Declaration: When subsequently referencing, use "the declaration." If necessary, use full name (with capitalizations) for clarity.

Amazon People's Resource Initiative (APRI)

American: "US" as adjective is preferable.

**American spelling:** Do not use British — exception is in direct quotes and in citations of book and article titles. (Common examples: "toward," not "towards," "labor," not "labour," "organization," not "organization," "while," not "whilst," etc.).

*amicus curiae* brief: This should be italicized.

#### antenatal

**anti:** Close up in some cases — e.g., antibiotic, antibody; but hyphenate when it helps reader — e.g., anti-discrimination, anti-tuberculosis, anti-abortion.

antiretroviral (ARV) treatment

Article: Capitalize and spell out — e.g., Article 12.2a (for UN covenants and declarations); do not abbreviate in text or endnotes.

**author addresses:** For articles with more than one author, write: "Please address correspondence to the authors c/o [lead author, address]."

#### B

**bear:** Use "borne" for past tense.

Beijing Conference: Fourth World Conference on Women (FWCW),

Platform for Action of the Fourth World Conference on Women, September 1995, UN Doc. No. A/CONF.177/20 (October 17, 1995).

#### biannual binational biomedical bioterrorism

**black:** For race, use African-American if context applies to US nationals; where "African-American" is not appropriate to context, author may prefer to use "black" or culturally acceptable terms. Do not capitalize; "white" is not capitalized.

**block quotes:** The punctuation between the text and the block quote will depend on narrative flow; in most cases a colon may be used but where the block quote reads as a natural continuation of the sentence in the preceding text there need not be any punctuation between the text and the start of the block quote. If a quote is more than three lines long, set off and indent.

#### blood borne

**bulleted items:** Set flush left and generally do not capitalize first letter of each item. For bulleted lists that may include long text, complete sentences, or occasionally several sentences: 1) if each item on the list completes a sentence that precedes the first bullet, do not capitalize first letter of first word, and punctuate with semicolon between bulleted points; add "and" before the last item, and end bulleted section with final period; 2) if any of the bullet points contains a full sentence, treat each of the bullet points as sentences: capitalize first letter of first word and end each of the bullet points with a period. Where a variant of these guidelines seems to make more sense in an individual situation, consistency should be the final rule. In general, pay particular attention to parallel structure throughout bulleted lists: all items need to be similar in structure — e.g., if one starts with a verb or a noun, all others must conform.

#### С

#### **Caesarean section**

**Cairo Conference:** International Conference on Population and Development (ICPD) Programme of Action of the International Conference on Population and Development, Report of the International Conference on Population and Development, September 5–13, 1994, UN Doc. No. A/CONF.171/13 (October 18, 1994). [**ICPD+5**; Do not use "Cairo+5."]

**capitalization:** 1) For article titles, main headings, and subheadings, capitalize only the first word and proper nouns. If there is a colon in the subheading, capitalize the first word after the colon. 2) Within the text, after a colon, follow capitalization guide in CMS 15, 6.64 — usually lower-case. If a colon is followed by two or more questions, the first word of each question should be capitalized. 3) For endnotes, follow *sentence style* — that is, use capital letter for first word only (except for proper nouns) — for titles of articles, chapters, reports, and books. Follow *title case* — that is, capitalize all major words — for titles of journals and newspapers. 4) In titles in endnotes, capitalize first word after colon or exclamation point if a subtitle is used. Generally, standardize French/Spanish titles that contain periods to conform with HHR style by replacing periods with colons. If period must be kept, capitalize first word that follows it. **capacity-building** 

#### capacity-buildin

CARE USA cell phone

centerpiece

Centers for Disease Control and Prevention (CDC)

#### **Central Europe**

**cf:** Do not italicize; capitalize at beginning of sentence. Means "see by way of comparison." Do not use if "see" alone, or "see also" is meant. In general, do not use, or limit use to notes only.

chair or chairperson: Do not use "chairman."

charter: Capitalize when referring to UN, etc. - e.g., UN Charter.

#### children's

**citation numbers:** Citation numbers must always be at the end of sentences. Each sentence should have only one citation number associated with it. Citation numbers are always sequential.

co-: Hyphenate all words that begin with "co-" — e.g., "co-author."

#### **Cold War-era war plans**

**colon:** A colon may be used to introduce statement, extract, or speech in dialogue, but do not use to introduce list that follows an introductory statement — e.g., "Care must be taken to 1) use series commas and 2) use colons properly. Furthermore, 1) note what follows numbers in a series, 2) decide how many elements will follow the statement, and 3) add colons and commas as needed." (exception: see "capitalization").

**colons with quotation marks:** colons should be placed after the closing quotation marks (see CMS 6.9) **coloureds:** This is the correct spelling for the South African racial group (term also used in other parts of Southern Africa).

**commas, special consideration:** 1) Do not add comma or any other punctuation mark after title of a publication if the title ends in a question mark — e.g., D. Kennedy, "The international human rights movement: Part of the problem?" *Harvard Human Rights Journal* 15 (2002), p. 101. 2) In a series, use commas before final item — e.g., HIV/AIDS, tuberculosis, and malaria.

**commercial sex workers:** Delete 'commercial'. Use sex workers, sex work, or sale of sexual services. **commission:** Use lower case when general reference; capitalize when specific.

**communism:** Use lower case generally but capitalize for specific reference — same with "democracy": Communist Party/Democratic Party.

#### community-based organizations (CBOs)

**community health worker** (CHW): Always spell out on first use; acceptable alternative to "village health worker."

conventions and covenants: Use lower case when referred to generally.

counseling: Use one *l*.

**Country Coordinating Mechanisms** (CCMs)

covenants: Always capitalize when referring to ICESCR and ICCPR.

crackdown

cross-section

**currencies:** Do not use spaces — e.g., US\$1, FF1 (French francs), \$4 million. **cut-off** 

#### D

**data:** "data" is the plural form of "datum," so the correct usage is "data are/were" rather than "data is/was"

**dates:** 1) Use American style, with comma between day and year — e.g., June 16, 2005. Do not use comma between only month and year — e.g., September 2005; comma should follow year in introductory phrases — e.g., "In January 1999, the UN . . . . 2) Within endnotes, if no date is available, indicate as "n.d." for "no date." 3) Within endnotes, include a date for cross-references only when referring to a previous publication by an author who has more than one publication cited in one note — that is, to distinguish one publication from another by the same author within one note — e.g., Farmer (2005, see note 4) *if and only if* Farmer has more than one publication in note 4. Otherwise, do not use date — e.g., Farmer (see note 6).

**decision making:** Do not hyphenate as an unmodified noun ("The team responsible for decision making") but do hyphenate if it is used as one term modified by an adjective ("fast decision-making"), when it is used as an adjective ("decision-making body"), or when describing a person's role ("decision-maker"). Note that this differs from journal style on "policymaking" due to considerations of best clarity in most cases)

defining terms: Put word in quotation marks on first use.

**Democratic Republic of the Congo (DRC)**: note the correct official name includes the word "the". **developed** (e.g., countries): Do not use; substitute "industrialized," "resource-rich," and "affluent." The use of "rich" v. "poor" is acceptable.

developing (e.g., countries): Usage is OK.

de facto and de jure: Do not italicize as this is common usage.

diarrheal diseases Directly Observed Treatment (DOT) Directly Observed Treatment, Short-course (DOTS) Down syndrome drug-resistant TB drug-susceptible duty-bearers

#### E

#### Eastern Europe

**e.g**. (meaning, "for example"): Do not abbreviate; spell out and follow with comma, even within parenthetical usage — for example: (for example, when referring to the "governing bodies" of WHO, use lower-case letters).

**ellipsis:** Use "CMS sets" — three dots with a space on either side of the three; add a fourth dot if the preceding phrase is the end of a full sentence. When four periods are used, the initial period should be a "true" period and follow immediately after the last letter of the final word (other punctuation here may be used, e.g. a comma or question mark). The standard ellipsis character (...) is easiest for layout search and replace. In the Word file for four periods: add a period at the end as usual, then add the 3 dots which Word automatically converts into ellipses.

email: Do not hyphenate.

em dashes: Use for emphasis and to set off phrases; close up spaces before and after.

**en dashes:** Use between inclusive numbers such as dates, times, page numbers, etc. Do not add space before and after: 1972–1978.

**endnotes:** The FXB Center uses endnotes, not footnotes. Note that endnotes are for citation purposes only and must not contain contextual material. Authors will be asked to remove substantive notes into the body of the paper.

**endnote numbers:** Citation numbers must always be placed at the end of sentences, not in the middle. Each sentence can have only one citation number associated with it. Citation numbers are always sequential. If there are several endnotes in each sentence, combine into one endnote and place under one citation number.

**epigraph**: center quote underneath the first main heading within the paper (after the abstract). Example: <u>http://www.hhrjournal.org/wp-content/uploads/sites/13/2013/06/Samra21.pdf</u>

**et al.:** This means "and others"; do not use comma before it. 1) In first full reference: use "et al." only if there are more than 3 authors (name first three, then add "et al." as "et al." implies 2 or more); 2) In repeat citations where full reference has already been given, if there are only 1 or 2 authors, list all; if there are more than 2, list as first author "et al." followed by "(see note [number])." Include year only if it would otherwise be confusing (see "dates," above, #3).

etc.: Do not use. Spell out "and so forth," or initiate sequence with ", including," or "such as." **European Convention for the Protection of Human Rights and Fundamental Freedoms**, opened for signature by the Council of Europe on November 4, 1950; entered into force on September 3, 1953. evidence-based reports

ex gratia: Use italics.

**executive orders:** Write as follows: William J. Clinton, Executive Order: Access to HIV/AIDS Drugs and IP/Trade Issues, May 10, 2000.

extrajudicial

F fall out: As verb, use "fall out"; as noun, "fallout." FY1999: Close up. female genital cutting (FGC) female genital mutilation (FGM)

#### fieldworker

**First World War** 

follow up: As verb, use "follow up"; as adjective, "follow-up" (e.g., strategies).

#### foreignness

**foreign words**: Do not use quotation marks if italicized — e.g., write either "doble discurso" (double discourse) or *doble discurso*; italicize foreign words when not in common usage. See also below, "translated articles and related; quoting foreign language material."

#### former Soviet Union

**François-Xavier Bagnoud Center for Health and Human Rights**: Refer to it as either "the FXB Center," or "the Center"; for programs within the Center, always spell out at first mention and supply standard abbreviations if applicable.

**Frendeskreis Indianerhilfe/Fundacion Alemana Ayuda a los Nativos** (FAAN) **fueled fulfill fulfillment:** Use two *l*'s.

#### G

**Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM):** This can also be referred to as "the Global Fund" after the full name has been spelled out.

#### Global Network of People Living with HIV/AIDS (GNP+) Global South

Grand Rounds

#### H

harm reduction program

the Hague: "the" is lowercase.

health care: Open in all cases: do not hyphenate as adjective.

helminthes

Hepatitis A

hermaphrodite: Do not use; use "intersex" instead.

#### high-risk behavior

**HIV: HIV-positive** women; people living with HIV/AIDS; note that the phrase "affected by HIV/AIDS" refers to social/environmental influences on non-infected persons who live in high-prevalence communities or countries.

#### HIV prevention efforts

homosexual/s: Do not use; see entry on "sexuality" for recommended alternative terms.

**HM Government:** stands for "Her/His Majesty" (UK government publication); do not use periods between initials.

human rights: Do not hyphenate as adjective.

human rights: This is generally used as plural noun.

#### human rights-based approaches (HRBAs)

human rights-holders: Do not use "human right-holders."

**hyphenation:** Hyphenate all words that begin with "co-" (e.g., co-author); also, four-year-old girl; five-to eight-year-old children; also one-and-a-half times the national average.

#### I

i.e. (meaning, "that is"): Do not abbreviate — spell out and follow with comma.

illegal immigrant: Do not use; use "undocumented immigrant."

indigenous peoples

**information, education and communication (IEC);** May be capitalized, as Information, Education and Communication Programmes.

injecting drug use (IDU): Can keep if the author uses this term.

inter alia (meaning, "among other things"): Use italics.

inter-agency: Retain hyphens in words with *inter*-prefixes if it helps readability.

International Committee of the Red Cross (ICRC)

International Community of Women with HIV/AIDS (ICW)

International Reproductive Rights Research Action Group (IRRRAG)

internet: Do not capitalize.

intravenous drug use (IDU): use this term unless the author strongly prefers "injecting drug use" in vitro fertilization: Do not italicize.

**italics:** Never use both italics and quotations together; use one or the other and be consistent in usage throughout the document.

#### J

**journal**: When referring to the *Health and Human Rights* journal, do not capitalize the *j*. The preferred formal title is *Health and Human Rights Journal*.

Jr.: follow with a period; do not set off with commas, e.g., John Smith Jr.

judgment: Do not use *e*.

**juvenile prostitution** : can use this (when juvenile is expressly written) but do not use "prostitution" alone (replace with "sex work")

#### K

Kolkata Kazakhstan kilometers: State: "8,000 square kilometers," but "10–50 km."

L

#### least-developed countries

**legal cases:** These should be set in italic — e.g., *Toronto (City) Board of Education v. Quereshi* (1991), 14 C.H.R.R. D/243 at D/249; *State v. Tapley*, (1952) I.R. 62, December 12, 1950; Case 13/63 *Italy v. Commission* [1963] ECR 31. Use "v." rather than "vs."

**letters:** Letters referred to as letters should be set in italics rather than quotation marks — e.g., the letter *l. locus standi:* Use italics; in law, the meaning is "place to stand," "the right to bring an action." **long-term** 

#### M

Maastricht Guidelines on Violations of Economic, Social and Cultural Rights, Maastricht, January 22–26, 1997. Magna Carta: Do not use italics. mega: Hyphenate generally as a prefix — e.g., "mega-corporations." men who have sex with men (MSM): See entry on "sexuality." Millennium Development Goals (MDGs) mixed-methods study mother-to-child transmission (MTCT) Ms.: Do not use "Miss." multi-country studies multidrug multidrug resistant: As adjective, note: "multidrug-resistant parasite." Also, multidrug-resistant TB (MDRTB). multisectoral

Myanmar: Do not use "Burma."

#### Ν

#### naïve

**names:** Within text, always include first names at first mention; use only last names in subsequent mention. An exception to the latter may be made if the name starts a new paragraph or section. **nation-state** 

#### nationwide

nd: Do not use superscript — e.g., 2nd, and do not use superscript for "th" or "rd," etc.

#### neoliberal

**non:** Close up in most cases — e.g., noncompliant, nongovernmental, nonprofit, nonrecognition. Exceptions: hyphenate if not in dictionary or if it helps with readability — e.g., non-criminals, non-disabled, non-payment, non-reproductive, non-response. *Do* hyphenate non-discrimination.*Do* hyphenate when the phrase is part of a fixed-text legal statement (such as "non-commercial" in the journal's Creative Commons copyright statement).

**numbered lists in text**: Use numbers in parentheses in lists as follows: "1) point one and 2) point two"; "1) point one, 2) point two, and 3) point three." Limit use of numbers to short lists; if text refers to serial list that is longer (e.g., paragraph-length), adjust use of numbers in a manner that enables the flow of the narrative to remain as smooth as possible — e.g., by spelling out numbers.

**numbers:** 1) Spell out if less than 10; otherwise use numerals. The exception is the use of numbers at the beginning of sentences — always spell out: "Twenty-seven out of the 259 members were absent." Use "20th century" rather than twentieth century, unless at the beginning of a sentence. Another exception: when numbers are within a sentence, adjust for consistency in prose, and do not mix — e.g., "three out of ten," or "3 out of 10," but not "three out of 10" [but "Three out of 10 is ok when "Three" begins the sentence]. 2) When referring to large numbers, generally use numerals rather than spell out — e.g., "1.5 million," rather than "one and a half million. 3) When referring to fractions, spell out and hyphenate — e.g., "one-third," "three-quarters." 4) Reference numbers within the text should always be placed at the end of a sentence, not in the middle. 5) All numerals (except years, e.g., 1999) with four (or more) digits should contain a comma between the hundreds and thousands place, e.g., 1,234.

#### 0

**offense**: Use this American spelling unless in direct quote where British spelling (offence) appears. **Ombuds Office** (with caps): Use this instead of "Ombudsman." When referring to such offices in the plural, do not capitalize "office"— as in the following excerpt: "Some are formal and mandated to hold the government to account in terms of its legal obligations (for example, courts, Ombuds offices, and human rights commissions)."

#### ongoing

online

open access: Never hyphenate, even if used as an adjective — e.g., "open access periodical." Organization of African Unity (OAU) Organization of American States (OAS) overall over-reporting

#### Р

"p." v. "pp.": Use "p." when referring to single page numbers in endnotes — e.g., "p. 23"; "pp." precedes multiple pages — e.g., "pp. 23–25."

**page numbers in endnotes:** These should be inclusive (1031–1038), not shortened (1031–38). Also see above. If un-numbered document is hyperlinked, there is no need to provide page numbers, since the reader can do a word search online.

**para:** Spell out in text but okay to abbreviate in endnotes — e.g., para. 3; paras. 34–37. **peer-reviewed journal**: Hyphenate as an adjective.

**PEPFAR:** President's Emergency Plan for AIDS Relief (president is US president).

per capita: common English usage; do not italicize.

**percentages:** Use symbols in our journal and in scientific, technical text — e.g., 5% — but may want to spell out in proposals, annual reports — e.g., "5 percent."

**periods:** A period should follow a URL at the end of a sentence or reference.

#### per se: common term so do not italicize

**policymaking: use as single word for both adjective and noun; however: policy maker** (do not hyphenate); note that this differs from journal style on "decision making" due to considerations of best clarity in most cases.

**poor:** It is acceptable journal style to use this word as an adjective for "people" and "country"; may wish to replace with other phrases such as "developing country," "those with scant resources," etc.

#### post-infection

#### post-2015 Development Agenda

Preamble: Use an initial capital letter for covenants, etc. — e.g., "the Covenant."

#### pre-test counseling

**press releases**: Use as a style sample: UNAIDS, "New public/private sector effort initiated to accelerate access to HIV/AIDS CARE and treatment in developing countries" [press release], May 11, 2000. *prima facie*: Use italics; means "at first sight; before closer inspection": They had, *prima facie*, a legitimate complaint. A *prima facie* case is one that, at first glance, presents sufficient evidence for the plaintiff to win.

#### Principles for the Protection of Persons with Mental Illness (MI Principles)

priority setting: no hyphen unless used as an adjective

pro bono: Do not italicize.

#### problematic

programmatic

promiscuity: Do not use; substitute "high levels of sexual activity."

prostitutes: Do not use; substitute "sex workers." However, can talk of juvenile prostitution.

psycho-: Close up — e.g., "psychosocial."

#### publicly (not publically)

**punctuation exception:** Do not add comma after title of publication if the title ends in a question mark: D. Kennedy, "The International Human Rights Movement: Part of the Problem?" *Harvard Human Rights Journal* 15 (2002), p. 101.

#### Q

**question marks:** In punctuating references, question marks and exclamation marks should always replace rather than occur next to commas or colons. For example, if a title ends in a question mark, punctuate as follows: D. Kennedy, "The international human rights movement: Part of the problem?" *Harvard Human Rights Journal* 15 (2002), p. 101.

**quotations, including block quotations (extracts):** 1) Introduce block quotations with a colon, unless phrased as [According to John Surlap, "The issue is a matter of great urgency."]. Otherwise, generally use a comma to introduce quotations within text. 2) Use block quotation — indent the quotation — if a) the meaning is "self-contained"— that is, the quotation can stand alone as is and is still meaningful and b) the quotation is quite long (HHR does not set an exact minimum line number). However, if the quotation depends heavily on the immediate context for full meaning AND it is short, it should remain in quotation marks within the paragraph.

**quotation marks:** Never use both quotation marks and italics together; use one or the other and be consistent throughout document. Do not use quotation marks for longer quotations that are indented. **quotations followed by a colon or semicolon:** colons and semicolons should be placed after the closing quotation marks (see CMS 6.9)

quotations with commas: See CMS 15, 6.52–6.55.

#### R

**re-emergence:** Hyphenate "re" compounds for words beginning with "e" (but note: "preeminent"). **reference numbers:** Always place outside end-of-sentence punctuation.

#### reframe

**right to health:** do not hyphenate when used as an adjective ("right to health framework") **rights-based approaches** 

#### rights-holders

**right wing and left wing:** Capitalize "the Left," the "Far Right," and the "radical Right," but not "left-wingers," "on the left," or "members of the right wing."

rivers: Capitalize as: Amazon River and Amazon River basin, but Marañon and Amazon rivers.

#### S

safer sex

scale up: do not hyphenate as verb, but do as adjective — e.g., "scale-up activities."

2nd International Conference on Health and Human Rights: Do not spell out "2nd."

#### Second World War

#### Secretary-General

**see, for example:** Use commas after "see" and "for example." "See also" should be followed by comma, as well as "see generally."

#### self-determination

self-selected

semicolons: place after closing quotations marks (see CMS 6.9)

semi-nomadic: Hyphenate most "semi" compounds.

serial comma ("a, b, and c"): Always use comma before final item in a series.

seroprevalance/seropositive: do not hyphenate; close up.

#### service-provider initiated testing

**sexuality:** Avoid the use of the term "homosexual/s"; instead, choose one of the following for better accuracy: "sexual minorities"; "lesbian, gay, bisexual, and transgender (LGBT) persons"; "lesbian and gay persons"; "men who have sex with men (MSM)." Use "transgender" instead of "transgendered" i.e., "transgender persons." "Lesbian," "gay," "bisexual,"and "transgender" should be used as adjectives, not nouns; thus, "Many gay and lesbian individuals were disheartened over the passage of Proposition 8 in California" would be incorrect.

sexual preference: Do not use; use "sexual orientation" instead.

sex workers: Us this instead of "prostitutes."

socio-cultural

socioeconomic

socio-legal

so-called: Do not use quotation marks after "so-called" — e.g., "so-called multi-drug treatment."

#### sodomy: Do not use. Preferred: "oral and anal sex"

#### Southeast Asia

**spacing:** 1) Always include a space between author's initials in references and elsewhere (A. B. Smith, never A.B. Smith). 2) Use only one space between sentences. 3) Colons, semicolons, and question marks should also be followed by a single space only. *Copy editors*: search for *double spaces* before submitting final article.

**Special Rapporteurs**: capitalize but use sentence case for the text that follows describing the mandate of the particular rapporteur (e.g., Special Rapporteur on the right to food). Rapporteurs whose mandate titles are quite long may be abbreviated within the text but please spell out the full title in the first reference note that follows and provide the appropriate url, if applicable. For example, text may say, "Paul Hunt, the Special Rapporteur on the right to health..." but the reference note should spell out his full title, "Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of

physical and mental health." For more details, see citation notes below for United Nations documents, subsection (d). Information on UN-related websites and hints for standard citation formats is also available at http://www2.ohchr.org/english/bodies/chr/special/index.htm.

Sr.: follow with a period; do not set off with commas, e.g., John Smith Sr.

#### Standard Rules on Equalization of Opportunities for Persons with Disabilities (StRE)

state: Use lowercase, except in "States parties" (see following).

States parties (to covenants): Capitalize "States" but not "parties."

sub: Close up — e g., subsurface. Exception: sub-Saharan Africa.

**Supplement:** In notes, use "Suppl." (capitalized, followed by a period) to indicate that a paper is from a supplement. For example, "*AIDS Education and Prevention* 14/5 Suppl. B (2002), pp. 114–123." **Sudan:** Use Sudan, not "the Sudan."

#### super-annuated

**superscript**: Do not use in text; use standard size font instead — e.g., 2nd, 3rd, 4th, etc. **Sustainable Development Goals: SDGs** 

#### Т

task force

#### Thai AIDS Treatment Action Group (TTAG)

th: Do not use as superscript for this or "nd," etc.

**the:** Generally, omit "The" in reference titles, including *New York Times, Boston Globe*, and *Lancet*. Some flexibility may be necessary. Exceptions: the Netherlands, The Hague.

#### The AIDS Support Organization (TASO) [in Uganda]

**titles:** 1) Do not use periods with MD, PhD, etc., but do for Mr., Dr., etc. 2) Use a comma after title in prose — e.g., "Joe Saturn, MD, is a director." 3) Do not use commas around Jr. or Sr., so "John Smith Jr. says" should be used and not "John Smith, Jr., says." Cite the name first and then title — e.g., "John Smith, Director of the Program on Health and Human Rights, was instrumental in..." 4) Do not use formal civil or other titles in text — e.g., "Prof. John Martin." Instead use "John Martin" (and if necessary, follow with "professor of law at xx...) Generally write out titles such as "professor," and "president," if describing a person's function (following capitalization guidelines in CMS 15, 15.11–15.20), but these may occasionally be abbreviated before name within the references — e.g., Msgr. Jimenez v. the Right Reverend Monsignor Jimenez. 5) If the official title is not capitalized in its original (foreign) language, capitalize it according to English-language conventions as in examples.

#### totaled: Use one *l*.

**transgender:** Never use "transgendered"— e.g., a transgendered person. Use "transgender" instead: "transgender person."

traveler: Use one *l*.

Treatment Action Campaign (TAC) (South Africa) tuberculosis (TB)

#### U

**Ukraine:** Do not use "the Ukraine."

underserved/underreported

UNICEF: In general, this does not need to be spelled out, as is the case with WHO.

United Nations (UN): Do not use periods.

United Nations Development Programme (UNDP): As in this instance, retain British spelling if actual name is spelled that way.

United Nations General Assembly Special Session's five-year review of the International Conference on Population and Development (ICPD+5)

**URLs:** Use Roman type — e.g., http://www.hsph.harvard.edu. Use "http://" and "Available at" followed by URL and period at the end. It is not necessary to state date of access. Link and underline URLs. A

URL must be provided for an online-only publication and is optional if the full print citation is included. The provided URL must open directly to the indicated document.

United States (US): Do not use periods or space between letters.

**US\$1.00**: Do not use spaces, but use them to separate the number from "million," etc. — e.g., US\$64 million.

#### **US dollars**

USA: Do not use periods.

#### V

vis-à-vis: Do not italicize. vs.: Do not italicize unless in title of legal case; should be consistent use of "v." for cases. village health workers (VHW) — It is preferable not to use this acronym. May substitute with "community health workers" if appropriate. voluntary counseling and testing (VCT)

#### W

#### water borne

**web**: Capitalization is not necessary if used alone and meaning is obvious due to common usage, e.g., "It is posted on the web." In case of potential confusion, edit content (e.g., using website or internet).

website: Spell as one word and do not capitalize.

#### well-being

western Europe

**the West: Western world**: Capitalize when referring to region; same for the South, East, and North. **whilst:** Use "while" instead.

widows: single lines of text that proofreaders note at the bottom of columns in final design documents are acceptable in the references, but should be adjusted in the body of the text to include at least 2 lines. women's and girls' rights

World Health Organization (WHO): Do not use "the WHO."

# WHO's 3 by 5 Initiative worldwide

wrongdoing

Y

**year-old:** Hyphenate as: "20-year-old." **yes:** Do not use quotation marks around "yes" or "no" — e.g., "The answer is yes."

#### II. AUTHOR NAMES AND AFFILIATIONS FOR ARTICLES

#### Basic structure:

Names of author/s, their degrees, and their titles at corresponding department(s) and institution(s) to which the work should be attributed. Due to space limitations, authors with multiple institutional affiliations should list only one (or at most, two). For articles with multiple authors, the bio section may be further abbreviated to fit journal space.

Name, mailing address, and email address of the author responsible for correspondence about the manuscript (this author may or may not be the "guarantor" for the integrity of the study as a whole); do not list telephone and fax numbers unless author strongly prefers.

#### Examples:

**Judith Sohmen,** MD, MPH, MSc, is Professor of Clinical Medicine in the Department of Internal Medicine and Department of Family and Social Medicine at Montefiore Medical Center, Albert Einstein College of Medicine, Bronx, NY, USA.

**Raul Fernandez**, MD, PhD, is Professor of Psychiatry in the Department of Health Behavior and Health Education at the University of North Carolina at Chapel Hill, NC, USA, and research and policy consultant for Ipas Central America, Managua, Nicaragua.

Please address correspondence to the authors c/o Judith Sohmen, Department of Internal Medicine, Montefiore Medical Center, Albert Einstein College of Medicine, Bronx, New York, USA 02335, email: jsohmen@dimm.edu.

#### **III. DOCUMENTATION**

#### General

The Center uses endnotes, not footnotes, for citations. Endnote numbers within the text should be placed at the end of the sentence, rather than within the sentence. Each sentence may include only one. Combine into this note all relevant reference material from the sentence.

#### Example:

I situate open access publishing within a broader movement that has emerged in the digital era to create a public "knowledge commons," which can play a crucial role in supporting an informed citizenry in its efforts to promote human rights.<sup>3</sup>

#### Style

For titles within endnotes, follow *sentence style* — that is, use capital letter for first word only (except for proper nouns) — for titles of articles, chapters, reports, and books. Follow *title case* — that is, capitalize all major words — for titles of journals and newspapers.

#### Example:

J. Pitanguy, "From Mexico to Beijing: A new paradigm," *Health and Human Rights: An International Journal* 1/1 (1995), pp. 454–460.

In titles in endnotes, capitalize first word after colon or exclamation point if a subtitle is used. Generally, standardize French/Spanish titles that contain periods to conform with HHR style by replacing periods with colons. If period must be kept, capitalize first word that follows it. English translations of foreign language titles should be enclosed in parentheses and quotation marks should be used:

F. Vieira and P. Zucchi, "Distorções causadas pelas ações judiciais à política de medicamentos no Brasil" ("Distortions to national drug policy caused by lawsuits in Brazil"), *Revista de Saúde Pública* 41/2 (2007), pp. 214–222.

#### Book, first citation, one author

#### Basic structure:

Author's first initial Author's last name (followed by "ed" or "eds" in parentheses if it is an edited work) followed by comma Title of book in italics (use sentence case, not title case) Mention of 2<sup>nd</sup> (3<sup>rd</sup>, etc) edition, separated from title by a comma; do not italicize Within parentheses, place of publication (forward slash to separate multiple places of publication [mindful that the journal may need to insert a space following the slash to facilitate final layout]), colon, name of publisher, comma, year of publication, followed by final parenthesis and a period (full stop) or comma and page numbers, using p. or pp.

#### Examples:

P. Farmer, *Health, human rights and the new war on the poor* (Berkeley, CA: University of California, Berkeley, 2003), pp. 23–25.

F. Terry, *Condemned to repeat?: The paradox of humanitarian action* (Ithaca, NY: Cornell University Press, 2002).

See B. G. Ramcharan (ed), *The right to life in international law* (Dordrecht/ Boston: Martinus Nijhoff Publishers, 1985).

See, for example, C. L. R. James, *The black Jacobins: Toussaint L'Ouverture and the San Domingo Revolution* (London/New York: Penguin Books Ltd., 2001).

O. Solar, A. Irwin, and J. Vega, "Determinants of health and disease: Overview and framework," in R. Detels, R. Beaglehole, M. A. Lansang, and M. Gulliford (eds), *Oxford textbook of public health*, 5th ed. (Oxford/New York: Oxford University Press, 2009), vol. 1, pp. 329–382.

#### **Book, multiple authors**

Note: Author names should appear in the same order as they appear in the original publication.

P. Dauvin and J. Siméant, *Le travail humanitaire: Les acteurs des ong, du siège au terrain* (Paris: Presse de la Foundation Nationale des Sciences Politiques, 2002).

Note: Use "et al.":

1) in first full reference only, if there are more than 4 authors (list first three, then add "et al." since "et al." implies 2 or more);

2) for repeat citations where full reference has already been given. If there are only 1 or 2 authors, list these; if there are more than 2, list as first author "et al." followed by "(see note [number])." Include year only if it would otherwise be confusing.

J. C. Semenza, L. Roberts, A. Henderson, et al., "Water distribution system and diarrheal disease transmission: A case study in Uzbekistan," *American Journal of Tropical Medicine and Hygiene* 59 (1998), p. 941.

Kim et al. (2007, see note 15). [Use year only if a preceding note contains more than one publication by the same author.]

#### **Book, subsequent mention**

#### Use "Ibid." if the citation immediately follows same citation:

P. Trouiller et al., "Drug development for neglected diseases: A deficient market and a public health policy failure," *Lancet* 359 (2002), p. 2188.

Ibid., p. 2189.

## If citation is the same as one that does not immediately precede it, use 1) the last name of the author or the name of the organization and 2) (see note [number]):

Willinsky (see note 4).

London (2007, see note 14). [Include year if more than one preceding reference with same author.]

Kamara, "Maternal mortality: A public health perspective," in *Learning to dance* (see note 1). See also, C. Overs, J. Doezema, and M. Shivdas, "Just lip service? Sex worker participation in sexual and reproductive health interventions," in A. Cornwall and A. Welbourn, *Realizing rights: Transforming approaches to sexual and reproductive wellbeing* (London: Zed Books, 2002) (see note 7), pp. 21–35.

#### Chapter from a book

C. Overs, J. Doezema, and M. Shivdas, "Just lip service? Sex worker participation in sexual and reproductive health interventions," in A. Cornwall and A. Welbourn (eds), *Realizing rights: Transforming approaches to sexual and reproductive well-being* (London: Zed Books, 2002), pp. 21–35.

#### Journal articles, first citation

Basic structure:

Name of author followed by comma Within quotation marks, title of chapter, in sentence case, followed by comma, end quotation marks Name of journal, in full (no abbreviations), italicized Number of journal / issue followed by year in parentheses, followed by either period or comma and page numbers. Use "Suppl" to indicate that an article is from a supplement.

#### Examples:

J. Pitanguy, "From Mexico to Beijing: A new paradigm," *Health and Human Rights: An International Journal* 1/1 (1995), pp. 454–460.

The PLoS Medicine Editors, "How can biomedical journals help to tackle global poverty?" *PLoS Medicine* 3/8 (2006), p. e380.

D. Blane, "Social determinants of health — socioeconomic status, social class, and ethnicity," *American Journal of Public Health* 85/7 (1995), pp. 903–904.

C. Hess and E. Ostrom, "Ideas, artifacts, and facilities: Information as a common-pool resource," *Law and Contemporary Problems* 66 (2003), pp. 111–145. Available at http://www.law.duke.edu/journals/66LCPHess.

Kennedy et al. (eds), "Income distribution and mortality: Cross sectional ecological study of the robin hood index in the United States," *British Medical Journal* 312 (1996), pp. 1004–1007.

S. Gruskin, L. Ferguson, and J. O'Malley, "Ensuring sexual and reproductive health for people living with HIV: An overview of key human rights, policy and health systems issues," *Reproductive Health Matters* 15/Suppl 29 (2007), pp. 18–19.

See, for example, L. Highleyman, "The global epidemic: Affordable drug access for developing countries," *Bulletin of Experimental Treatments for AIDS* (Summer/Autumn 2001).

#### Journal articles, subsequent mention

#### Use same guidelines as for books:

#### Use "Ibid." if the citation immediately follows same citation:

Ibid., p. 29.

Ibid., pp. 135–136, citing F. Fernand, A. Ross, and H. Perry, "Assessing the causes of under-five mortality in the Albert Schweitzer Hospital service area of rural Haiti," *Panamerican Journal of Public Health* 18/3 (2005), pp. 178–186.

## If the citation is the same as one that does not immediately precede it, use 1) the last name of the author or the name of the organization and 2) (see note x):

See, for example, Copelon (see note 24), pp. 116–152.

Eaton (2005, see note 12).

A. Yamin, "Transformative combinations: Women's health and human rights," *Journal of the American Medical Women's Association* 56 (1997), pp. 169–173; Freedman (see note 19), p. 324.

Physicians for Human Rights (see note 21), pp. 33–53.

#### General citation of an edited book or compilation

A. Yamin, "Embodying shadows: Tracing the contours of women's rights to health," in N. Gordon (ed), *From the margin of globalization: Critical perspectives on human rights* (New York: Lexington Books, 2004), pp. 223–257.

See generally, R. Künnemann, "Extraterritorial application of the International Covenant on Economic, Social and Cultural Rights," in F. Coomans and M. T. Kamminga (eds), *Extraterritorial application of human rights treaties* (Antwerp: Intersentia, 2004).

#### Reports

#### Use same guidelines as for books:

A. Sha'ar, P. Kelly, and E. Kleinau, USAID village water and sanitation program. West Bank of Palestine. Environmental health assessment — Phase II (Washington, DC: Environmental Health Project, June 2003).

#### If a report is credited to an organization rather than an individual:

Amnesty International, *Torture worldwide: An affront to human dignity* (New York: Amnesty International, 2000), pp. 2–6.

HM Government, *Health is global: A UK Government strategy 2008–13* London: Central Office of Information, 2008). Available at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndG uidance/DH\_088702.

World Bank, *Development and human rights: The role of the World Bank* (Washington, DC: World Bank, 1998). Available at http://www.worldbank.org/html/extdr/rights/.

World Health Organization, *The world health report 2004: Changing history* (Geneva: WHO, 2004).

WHO and UNAIDS, *Progress on global access to HIV antiretroviral therapy: A report on "3 by 5" and beyond* (Geneva: WHO, 2006), p. 34.

## **Contribution to a series**

Basic structure:

Author's first initial Author's last name, followed by comma Title of article within quotation marks, followed by a comma Name of series followed by parentheses Within parentheses, publication place, followed by colon, publisher, a comma and date.

## Example:

M. Yahya, *Polio vaccines* — *Difficult to swallow: The story of a controversy in northern Nigeria*, University of Sussex Working Paper 261 (Brighton, UK: Institute for Development Studies, 2006); M. Yahya, "Polio vaccines: 'No thank you!' Barriers to polio eradication in Northern Nigeria," *African Affairs*, 106/423 (2007), pp. 185–204.

#### **Newspaper articles**

Basic structure:

#### Author's first initial

Author's last name, followed by comma Title of article within quotation marks, followed by comma Name of newspaper, in italics and title case Within parentheses, month, day, and year of publication, followed by period May be followed by URL and period.

#### Examples:

J. Boyle, "Sold out," *New York Times* (March 31, 1996). Available at http://www.law.duke.edu/boylesite/Sold\_out.htm.

"Patent wrongs," *Washington Post* (Editorial, February 25, 2001); T. Karon, "AIDS drugs case puts our ideas about medicine on trial," *Time World* (March 5, 2001).

Agence France Presse, "WHO backs South Africa in anti-AIDS drug case" (March 6, 2001).

#### **Presentations at conferences**

#### Basic structure:

Name of presenter, followed by comma Name of presentation, in quotation marks and in sentence case Within parentheses, "presentation at" followed by name of conference in title case, followed by place and date of conference, all separated by commas.

#### Examples:

D. Gordon, "Monitoring the right to health" (presentation at Exclusion and the Right to Health: The Role of Health Professionals, IFHHRO Conference, Lima, Peru, October 13, 2006). Available at http://www.edhucasalud.org/documents/DAVE\_GORDON\_PGS.pdf.

See also, R. K. Murthy, B. Klugman, S. Weller, and L. Aizenberg, "Draft 2: Sexual and reproductive rights in service: Accountability and community participation" (presentation at The Expert Consultation on Decentralization, Integration of Service Programs, Community Participation and Accountability As These Pertain to Sexual and Reproductive Rights and Health, Capetown, South Africa, April 24 and 25, 2003).

C. Juma, "Reinventing African economies: Technological innovation and the sustainability transition" (presentation at The John Pesek Colloquium on Sustainable Development, Iowa State University, Ames, Iowa, USA, April 6–7, 2006).

P. Hunt, "Keynote address" (presented at Lessons Learned from Rights Based Approaches to Health, Emory University, Atlanta, GA, USA, April 14–16, 2005).

For example, see M. Heywood, "Debunking 'Conglomo-talk:' A case study of the *amicus curiae* as an instrument for advocacy, investigation and mobilisation" (paper presented at Health Law and Human Rights: Exploring the Connections, an International Cross-disciplinary Conference Honouring Jonathan M. Mann, September 29–October 1, 2001, Philadelphia, PA).

#### Government sources (see also "Legal citations" and "US law/legislation" sections below)

South African Department of Education, *Draft national policy on HIV/AIDS for learners and educators in public schools, and students and educators in further education and training institutions*. Notice Number 1926 of 1999 (Pretoria: Department of Education, 1999).

The Socialist Republic of Vietnam, *The national target program on poverty reduction for the period 2006-2010*, 5th draft (Hanoi: 2005).

US Department of Health and Human Services, Centers for Disease Control and Prevention, *HIV/AIDS Prevention Bulletin* (April 19, 1993). Central Bureau of Statistics, Kenya, *Demographic and health surveys*, 2003, preliminary report (Nairobi: Central Bureau of Statistics, 2003). Available at http://www.measuredhs.com/countries/country.cfm?ctry\_id=20.

This section draws extensively from the UK Department of Health, *Health is global: Proposals for a UK government-wide strategy* (A Report from the UK's Chief Medical Adviser, Sir Liam Donaldson, 2007), especially at p. 46.

#### **United Nations documents**

# (Please note that not every citation will include a reference to an article or paragraph; references to them below are included as examples of where these would be placed.)

#### a) Resolutions (including Declarations)

Universal Declaration of Human Rights (UDHR), G.A. Res. 217A (III) (1948), Art. xx. Available at http://www.un.org/Overview/rights.html.

Declaration on the Right to Development, G.A. Res. 41/128 (1986), para. xx. Available at http://www.un.org/documents/ga/res/41/a41r128.htm.

Security Council Res. 940, UN Doc. No. S/RES/940 (July 31, 1994) para. xx. Available at http://www.un.org/docs/scres/1994/scres94.htm.

#### b) International conventions, treaties, covenants, and other binding instruments

International Covenant on Civil and Political Rights (ICCPR), G.A. Res. 2200A (XXI) (1966), Art. xx. Available at http://www2.ohchr.org/english/law/ccpr.htm.

International Covenant on Economic, Social and Cultural Rights (ICESCR), G.A. Res. 2200A (XXI), Art. xx. (1966). Available at http://www2.ohchr.org/english/law/cescr.htm.

Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, G.A. Res. 39/45 (1984). Available at http://www2.ohchr.org/english/law/cat.htm. International Convention on the Elimination of All Forms of Racial Discrimination, G.A. Res. 2106A (XX) (1965). Available at http://www2.ohchr.org/english/bodies/ratification/2.htm.

Convention on the Rights of the Child (CRC), G.A. Res. 44/25 (1989). Available at http://www2.ohchr.org/english/law/crc.htm.

Convention on the Rights of Persons with Disabilities, G.A. Res, 61/106 (2006). Available at http://www2.ohchr.org/english/bodies/ratification/15.htm.

International Convention on the Elimination of All Forms of Discrimination against Women, G.A. Res. 34/180 (1979). Available at http://www2.ohchr.org/english/law/cedaw.htm.

#### c) Documents of world summits and conferences

Platform for Action of the Fourth World Conference on Women, UN Doc. No. A/CONF.177/20 (1995), para. xx.

United Nations, World Conference on Human Rights: Vienna Declaration and Programme of Action, Vienna, June 14–25, 1993, UN Doc. No. A/CONF.157/24 (Part I) (1993), reprinted in *International Legal Materials* 32, p. 1661, para. xx.

#### d) Reports of committees, special procedures, and subsidiary bodies

Committee on the Rights of the Child, Concluding Observations on Viet Nam, UN Doc. No. CRC/C/15/Add.200 (2003), para. xx.

UN Sub-Commission on the Promotion and Protection of Human Rights, Report on the Right to Food as a Human Right, UN Doc. E/CN.4/Sub.2/1987/23 (1987), para. xx.

UN Human Rights Committee, General Comment No. 31, The Nature of the General Legal Obligations Imposed on State Parties to the Covenant, UN Doc. No. CCPR/C/21/Rev.1/Add.13. (2004).

UN Human Rights Committee, General Comment No. 28, Equality of Rights between Men and Women (Article 3), UN Doc. No. CCPR/C/21/Rev.1/Add.10 (2000).

Committee on Economic, Social and Cultural Rights, General Comment No. 14, The Right to the Highest Attainable Standard of Health, UN Doc. No. E/C.12/2000/4 (2000). Available at http://www.unhchr.ch/tbs/doc.nsf/0/40d009901358b0e2c1256915005090be?Opendoc ument.

Committee on Economic, Social and Cultural Rights, General Comment No. 3, The Nature of States Parties' Obligations, UN Doc. No. E/C.12/1991/23 (1990).

Committee on the Elimination of Discrimination Against Women, General Recommendation No. 24, Women and Health, UN Doc. No. CEDAW/C/1999/I/WG.II/WP.2/Rev.1 (1999).

UN Human Rights Committee, General Comment No. 6, The Right to Life, UN Doc. No. A/37/40 (1982).

Paul Hunt, UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Title of Report, UN Doc. No. xx. Available at http://www2.ohchr.org/english/issues/health/right/.

#### e) UN publications

United Nations Population Fund, Culture matters (Geneva: UNPF, 2000), p. xx.

#### **Documents of regional organizations**

European Convention on Human Rights, European Treaty Series No. 5 (1950), Art. xx. Available at http://www.conventions.coe.int/Treaty/en/Treaties/Word/005.doc.

African Commission on Human and Peoples' Rights, Declaration of Principles on Freedom of Expression in Africa (2002), Art. xx. Available at http://www1.umn.edu/humanrts/achpr/expressionfreedomdec.html<sup>-</sup>.

American Convention on Human Rights, O.A.S.Treaty Series No. 36 (1969). Available at http://www.cidh.oas.org/Basicos/basic3.htm.

European Social Charter, 529 U.N.T.S. 89 (1961). Available at http://conventions.coe.int/treaty/en/treaties/html/035.htm.

African Charter on Human and Peoples' Rights, OAU Doc. No. CAB/LEG/67/3 rev. 5 (1981), reprinted in *International Legal Materials* 21 (1982), p. 58. Available at http://www1.umn.edu/humanrts/instree/z1afchar.htm.

African Charter on the Rights and Welfare of the Child, OAU Doc. No. CAB/LEG/24.9/49 (1990). Available at http://www.un.org/children/conflict/keydocuments/english/africancharteron22.html.

Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador) (1988). Available at http://www.oas.org/juridico/English/Treaties/a-52.html.

#### **General style format**

Name of Special Rapporteur, UN Special Rapporteur on (name — e.g., Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health), Title of Report, UN Doc. No. xxx/xxx (year), para. xx.

Committee on xx, General Comment No. xx, Title of General Comment, UN Doc. No. xxx/xxx (year), para. xx.

#### **Internet sources**

Basic structure:

Document title and complete URL, including http://www. (followed by period) "Available at" (no comma) followed by URL Do not underline or link; black type only. Use http://www. for all URLs.

#### *Examples*:

The MARAM Project, *Prevalence of vitamin a deficiency among children, aged 12–59 months, in the West Bank and Gaza Strip* (June 2004). Available at http://www.healthinforum.net/files/nutrition/VitamnA\_report.pdf.

C. A. Odinkalu, "Why more Africans don't use human rights language," *Human Rights Dialogue* 2/1 (New York: Carnegie Council on Ethics and International Affairs, Winter 2000). Available at

http://www.cceia.org/resources/publications/dialogue/2\_01/articles/602.html.

SQW Limited (compiled by), *Economic analysis of scientific research publishing*; commissioned by the Wellcome Trust (revised edition, October 2003). Available at http://www.wellcome.ac.uk/assets/wtd003182.pdf.

#### Newsletters

U. von Pilar, "Sharing knowledge! The La Mancha Training Center," *La Mancha Gazette* (MSF Internal Newsletter, May 2006), p. 12.

#### **Unpublished works**

See H. Potts, *Human rights in public health: Rhetoric, reality and reconciliation*, PhD thesis (2006).

#### Legal citations

#### Note: Legal cases should be italicized.

See, for example, *Paschim Banga Khet Mazdoor Samity v. State of West Bengal* (1996), 4 S.C.C. 37; *Eldridge v. British Columbia* (Attorney General) (1997), 3 S.C.R. 624; *Minister of Health and Another v. Treatment Action Campaign and Others* (2002), 5 South African Law Report 721 (South African Constitutional Court); *Viceconti v. Ministry of Health and Social Welfare* (1998) (Argentina, Poder Judicial de la Nación, Causa no. 31.777/96, June 2, 1998); *Cruz Bermudez et al. v. Ministerio de Sanidad y Asistencia Social* (Supreme Court of Justice of Venezuela, Case No.15.789, Decision No. 916, July 15, 1999).

#### US law/ legislation

Refer to CMS 17.310 for general format; preferred index to use is the *US Statutes at Large*. A searchable database of this source is available at http://www.constitution.org/uslaw/sal/sal.htm. For capitalization, follow that found in formal text of act (i.e. NOT sentence case). Italicize title of act and *US Statutes at Large*. For page number, include p. or pp. (NB: this is slightly different from CMS).

Example:

See, for example, the *National Industrial Recovery Act of 1933*, Public Law 73-67, *US Statutes at Large* 48 (1933), p. 195. Available at http://www.ourdocuments.gov/doc.php?flash=true&doc=66; see also the *United States Housing Act of 1937*, Public Law 93-383, *US Statutes at Large* 88 (1937), p. 653 as amended by the *Quality Housing and Work Responsibility Act of 1998*, Public Law 105-276, *US Statutes at Large* 112 (1998), p. 2518 in addition to others as of March 2, 1999. Available at http://www.nhl.gov/offices/ogc/usha1937.pdf.

## **IV. FORMATTING GUIDE**

#### capitalization:

Author names: Capitalize first letter of each name.

#### Capitalize first letter and proper nouns for:

Article title Main section headings in text

For *subheadings*, italicize, and capitalize only first letter of first word, proper nouns, and first letter of first word that follows a colon.

Do not use third-level sub-headings.

main section headings: 1) Bold main headings.

**subheadings:** 1) Italicize; 2) Capitalize first word, any proper nouns, and first word that follows any colon in subtitle.

em dashes: Use for general interruptions; close up space before and after.

**en dashes:** Use for dates, times, range of page numbers, etc. Do not use dashes/hyphens between page numbers; use dashes/hyphens only to designate hyphenated words. Do not use spaces before or after en dash: September 29–October 1, 2001, pp. 34–56.

**font:** Use Times New Roman, size 12, for text and endnotes. Format as flush left for entire text, including endnotes.

**indents:** Make all text flush left — do not indent paragraphs — but do not worry about size of tab. This includes title.

**long quotes:** Leave one line space above and below the quote. Indent and offset quotes longer than three lines. Add citation number at the end of the quotation. See notation for "quotations" above.

**numbering:** For numbering endnotes, use regular size font (not superscript) — 12 pt — followed by a period and *tabs*. *Do not use space bar to move text after numbers*.

order:

#### Article title (*bold*, *flush left*)

Author/s name/s (not in bold, flush left)

**Author** bio (for each author; if 2 authors, limit to less than 50 words; if more than 2 authors, will need to be very brief due to space limitations; see "Author names and information"). (in bio, always **bold** <u>author names but text of bio beginning with comma after each author name should *not* be in bold)</u>

Contact info: "Please address correspondence to the author" followed by name and desired contact information for the contact author

Competing interests: ("Competing interests") None declared.[final wording can depend on authors' preference in asserting competing interests, if any]

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#### Abstract

Text (primary subheads are all lower case, Roman font; secondary subheads in sentence case, italics, with appropriate capitalization; HHR does not have level-3 subheads; see further below)

Introduction

Acknowledgments

References [here place endnotes but the section should be titled References] Note regarding translated material — e.g., *This article, including all quotations from cases and other Spanish-language material, has been translated from Spanish into English by xxxx xxxxx.* 

#### spacing:

1) Use single space for everything except between paragraphs and sections. Do not use a line space between subtitles (primary or secondary) and text that follows — i.e., use only one line/space before each heading, following the previous paragraph. Do not add line space after heading the text that follows.

Example (showing primary and secondary subtitle):

#### **Politics of power**

Lack of clean water is among the most severe human rights challenges faced by the people of Haiti today. In 2002, Haiti ranked 101 of 127 countries in terms of the quantity and quality of fresh water; the existence of wastewater treatment facilities; and the presence of legal structures, such as pollutant regimes. Relying on a human rights-based framework, the authors argue that actors have corresponding obligations that they should observe.

#### A nation in jeopardy: Historical burdens

The Republic of Haiti declared its independence from France on January 1, 1804, after 12 years of revolutionary war that claimed over 100,000 Haitian lives and destroyed the

colonial infrastructure, such that clean water, adequate sanitation, health care, and stable food supplies were virtually eliminated.

2) For long quotations (also see above section, "quotations"), leave one line space above and below the quote. *Indent and offset if the quote is longer than three lines*.

3) Add space between initials (letters) of names in endnotes: J. Y. Kim and P. Farmer, "AIDS in 2006 — Moving toward one world, one hope?" *New England Journal of Medicine* 355 (2006), pp. 645–647. Also use space before and after em dashes, such as title in preceding line, but not before en dashes, such as pp. 645–647.

4) Use single space between sentences.

**tables:** Use sentence case as in reference style. Except in rare cases for emphasis, the text of tables should not be in bold..

## translated articles and related; quoting foreign language material:

## A. In HHR articles for which the original language was English:

1. If a text cited is taken from a source originally in a language other than English: it is preferred that the manuscript text be in an accepted English translation, if one exists. If the authors have produced their own translation of a foreign phrase or passage, that should be stated.

2. Use of short foreign terms: If the foreign term is a 1-2 word phrase that is part of the narrative: provide a brief translation in parentheses immediately following first usage; repeat uses in the paper do not need any further comment. No endnotes are required for such a use.

3. Use of foreign words from a cited source: if use of foreign language words from a cited source (requiring an endnote) is essential within the manuscript text, please limit these to short words or phrases, with English translation immediately following in brackets; for more information on acceptable formatting in such usage, see CMS.

## **B.** In articles for HHR for which the original language was other than English:

[e.g., those for which *HHR* obtains an English translation by a translator]:

1. Use the English translation that is provided by the individual who does the translation for HHR, and in the first citation linked to such a translation (in the notes), add a statement to the effect that "all translations of sources within this article are by [name of translator] unless stated otherwise."\*\* EXCEPTION:

2. If it is known that there is an official English version of the source that is readily available online and the translator did not use an "official" version, it is permissible (but not essential) that the translator's text of this source be replaced with this "official" translation. Adapt the reference that is associated with the quotation to reflect the source used.

Whether B.1. or B.2. is used, the source of the translation should be listed in the first note citing that translation.

\*\*NOTE: Citing translation source in first note should be *in addition to* a statement provided at the end of all manuscripts published in HHR that have been translated by a consulting translator. The translator should be credited by a note at the end of the manuscript that reads, for example (with modifications as appropriate):

This article, including all quotations from cases and other Spanish-language material, has been translated from Spanish into English by Victoria Furio.

# C. General comments on citing words/phrases/block quotations that are originally in a foreign language:

1. A translation is always preferable to a paraphrase.

2. Apply the above translation guidelines with the primary goal of producing a narrative that flows smoothly; we strongly advise that explanations and use of foreign words be confined as much as possible to the notes.

3. If a translation is provided, the original-language text does not need to be included in the manuscript; citing the source/translation is sufficient.

## V. PREPARING GRAPHICS (figures, tables, and photographs)

Manuscripts for publication in *Health and Human Rights: An International Journal* may include figures, tables, and/or photographic images. The journal's online media also allows linked postings of dynamic graphics, such as video narratives and other illustrative or supplementary material. The guidelines below apply to figures, tables, and photographic images that authors wish to include as part of the online published manuscript.

## **General guidelines:**

- Please state the number of figures, tables, and illustrations accompanying your submission so that editorial staff and reviewers can verify their receipt.
- Please supply figures in a format that can be edited so that we can regularize and edit spelling, the font and size of labels and legends, and the content and presentation of captions.
- Please include your data spreadsheet with figures prepared as charts and graphs.
- If you are submitting an illustration, ensure that it is of publishable quality (as we do not have a dedicated graphics department).
- If you are submitting a figure as a picture file (e.g., .png, .jpg, .tif), do NOT include the caption as part of the figure; instead, provide the captions with the Word file of the main text of your article.

#### Specific guidelines:

## 1. Format

When you submit the text of your manuscript, please also submit each graphic image as a discrete additional file. Format will depend on content but should be easily editable.

- Tables that consist of words in bulleted narrative, lists, or charts, created in Microsoft Word, can be included in the Word document or supplied as a supplemental Word text.
- Tables or figures that include graphic illustrations may be provided as Word, Excel, or PowerPoint images. PDF files are not editable; if PDF is the only format you have available, please query us to discuss.
- Photographs for publication within the text are categorized as figures and require a legend (described below).
- All photographs require a credit attribution and copyright information (if applicable).
- Please provide the highest quality image available for all tables and figures.

## 2. Legends and citations:

• Each graphic should have a legend (or "caption") that summarizes its message and gives full credit/citation source. The text of the legend should follow CMS 12.32. Text should be in sentence case with a period after the Table or Figure number. Following the legend text, no punctuation is needed after an incomplete sentence; if the legend consists of one or more sentences, each (including the opening phrase) has closing punctuation. For example:

a. Figure 1. Number of human rights laws effected between 1946 and 2000 b. Table 1. Types of injections during survey period. Source: Based on data

collected by the World Health Organization, *Injection practices in the third world* (Geneva, Switzerland: WHO, 2004), pp. 45–48.

- Provide source or credit citations for each image that is not an original creation of the authors or has been previously published elsewhere. No source information is necessary if the graphic is an original creation by the manuscript's author(s) and intended for exclusive publication in this manuscript.
- If the graphic is copied or derived from a published source (including any published by the same author[s]), the source *must* be listed below the figure/table *in full*, *including page number of the published source*, and condition of copyright permission must be obtained from the appropriate copyright holder (e.g., permissions department of the book or journal publisher).
- It is the responsibility of the authors to identify the need for copyright permission of all graphics (including photographs and material previously published by the same authors) and to obtain all necessary copyright permission prior to the layout "proof" stage.
- Authors must provide our editors with a copy of all permission statements before previously published material may be included in *Health and Human Rights*.
- Do not include the legend as part of the figure; instead, provide the captions with the Word file of the main text of your article. Legend and citations in Word text within the document will facilitate copyediting and layout decisions. Citations should follow the same style as other references.



Research Integrity Human Research Ethics Committee

Friday, 26 June 2015

Prof Stephanie Short Health Systems and Global Populations; Faculty of Health Sciences Email: stephanie.short@sydney.edu.au

Dear Stephanie

I am pleased to inform you that the University of Sydney Human Research Ethics Committee (HREC) has approved your project entitled "**Do professional training courses include adequate information about disability, based on Human Rights principles?**".

Details of the approval are as follows:

Project No.: 2015/460

Approval Date: 26<sup>th</sup> June 2015

First Annual Report Due: 26<sup>th</sup> June 2016

Authorised Personnel: Short Stephanie; Bowley Claire; Furmage Ann-Mason;

#### **Documents Approved:**

DATE	TYPE	DOCUMENT NAME
11/05/2015	Advertisements/Flyer	Recruitment email letter
11/05/2015	Other Type	Most recent similar research reference
21/06/2015	Participant Consent Form	Participant Consent Form (Version 2 - 21 June 2015)
21/06/2015	Participant Info Statement	Participant Information Statement (Version 2 - 21 June 2015)
21/06/2015	Interview Questions	Interview Guide (Version 2 - 21 June 2015)

HREC approval is valid for four (4) years from the approval date stated in this letter and is granted pending the following conditions being met:

#### Condition/s of Approval

- Continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans.
- Provision of an annual report on this research to the Human Research Ethics Committee from the approval date and at the completion of the study. Failure to submit reports will result in withdrawal of ethics approval for the project.
- All serious and unexpected adverse events should be reported to the HREC within 72 hours.
- All unforeseen events that might affect continued ethical acceptability of the project should be reported to the HREC as soon as possible.

Research Integrity Research Portfolio Level 6, Jane Foss Russell The University of Sydney NSW 2006 Australia T +61 2 8627 8111 F +61 2 8627 8177 E ro.humanethics@sydney.edu.au sydney.edu.au

ABN 15 211 513 464 CRICOS 00026A



- Any changes to the project including changes to research personnel must be approved by the HREC before the research project can proceed.
- Note that for student research projects, a copy of this letter must be included in the candidate's thesis.

#### Chief Investigator / Supervisor's responsibilities:

- 1. You must retain copies of all signed Consent Forms (if applicable) and provide these to the HREC on request.
- 2. It is your responsibility to provide a copy of this letter to any internal/external granting agencies if requested.

Please do not hesitate to contact Research Integrity (Human Ethics) should you require further information or clarification.

Yours sincerely

Mure

Professor Simon Wilcock Chair Human Research Ethics Committee

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice. Allied health education for disability rights HSBH5006 Research Elective Dissertation



Discipline of Behavioural & Social Sciences in Health Faculty of Health Sciences

USYD HREC Approval No. XXXX

CHIEF INVESTIGATOR Prof Stephanie Short

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#### Health professional education about disability based on Human Rights

USYD HREC Approval No. 2015/460 PARTICIPANT RECRUITMENT EMAIL LETTER

Hello [Insert Name],

You are invited to participate in a study with the objective of researching what education about disability based on Human Rights is provided by the University of Sydney's Faculty of Health Sciences. You have been invited to participate in this study because you coordinated a Unit of Study that had a focus on disability and/or Human Rights in 2014, as identified through a review of 2014 Faculty of Health Sciences Unit of Study outlines. This study is being conducted by Claire Bowley, as part of a Master of Occupational Therapy research project, supervised by Prof Stephanie Short.

Participant Information Statement and Consent Forms have been attached to this email. Participation is completely voluntary. If you would like to participate please return a completed consent form via email. If you do not wish to participate please advise by email.

Thank you for considering this request.

Yours Sincerely,

Claire Bowley Master of Occupational Therapy student

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact The Manager, Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

Allied health education for disability rights HSBH5006 Research Elective Dissertation



Discipline of Behavioural & Social Sciences in Health Faculty of Health Sciences

USYD HREC Approval No. 2015/460

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#### Health professional education about disability based on Human Rights

#### PARTICIPANT INFORMATION STATEMENT

#### (1) What is the study about?

People with disabilities are vulnerable for Human Rights violations, particularly when accessing healthcare. It is therefore important that health professional education include information about disability based on Human Rights, recently recommended in the World Report on Disability (WHO & The World Bank, 2011). Despite this, the provision of education about disability based on Human Rights for health professional students remains unclear.

The University of Sydney's Faculty of Health Sciences offers health professional education across 6 disciplines: Occupational Therapy, Speech Pathology, Physiotherapy, Diagnostic Radiography, Exercise Physiology and Rehabilitation Counselling. This study aims to research what education about disability based on Human Rights is provided by these disciplines. The education provide by the 6 disciplines will be compared to the Human Rights competencies expected by the 6 respective Australian health professional governing bodies (e.g. Occupational Therapy Australia) and the United Nations Convention on the Rights of Persons with Disabilities (2006).

You have been invited to participate in this study because you coordinated a Unit of Study that had a focus on disability and/or Human Rights in 2014.

#### (2) Who is running the study?

Claire Bowley is conducting this study as the basis for the degree of Master of Occupational Therapy at The University of Sydney. This will take place under the supervision of Prof Stephanie Short, of the Discipline of Behavioural and Social Sciences in Health, and in collaboration with disability advocate Ann-Mason Furmage, member of the Occupational Therapy External Advisory Committee for the University of Sydney.

## Allied health education for disability rights HSBH5006 Research Elective Dissertation (3) What will the study involve for me?

This study will require you to participate in a semi- structured telephone interview with Claire Bowley, taking approximately 30 minutes. The interview will include questions relating to your 2014 Unit of Study. This study will also require you to review a summary of the main themes identified in your interview via email, taking approximately 15 minutes.

## (4) Can I withdraw from the study?

Being in this study is completely voluntary. Your decision whether to participate will not affect your current or future relationship with the researchers or anyone else at the University of Sydney. If you decide to take part in the study and then change your mind, you are free to withdraw at any time. You may stop the interview at any time if you do not wish to continue. Unless you say that you want us to keep them, any data recordings will be deleted and not included in the study results. You may also refuse to answer any questions that you do not wish to answer during the interview.

#### (5) What will happen to information about me that is collected during the study?

Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Results of the study will be written up for publication as a student thesis, for a journal and will be submitted for presentation at a relevant conference. There may also be opportunities to present findings within University or Faculty newsletters or bulletins, or through relevant disability organisations (e.g. Physical Disability Council of NSW). Although every effort will be made to protect your identity, through the use of personal and de-identified Unit of Study codes, there is a risk that you might be identifiable in publications due to the nature of the study and/or the results.

#### (6) Are there any risks or benefits associated with being in the study?

Aside from giving up your time and potential identification in publications, we do not expect that there will be any additional risks or costs associated with taking part in this study. If you participate in this study you can elect to can receive feedback about the overall results of the study, providing you with curriculum feedback for future curriculum development.

## (7) What if I would like further information about the study?

If you require further information about the study, please contact Claire Bowley on 0423645189 (Telephone) or cbow5832@uni.sydney.edu.au (Email).

#### (8) What if I have a complaint or any concerns about the study?

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact The Manager, Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

This information sheet is for you to keep

Allied health education for disability rights HSBH5006 Research Elective Dissertation



Discipline of Behavioural & Social Sciences in Health Faculty of Health Sciences

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#### Health professional education about disability based on Human Rights

#### PARTICIPANT CONSENT FORM

I, ......[PRINT NAME], agree to take part in this research study.

In giving my consent I state that:

- ✓ I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved.
- ✓ I have read the Participant Information Statement and have been able to discuss my involvement in the study with the researchers if I wished to do so.
- ✓ The researchers have answered any questions that I had about the study and I am happy with the answers.
- ✓ I understand that being in this study is completely voluntary. I do not have to take part and can withdraw from the study at any time. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of Sydney now or in the future.
- ✓ I understand that I may stop the interview at any time if I do not wish to continue, and that unless I indicate otherwise any data recordings will then be deleted and not be included in the study. I also understand that I may refuse to answer any questions I don't wish to answer.
- ✓ I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand

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that information about me will only be told to others with my permission, except as required by law.

✓ I understand that the results of this study may be published. Although every effort will be made to protect my identity, I may be identifiable in these publications due to the nature of the study or results.

I consent to:						
Participating in a semi- structured telephone interview YES 🛛				NO		
Providing feedback on the themes from my interview via emain		ail	YES		NO	
Would you like to	o receive feedback about the overall results	of th	is stı	udy?		
		YES			NO	
If you answe	red <b>YES</b> , please indicate your preferred form	of fe	edba	ack and a	ddress:	
□ Postal:						
Email:						
Signature						
PRINT name			D	ate		

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact The Manager, Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

## Health professional education about disability based on Human Rights Unit of Study Interview Guide

This interview is part of a Master of Occupational Therapy research project, supervised by Professor Stephanie Short. This study aims to research what education about disability based on Human Rights is provided by The University of Sydney's 6 Faculty of Health Sciences disciplines.

**Team:** Professor Stephanie Short, Head, Discipline of Behavioural & Social Sciences in Health; Claire Bowley, Master of Occupational Therapy student; Ann-Mason Furmage, Member of the OT External Advisory Committee for the University of Sydney.

Discipline:	
Unit of study Code:	
Unit of study Name:	
Unit of Study Coordinator:	
Phone:	
Email:	
Mode of Delivery:	1. Face-to-face     2.Distance     3. Flexible Delivery
Enrolment:	Semester 1 Semester 2
Level:	Undergraduate Postgraduate
Requirement:	Compulsory Elective

## In your opinion, what education about disability based on human rights is provided by your UOS?

## Part I: Unit of Study Details (Formal Curriculum)

Questions	Answers	Comments
<b>1.1</b> Do you teach Human Rights	Health in general	
principles for health in general		
or specifically for persons with	Specifically for persons with	
disabilities?	disabilities	
<b>1.2</b> Does this unit refer to the		
UN Convention on the Rights	Yes No	
of Persons with Disabilities?		
If No, continue to question 1.4.		
1.3 Does this unit teach	Yes No	
students how to recognize and		
document Human Rights		
violations in accordance to the		
UN Convention on the Rights		
of Persons with Disabilities?		

HSBH5006 Research Elective D		
1.4 Does this unit refer to the rights of persons with disabilities for:	<ul> <li>Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;</li> <li>Non-discrimination;</li> <li>Full and effective participation and inclusion in society;</li> <li>Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;</li> <li>Equality of opportunity;</li> <li>Accessibility;</li> <li>Equality between men and women;</li> <li>Respect for the evolving capacities of children with disabilities to</li> </ul>	
<b>1.5</b> Does this unit define disability? If so, how?	preserve their identities. Yes No Definition:	
<b>1.6</b> Does this unit provide information on the history of Human Rights?	Yes No	
<b>1.7</b> Does this unit address the universality of Human Rights?	☐Yes No	
<b>1.8</b> Does this unit address the interrelated, interdependent and indivisible nature of Human Rights?	Yes No	
1.9 Does this unit teach	Yes No	

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students about treatment and support for victims of Human Rights violations?		
<b>1.10</b> Does this unit teach students to help their clients/patients understand and defend their Human Rights?	Yes No	
<b>1.11</b> How much time is devoted to teaching Human Rights principles within this unit?		
<b>1.12</b> How are Human Rights principles taught in this unit?	<ul> <li>1.As the sole subject (i.e. standalone subject)</li> <li>2.As a module within a unit containing other subjects</li> <li>3.As a theme integrated throughout the entire unit of study</li> <li>4.Other (please specify):</li> </ul>	
<b>1.13</b> What instructional activities are used in this unit?	<ul> <li>1.Lectures</li> <li>2.Small group discussions</li> <li>3. Large group discussions</li> <li>4. Debates</li> <li>5.Group activities</li> <li>6.Film/video</li> <li>7.Guest speakers</li> <li>8.Community based learning</li> <li>9. Case Studies</li> <li>10.Fieldwork</li> <li>11.Role-play</li> <li>12.Simulation</li> <li>13.Theatre/drama</li> <li>14.Other (please specify):</li> </ul>	
<b>1.14</b> What forms of assessment are used to evaluate learning in this unit?	<ul> <li>1.Essays</li> <li>2.Written Exams</li> <li>3.Case studies</li> <li>4.Papers</li> <li>5.Reflective journals</li> <li>6.Presentations</li> <li>7.Other (please specify):</li> </ul>	

# Allied health education for disability rights HSBH5006 Research Elective Dissertation

TISDITS000 Research Elective D	issertation	
1.15 Are you aware of any	Yes No	
other 2014 Faculty of Health	If Yes, record details below:	
Sciences units that provided		
information about disability		
based on Human Rights?		

## Part II: Extra-Curricular Activities (Informal Curriculum)

Questions	Answers	Comments
<b>2.1</b> Does your unit provide	Yes No	
information about disability	If Yes, record details below:	
based on Human Rights in	,	
ways other than the formal		
unit of study?		
<b>2.2</b> Are you aware of any other	1. Human Rights electives	
strategies that the Faculty has	2. Human Rights study modules	
used to incorporate Human	3. Human Rights speaker series	
Rights intoinformal	4. Human Rights film series	
curriculum/extra-curricular	5. Health and Human Rights	
activities?	interest groups	
	6.Admissions policies to recruit	
	educationally disadvantaged	
	students	
	7. Staff recruitment policies to	
	achieve equity targets in historically	
	disadvantaged groups	
	8.Research initiatives in health	
	and Human Rights	
	9.Methods of teaching and	
	learning that emphasise a Human	
	Rights based approach (e.g. using a	
	patient centered approach to	
	clinical teaching; emphasising the	
	socioeconomic context of health	
	and illness)	
	10.Staff/faculty development in	
	Human Rights	
	11.Development of a new health	
	professional oath or code of ethical	
	conduct	
	12.Other (please specify):	

# Allied health education for disability rights HSBH5006 Research Elective Dissertation

## Part III: Supports and barriers

Questions	Answers	Comments
<b>3.1</b> Which people within the Faculty have been helpful in implementing Human Rights principles for disability into the curriculum?	<ul> <li>1. Dean</li> <li>2. Head of Discipline</li> <li>3. Colleagues</li> <li>4. Students</li> <li>5. Other (please specify):</li> </ul>	
<b>3.2</b> How has the Faculty supportedthe implementations of Human Rights principles for disability into the curriculum?	<ul> <li>1. Increased the budget</li> <li>2. Provided you with additional resources (e.g. staff, office space, computers)</li> <li>3. Formed new committees</li> <li>4. Established a fellowship or internship</li> <li>5. Funded training for staff or students</li> <li>6. Provided support for additional training in Health and Human Rights education</li> <li>7. Given a sabbatical or study or research leave</li> <li>8. Funded Human Rights research</li> <li>9. Other (please specify):</li> </ul>	
<b>3.3</b> What barriers have been faced when attempting to implement Human Rights principles for disability into the curricula?	<ul> <li>1. Competition for time</li> <li>2. Lack of qualified instructors</li> <li>3. Lack of funding</li> <li>4. Lack of administrative support</li> <li>5. Lack of curriculum board support</li> <li>6. Lack of student interest</li> <li>7. Lack of resource material</li> <li>8. Other (please specify):</li> </ul>	

Allied health education for disability rights HSBH5006 Research Elective Dissertation **Do you have any other comments regarding your 2014 Unit of Study?** 

Do you have any other comments regarding the implementation of Human Rights within the University of Sydney's Faculty of Health Sciences?

Can you suggest any additional resources not already listed in your Unit of Study Outline that may assist us in our theoretical research?

ournals:	
ooks:	
Vebsites:	
)ther:	

Thank you very much for taking the time in completing this interview. Your contribution is extremely valuable.