

# bioethics

A Nursing Perspective

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A Nursing Perspective

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Megan-Jane Johnstone AO, PhD, BA, RN

Retired Professor of Nursing and Independent Scholar Victoria, Australia





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15 Ethics and Public Health Emergencies: Climate Change, Antimicrobial Resistance, Health Inequities and Emergency Preparedness, 320 Introduction, 320

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Conclusion, 329

Bibliography, 332 Index, 397 It is more than 30 years since the first edition of this book was published, and it is no small measure of the continuing importance of ethical issues in nursing and health care that a demand for this eighth, revised edition exists. When the first edition of this book was published in 1989 (the first to be written from an Australian and New Zealand perspective), nursing ethics - its broad theoretical basis and the implications of the burgeoning field of bioethics for nurses - had received relatively little attention in the depth and breadth required. Over the past three decades since the first edition of this book was published, nursing ethics has strengthened both in focus and in sophistication as a distinct field of inquiry and practice. In all the subsequent editions of Bioethics: a nursing perspective, substantive revisions were made to reflect the emergence of contemporary ethical issues, and the revitalisation of old debates and the emergence of new debates on both old and new issues.

The revision of this eighth edition was undertaken during the COVID-19 pandemic and extended periods of lockdown. Writing about the ethical issues that emerged during the pandemic was a surreal experience: what had been only theorised and anticipated in the previous sixth and seventh editions had become a grim reality. The pandemic also impressed on me the humbling insight that merely *writing about* a public health emergency is a very different experience to *actually living through* one.

As I, like so many others, witnessed the 'bad behaviours' of small sections of the community throughout the pandemic (examples of which are given in the new Chapter 14 on 'Pandemic ethics') and the extraordinary demands placed on nurses during this time, I came to question the relevance, value, authority and power of bioethics and nursing ethics discourse to question and call into question the status quo and to 'make for a better world'. It soon became clear to me, however, that the need for ethics in today's post-truth world has perhaps never been greater, particularly in socio-cultural-political contexts where the behavioural norms of civility, common decency and respect for others are displaced, and where people falsely claim 'bogus rights' and 'moral entitlements' in defence of their bad behaviour. It is especially needed in a world in which protesters claiming their 'rights' resort to bullying, assaulting and even killing those with whom they disagree. And it is needed in this time of continuing uncertainty during which people are confronted by ambiguity, doubt and even helplessness as the world order that once seemed so

familiar and controllable to them has changed and continues to change each day.

It is generally accepted that nurses, as professionals, ought to subscribe to a higher standard of ethical conduct than ordinary people on the street. Against the backdrop of our changing world of displaced norms, however, there is room to question whether nurses are in fact obliged to conduct themselves in accordance with a higher moral standard than lay people, and what the basis of this expectation might be. Moreover, how ought nurses to conduct themselves when faced with a vocal minority of the population who flaunt, infringe or ignore even the most basic requirements of what it means to be an ethical ('good' and 'decent') person? How are nurses to maintain their professional moral standards, discipline and integrity when faced with sometimes-violent disagreement with others who justify their stance by espousing 'baseless facts' and violating communal moral interests? These and other questions are just some that are explored in this eighth revised edition.

In response to the helpful comments of those who have reviewed the previous edition of this book, some structural changes have been made to improve the reading and learning experiences of students using the book as a reference: the book is now divided into four sections, references have been updated throughout, and new material has been added - for example, on issues such as cultural racism, the importance and moral significance of culture and context in health care domains and their impact on moral decisionmaking, the nocebo effect and truth-telling in clinical contexts, the ethical quandaries posed by patients who refuse nursing care, the moral importance of a recovery-oriented approach to mental health care, the newly legislated role of nurse practitioners enabling them to participate and perform medically assisted deaths, and pandemic ethics exploring the ethics of solidarity, the harmful impact of medical conspiracism, vaccine ethics and equity, and the ethics of operationalising crisis standards of care during public health emergencies. Each of the four sections has a preamble in which a succinct summary of the issues examined in the relevant chapters is made.

In concluding this eighth revised edition, I would like to make special mention of and honour the tens of thousands of nurses in my home countries of Australia and New Zealand together with the millions of nurses in other countries around the globe who, during the COVID-19 pandemic, went well beyond the call of duty to provide

care and support to patients and their families in the most harrowing of circumstances. It is ironic that, in a work of this length, there really are not sufficient words to express the depth of gratitude and words of solace that are due to these nurses who turned up for work - day after day, week after week, month after month - as each new wave of the pandemic surged and hospitals were overwhelmed. Sadly, as those looking on from the sidelines we will never really 'know' the pain of the sacrifices these nurses made (many of whom lost their lives to COVID) and what the long-term impact will be on their future wellbeing. If there is a lesson to be learned, it is this: governments must adopt a 'justin-case' (stock inventory ahead of time) not a 'just-in-time' (only stock inventory as needed) inventory system (e.g. for PPE, medications, respirators) and a 'when' not 'if' stance on future pandemics (as they have failed so badly to do with COVID-19). Governments must also ensure that, in anticipation of the inevitability of future pandemics (which has been known about for years), the health care system and the nurses who staff them are properly prepared, equipped and supported to manage them.

As this book goes to press, the world continues to face unprecedented challenges: the global impact of the devastating war in Ukraine, disruptions to essential supply chains across the world, a substantial rise in global hunger numbers (estimated to be more than 828 million), a global energy crunch, a rise in cases of monkeypox throughout the world, and successive (more contagious) waves of the COVID-19 pandemic – all of which have placed renewed pressure on the world's health care systems with

some nearing breaking point. In addition, multiple heatwaves induced by climate change have occurred across the globe. These heatwaves have felled temperature records and fuelled wildfires forcing the evacuation of thousands of people from their homes in France, Spain, Portugal and Greece, with each of these countries seeing high numbers of heat-related deaths. Even the UK, known for its cooler climate, has not been spared, with record-breaking temperatures exceeding 40°C in some parts, placing great stress on the country's unaccustomed infrastructure – including its National Health Service.

Regrettably it was too late to incorporate discussion on the above events and other issues into the relevant chapters in this book (e.g. the winding back of abortion rights in the US following the Supreme Court's decision to overturn Roe v Wade; an increasing threat and, in some cases, outright assault of many hard-won human rights and freedoms otherwise enjoyed by people in democratic nations, e.g. gay marriage; outlawing the practice by some religious groups of so-called 'conversion therapy' to change a person's sexual orientation and gender identity). Nevertheless, the moral decision-making frameworks considered in this book are relevant to guiding deliberations on the range of complex ethical issues that these and other recent events inevitably raise. As stated throughout this book: there is still much work to be done to achieve a better, just and more peaceable world. Now, perhaps more than ever, ethics matter.

Dr Megan-Jane Johnstone AO

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This book would not be the success it has been were it not for the many registered nurses, students, patients, colleagues and others whose generosity in sharing their experiences and views over the past three decades has, in many ways, made this book possible. I extend my enduring gratitude to all. Thank you.

In keeping with the work required to undertake the revisions of this book, acknowledgment is due to the School of Nursing and Midwifery, Deakin University, for granting me visitor access to the Deakin University library. As with any scholarship, access to university libraries is essential to enable searching for and resourcing the world's best available literature. The Deakin University library was just wonderful in this regard.

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- University of Chicago Press, Chicago: Wong D (1992) Coping with moral conflict and ambiguity. *Ethics*, 102(4): 763–84

# LIST OF ABBREVIATIONS

ABC Australian Broadcasting Corporation

ABS Australian Bureau of Statistics ACN Australian College of Nursing ACP advance care plan/planning

evier Australie Australian Commission on Safety and Quality in Health Care **ACSQHC** 

**AHMAC** Australian Health Ministers Advisory Council **AHPRA** Australian Health Practitioner Regulation Agency

AIDS acquired immunodeficiency syndrome AIFS Australian Institute of Family Studies Australian Institute of Health and Welfare AIHW ALRC Australian Law Reform Commission Australian Medical Association AMA AMR antimicrobial resistance ANA American Nurses Association

Australian Nursing and Midwifery Federation **ANMF** 

ANH artificial nutrition and hydration

Australian Network for the Prevention of Elder Abuse ANPEA

ΑP Associated Press

culturally and linguistically diverse CALD

**CALDB** culturally and linguistically diverse background clinically assisted nutrition and hydration CANH **CCP** Compassion Cultivation Program

CDC Centers for Disease Control and Prevention **CLAS** cultural and linguistically appropriate services

Canadian Nurses Association **CNA** COAG Council of Australian Governments **CPR** cardiopulmonary resuscitation

**CRPD** Convention on the Rights of Persons with Disabilities **CSDH** Commission on Social Determinants of Health

DCS deep continuous sedation DNR Do Not Resuscitate DoH Department of Health DST deep sleep therapy EC **European Community ECG** electrocardiograph **ECT** electroconvulsive therapy ED emergency department ELP English language proficiency EN enrolled nurse

GFC Global Financial Crisis
GP general practitioner
HAI HelpAge International
HCP health care professional
HCW health care worker

HIV human immunodeficiency virus
HPP Homeless Persons Program
ICN International Council of Nurses

IMR infant mortality rate
IOM Institute of Medicine (USA)

ISPCAN International Society for the Prevention of Child Abuse and Neglect

IVF in vitro fertilisation

IWGIA International Work Group for Indigenous Affairs

LEF low English fluency
LEP limited English proficiency

LGBTIQA+ lesbian, gay, bisexual, transgender, intersex, queer / questioning, asexual, + other

LOTE language other than English
MAD medically assisted death
MAiD medical assistance in dying
MAS medically assisted suicide
MCT medical conspiracy theory/theories
NBV Nurses Board of Victoria
NCHK Nursing Council of Hong Kong

NES non-English speaking/native English speaker

Nursing Council of New Zealand

NESB Non-English speaking background

NFR Not For Resuscitation
NFT Not For Treatment

NCNZ

**PBS** 

NGO non-government organisation NHS National Health Service

NLCHP National Law Center on Homelessness and Poverty

Pharmaceutical Benefits Scheme

NMBA Nursing and Midwifery Board of Australia
NMC Nursing and Midwifery Council (UK)

NNA National Nursing Association **NNES** non-native English speaker NT Northern Territory (Australia) **NWRO** National Welfare Rights Organisation **NZNO** New Zealand Nurses Organisation Office of the Public Advocate **OPA** PAD psychiatric advance directive PAS physician-assisted suicide

PDCC Police Department's Communication Centre PEG percutaneous endoscopic gastrostomy

PHM People's Health Movement

PPE personal protective equipment

PPS proportionate palliative sedation

PTSD post-traumatic stress disorder

QLS Queensland Law Society

RCNA Royal College of Nursing, Australia
RDNS Royal District Nursing Service

RN registered nurse

RPC respecting patient choices

SARS severe acute respiratory syndrome

SBD self-binding directive

SCRGSP Steering Committee for the Review of Government Service Provision (Australia)

SNB Singapore Nursing Board

SOGI sexual orientation and gender identity

TMT Terror Management Theory

TNMC Thailand Nursing and Midwifery Council

TRC Truth and Reconciliation Commission (South Africa)

UK United Kingdom
UN United Nations

UNDP United Nations Development Programme
UNHCR United Nations High Commissioner for Refugees

US United States

WASP White Anglo-Saxon person

WEIRD Western, educated, industrialised, rich and democratic

WHA World Health Assembly
WHO World Health Organization
WMA World Medical Association

WWII World War Two

# Ethics, Dehumanisation and Vulnerable Populations

# LEARNING OBJECTIVES

Upon the completion of this chapter and with further self-directed learning, you are expected to be able to:

- Discuss critically the notion of vulnerability.
- Examine the possible relationship between human vulnerability and dehumanisation.
- Discuss critically the relationship between dehumanisation, delegitimisation and moral disengagement.
- Identify vulnerable individuals and groups for whom nurses may have special responsibilities.
- Explore the role, obligations and responsibilities of nurses in mitigating the morally harmful consequences of the dehumanisation of vulnerable individuals and groups in health care and society.

# **KEYWORDS**

aggregate vulnerability cultural racism dehumanisation delegitimisation dignity violations disadvantage discrimination humanness moral disengagement moral exclusion moral inclusion prejudice

racism rehumanisation stigma vulnerability vulnerable populations

# INTRODUCTION

During a conference presentation I was giving on the subject of vulnerability in health care, I asked those present to raise their hands if they had ever experienced feeling vulnerable. Interestingly, all those present raised their hands. I then asked if they would be willing to share what had triggered their experience of vulnerability. Only a few declined, as others, one-by-one, shared their stories several of which were harrowing. Drawing on what they had revealed, I then asked them to imagine the vulnerability that patients and their families might feel when encountering a health crisis, or how people who are homeless might feel when sleeping rough on the streets, or how refugees and asylum seekers might feel living in a world that is hostile to their presence. As the participants sat in quiet reflection on their shared vulnerability with *imagined others, a solemn silence enveloped the room ...* 

(Author)

National and international nursing standards, position statements, codes of conduct and related scholarship are replete with references to the role and responsibility of nurses: to consider the needs of the 'most' or 'especially' vulnerable, to give 'special attention' to vulnerable groups and populations, and to 'emphasise vulnerable groups' when applying human rights protection. Just what is meant by the notion 'vulnerability', who counts as being 'the most vulnerable', why perceived vulnerability might give rise to nurses' moral obligations and duties of justice, and how the notion might be operationalised as an action-guiding principle in nursing ethics discourse are, however, not well understood or theorised. In light of this, several questions arise (Box 7.1) which will be addressed in this chapter.

# **BOX 7.1 Questions about the Nature and Moral Significance of Vulnerability**

- What is vulnerability?
- When is it appropriate to describe a person or group as 'especially' or 'the most' vulnerable?
- How might the notion of 'human vulnerability' function as a guide to moral action?
- What special responsibilities and remedial measures should considerations of human vulnerability inspire and require of nurses in the course of their everyday practice?

### **VULNERABILITY**<sup>1</sup>

The idea of vulnerability has many meanings and applications, which, over the past three decades, have become the subject of increasing philosophical debate in the bioethics literature. A notable feature of this debate has been the emergence and ongoing critique of 'a taxonomy of vulnerability' (Box 7.2) (Delgado Rodriguez 2017; MacKenzie 2020; MacKenzie et al 2013a, 2013b; Rogers et al 2012). Although theorists disagree about whether vulnerability is universal (intrinsic to the human condition) or contextual (relational and context specific), there is agreement that it entails a sentient being having several characteristics (Box 7.3). These include an entity's capacity to be wounded or hurt physically and emotionally, and/or who is susceptible to being harmed through being exploited, or exposed to disaster, in morally significant ways (Delgado Rodriguez 2017; Hoffmaster 2006; MacKenzie et al 2013a; Masferrer & García-Sánchez 2016; Ruof 2004). It is also recognised

# **BOX 7.2 Taxonomy of Vulnerability**

- 1. Inherent vulnerabilities sources of vulnerability are universal and intrinsic to the human condition (i.e. our 'ordinary' physicality e.g. 'we all bleed', our need of and dependence on others).
- 2. Situational vulnerabilities sources of vulnerability are situational/context specific (i.e. personal, cultural, social, economic, political and environmental factors are at play and can either ameliorate or exacerbate an individual's or a group's vulnerability).
- 3. Pathogenic vulnerabilities these may arise when responses intended to remedy vulnerability have the paradoxical effect of making existing vulnerabilities worse or creating new ones (i.e. may undermine a person's autonomy and increase their sense of powerlessness engendered by their existing vulnerability). (Source: after Mackenzie et al 2013b)

### **BOX 7.3 Characteristics of Vulnerability**

The word *vulnerability* comes from the Latin *vulnerāre* meaning to wound, and encompasses:

- the capacity to be wounded or hurt physically and emotionally
- susceptibility to being harmed in morally significant ways through:
  - marginalisation
  - exploitation
  - rejection
  - abuse
  - neglect
  - humiliation
  - ostracisation
  - disadvantage
  - exposure to disaster.

that using vulnerability as a conceptual frame is 'an important way to capture disadvantage' – particularly of those who have been, or who are at risk of being, marginalised by mainstream society (Blacksher & Stone 2002: 421).

In his classic work *Protecting the vulnerable*, Goodin (1985: xi) clarifies that some vulnerabilities (and the responsibilities that emerge in response to them) are 'natural, inevitable, and immutable', whereas others are 'created, shaped, or sustained by current social arrangements'. Given this, there is scope to hold that 'vulnerability is a human condition from which we all suffer' and from which 'we all deserve equal protection' (Kottow 2003: 461; see also Andorno 2016; Cortina & Conill 2016; Masferrer & García-Sánchez 2016). To put this another way: 'None of us is invincible; all of us are vulnerable' and, as such, vulnerability needs to be addressed as a moral concern (Hoffmaster 2006: 43).

# **Identifying Vulnerable Populations**

Human vulnerability may indeed be a universal condition and a state from which we all deserve equal protection (Kottow 2003; Masferrer & García-Sánchez 2016). Even so, as can be readily demonstrated, there are some people who are more vulnerable than others and who, for various contextual reasons, are less able to protect their own interests when these are at risk of being harmed. Correct identification of these people is essential if the special protective responsibilities that others have towards them are to be realised in policy and practice, and to ensure that remedies are not imposed paternalistically.

Vulnerability can be *individual* (individual vulnerability) or *aggregate* ('vulnerable groups', 'vulnerable populations', 'social vulnerability') (de Chesnay & Anderson 2019;

# BOX 7.4 Individuals Commonly Identified as Vulnerable

Entities commonly identified as being 'vulnerable' include those who:

- are very young and lack maturity (e.g. infants, children and young adolescents)
- are highly dependent on medical care (and who may be unable to give consent)
- have a cognitive impairment or who have an intellectual disability
- have a mental health problem or illness
- have a physical disability (and who are dependent on others for their daily care)
- are very old, frail and isolated (e.g. the dependent older person)
- are of low socioeconomic status (e.g. the poor, homeless and/or unemployed)
- are serving a prison sentence for criminal offences (prison inmates)
- are members of an ethnic minority group or population
- are refugees, asylum seekers, displaced persons or stateless persons
- (in Australia) identify as being Aboriginal or Torres Strait Islanders
- (in New Zealand) identify as being Māori.

Masferrer & García-Sánchez 2016; Mastroianni 2009). In the case of individual vulnerability, examples of entities commonly identified (particularly in national research guidelines) are listed in Box 7.4. In the case of *aggregate vulnerability*, entire groups, populations and even countries can be characterised as being vulnerable – for example, groups and populations that are at risk of premature mortality or morbidity (Purdy 2004), and poorer nations or countries that are at risk of exploitation by researchers, drug companies, fast food companies, mining magnates and the like.

# **Vulnerability as a Guide to Action**

Not all agree that vulnerability is a useful concept or even that it has a place as a guide to ethical conduct. Some critics argue that labelling individuals and groups as vulnerable may have the undesirable consequence of paradoxically stigmatising them and also risk their being marginalised on the basis of the very characteristics for which they have been deemed to be vulnerable (e.g. old age, disability, decisional incapacity). Thus, individuals and groups labelled vulnerable may find themselves also carrying the burden of what Martha Minow (1990: 20) calls the 'stigma of difference' and the 'moral pathology

of prejudice' that underpins it. (According to Minow, the stigma of difference is so potent that it 'may be created both by ignoring it and by focusing on it'.) Underscoring this contention, Mackenzie and colleagues (2013b: 9) caution that, in some situations, a response intended to ameliorate vulnerability 'may have the paradoxical effect of exacerbating existing vulnerabilities or generating new ones'.

Other critics, meanwhile, object to identifying people as vulnerable on grounds that it could seem patronising, condescending and paternalistic. Danis and Patrick (2002: 320), for example, argue that 'Labeling individuals as "vulnerable" risks viewing vulnerable individuals as "others" worthy of pity', a view rarely appreciated (e.g. a healthy and active octogenarian may not appreciate being categorised as 'vulnerable' simply on the basis of his or her old age; likewise a pregnant woman, consenting to be interviewed for a research project, may not appreciate being categorised as 'vulnerable' simply because of being pregnant).

It is not clear that these criticisms are sustainable in some contexts, however. This is especially so when considered in relation to the possible link that exists between vulnerability and dehumanisation (to be considered shortly). Moreover, emerging works are increasingly suggesting that the notion of vulnerability not only gives functional structure to the moral obligations that people have towards others, but also inspires and requires them to engage in actions that respect, protect and remediate breaches of people's human rights and social justice violations (Andorno 2016; Masferrer & García-Sánchez 2016).

In light of these developments there is room to suggest that, despite ongoing debate about the concept of vulnerability, it remains essential if not foundational to contemporary bioethics (Andorno 2016; Cortina & Conill 2016; Delgado Rodriguez 2017; Goodin 1985; Hoffmaster 2006; Masferrer & García-Sánchez 2016; Rogers et al 2012). It also stands as an important signifier that, because of their corporeal fragility, all human beings have the capacity to be hurt or wounded in morally significant ways. Hence the capacity of people to be hurt needs constantly to be taken into consideration in day-to-day practices (whether clinical, administrative, educational or research related), underscoring the point that attempts to define and protect 'vulnerable populations' through codes, standards and institutional regulations are not necessarily a case of 'bureaucratic overreach' (Blacksher & Stone 2002; Goodin 1985). In short, the concept of vulnerability may, in practice, be the key to the prevention of ethics and social justice violations in both health and social care contexts.

The identification of vulnerability as a 'missing feature' of contemporary moral philosophy (Hoffmaster 2006) and as an understated source of our 'special responsibilities' to

protect others (Goodin 1985: 109) remains an important subject for further inquiry.

# **Vulnerability and Nursing Ethics**

Vulnerability has been identified as an 'understated foundation' of ethical sensibility in nursing (Nortvedt 2003) and as a construct that ought to have an important, if not pre-eminent, place in nursing ethics. At the time of writing, vulnerability as a foundational concept in nursing ethics has yet to be adequately and appropriately theorised. Even so, given the extensive 'vulnerability ethics' literature that is now available in the field of bioethics, nurses have a timely opportunity to learn about vulnerability and its importance as a foundational ethical concept. In the meantime there is scope to contend that nurses must also reflect on and feel their own vulnerability. This is because, as examples to be given in this and the following chapters of this book make plain, unless we feel our own vulnerability we will not be able to affirm either our own or others' humanity. And unless we 'recognise the depth and the breadth of our vulnerability' we will not realise 'how much we need the help of others to protect us from our weaknesses and our infirmities' (Hoffmaster 2006: 44) or, conversely, how much others may need us to assist them when weak and unable to help themselves.

Until nurses recognise the inherent (universal), contextual and pathogenic (exacerbated) vulnerabilities of people and the related moral obligations we all share to help and protect those who have become unable to protect their own interests, the risk of 'vulnerability tragedies' occurring and also being repeated will remain. To help further explain why this risk exists, an exploration of the notion of dehumanisation and its underrecognised link to human vulnerability is warranted.

# HUMANNESS, DEHUMANISATION AND VULNERABILITY

An understated cause and consequence of human vulnerability is *dehumanisation* and the unfair ways in which this can *disadvantage* people. Dehumanisation is a recognised predictor of prejudice, discrimination, marginalisation and extreme violence against people deemed 'other', notably by those who have a social dominance orientation (to be explained shortly) and who view those they have 'othered' as being less morally worthy and hence less morally deserving than themselves or their 'in-group'. In order to understand the possible relationship between vulnerability and dehumanisation, some understanding of the nature of dehumanisation and its capacity to have a devastating impact on the moral interests and the humanity of all people is warranted. To this end, in the discussion to follow, consideration will be

given to the interrelated notions of humanness, dehumanisation, delegitimisation, moral exclusion, moral inclusion, stigma, prejudice, discrimination and disadvantage.

### Humanness

In order to make sense of what dehumanisation is (commonly taken to mean the denial of humanness), an account of *what* is being denied – that is, what constitutes *humanness* – is first required (Haslam et al 2008). Humanness' and what it means to be human are 'slippery' notions and have occupied the attention of philosophers for centuries. More recently it has been the subject of a growing body of research and scholarship in the field of social psychology, which is giving rise to new and important insights into the phenomena of humanness and dehumanisation, although this work has by no means settled ongoing debates about the subject (Bain et al 2013; Kaufmann et al 2011a; Kronfeldner 2021; Vaes et al 2021). As Haslam (2013: 36) notes, 'one of the key developments in recent research and theory is that humanness is not a unitary idea'.

Conventional philosophical debates on what it means to be a human being have typically focused on drawing a distinction between an entity being genetically human and having personhood. Meeting the criteria of personhood has been quintessential to determining whether or not an entity ought to be categorised as 'human' and accorded moral status (Bastian et al 2011). This distinction has had particular resonance in the abortion debate, whereby the human fetus has been characterised as genetically human, yet not necessarily as having personhood (this issue will be discussed in more depth in Chapter 11), and likewise debates about the use of anencephalic infants for organ donation to help overcome organ shortages for transplantation in infants. On account of not meeting the criteria of personhood, human fetuses and anencephalic infants have tended to be positioned as beings without moral status and thus without any of the moral rights that might otherwise be commensurate with an entity having moral status.

Debate surrounding the issues of abortion and the use of anencephalic infants as organ donors are just two examples that may help to explain why addressing the question of humanness is important. Specifically, it highlights the normative belief that the 'qualities that make us human are also those that give us moral status' (Bastian et al 2011: 469). This, in turn, highlights the moral problem that there is a relatively short step between denying people their humanness and denying them their moral status. As Opotow (1993) has observed, when people are portrayed as being outside of the category 'human' they lose all the protections that being human entails. This is because the denial of humanness places people 'outside the boundary in which moral values, rules, and considerations of fairness

apply' and renders them 'nonentities, expendable and as morally undeserving' (Opotow 1990a: 1). Moreover, if they are harmed as a result of their moral exclusion, it is likely the harms experienced would be construed by its perpetrators as being not only acceptable, but also appropriate and just (Opotow 1990a; see also Bar-Tal 1990).

The questions remain: 'What is humanness?' and 'Is it something that one person or group can credibly deny another?'

Social psychologists suggest that, notwithstanding the difficulties in achieving a consensual definition of humanness, there are two senses in which humanness tends to be viewed, both of which serve the purpose of distinguishing humans from other species (Haslam 2006; Haslam et al 2008). The first sense, which contrasts humans with animals, is human uniqueness - meaning properties that are uniquely human and not shared by other beings (Haslam 2013: 36). An example would be the human capacity for complex emotions (such as disillusionment, felicity, embarrassment, optimism, admiration), which is in contrast to the basic emotions (such as anger, fear, sadness, surprise, pleasure) that other non-human animals also share (Leyens et al 2000). Other uniquely human characteristics that have been suggested include the properties of 'civility [culture], refinement, moral sensibility, rationality, logic and maturity' - properties which other species are presumed to lack (Haslam 2006: 257).

The second sense of humanness, which contrasts humans with inanimate objects (e.g. machines, robots and automatons), encompasses what is regarded to be *typically human* in that it reflects *human nature* (Haslam 2006; Haslam et al 2008). *Human nature*, in this instance, may manifest as 'emotional responsiveness, interpersonal warmth, cognitive openness, agency and individuality, depth [of character]' (Haslam 2006: 257) – properties that robots and machines do not have.

### **Dehumanisation**

Dehumanisation fundamentally entails denying the humanness of others. Such denial can take several forms, can be expressed in different ways and can result in morally significant harmful consequences (e.g. ethnocide). If the effects of dehumanisation are to be mitigated then the phenomenon itself needs to be understood. Specifically, the different forms that dehumanisation can take, the different ways it can be expressed in everyday life, why it occurs, what its consequences are and how, if at all, it might be deterred all require examination. It is to examining these issues that this discussion now turns.

### **Forms of Dehumanisation**

Research suggests that dehumanisation corresponds in varying ways to the two senses of humanness outlined in

the previous section – that is, that which is *uniquely human* and that which reflects *human nature* or is *typically human* (Haslam 2006; Haslam et al 2008). Accordingly, dehumanisation may take one or more of the forms such as those outlined in Box 7.5. Underpinning each of these forms of dehumanisation is a psychological process that Bar-Tal (1990: 65) has termed '*delegitimisation*', which he defines as the:

categorization of a group or groups into extreme negative social categories that are excluded from the realm of acceptable norms and/or values.

He further explains that delegitimisation (also a type of stereotyping and of prejudice) has five distinguishing characteristics as summarised in Box 7.6.

The processes of dehumanisation and delegitimisation, in turn, rest on what Bandura (1999: 193) has termed 'moral disengagement' (discussed earlier in Chapter 4). In this instance, moral disengagement sees perpetrators of dehumanisation cognitively restructure their inhumane conduct as being 'benign and worthy' via a complex interplay of the following processes:

moral justification, sanitizing language, and advantageous comparisons; disavowal of a sense of personal

### BOX 7.5 Three forms of dehumanisation

Dehumanisation can take one or more of the following forms:

- Animalistic dehumanisation whereby people are deemed to be more 'animal-like' than other categories of people, or summarily demoted to animal status (e.g. characterised as 'rats', 'pigs', 'dogs', 'cows', 'asses', 'monkeys', 'spiders', 'snakes', 'parasites', 'cockroaches' and other vermin).
- Mechanistic dehumanisation whereby people are reduced or demoted to inert, unfeeling automatons (e.g. the biomedical characterisation of the human body as a 'machine' with 'parts' that require fixing, replacing or removal; employees on an assembly line treated 'as if' they are robots).
- Superhumanisation whereby people are either elevated to the status of and/or idealised as gods and angels; or derogated as satans, devils and demons (e.g. a philanthropist characterised as a 'saint' or 'angel', a fiend characterised as 'the devil incarnate', a murderer portrayed as a 'monster').

(Sources: Bain et al 2013; Bar-Tal 1989, 1990; Haslam et al 2008; Hodson et al 2013; Utych 2017)

# BOX 7.6 Five Distinguishing Characteristics of Delegitimisation

- 1. It utilises extremely negative, salient and atypical bases for categorisations.
- 2. It denies the humanity of the delegitimised group.
- 3. It is accompanied by intense, negative emotions of rejection, such as hatred, anger, contempt, fear or disgust.
- 4. It implies that the delegitimised group has the potential to endanger one's own group.
- 5. It implies that the delegitimised group does not deserve human treatment and therefore harming is justified. (Source: Bar-Tal 1990: 66)

agency by diffusion or displacement of responsibility; disregarding or minimizing the injurious effects of one's actions; and attribution of blame to, and dehumanization of, those who are victimized.

As will be considered shortly, because these processes operate and can be advanced in extremely subtle ways, they can often be difficult to detect and hence difficult to deter and remedy.

### **Explicit and Subtle Expressions of Dehumanisation**

Research suggests that dehumanisation can be expressed in various ways, ranging from the 'obvious', overt and explicit expressions of dehumanisation (the kind that has tended to receive the most attention up until recently) to the less obvious, covert and subtle expressions – the everyday expressions that often go unnoticed. In the case of overt and explicit expressions of dehumanisation, 'othered' people are *consciously and deliberately* described as 'non-human'. There are many examples of this throughout recorded history, with some of the most notorious examples listed in Box 7.7.

In the case of subtle or covert expressions of dehumanisation, people subtly downplay or attribute fewer 'uniquely human' qualities to others – usually members of an 'outgroup' – that is, they portray them as being more 'animal like' than themselves. Also called 'infrahumanisation' (Haslam & Loughnan 2014; Leyens et al 2000, 2007), a distinguishing feature of subtle or covert dehumanisation (compared with its more explicit form) is that it tends not to be reported directly and is expressed by perpetrators without conscious awareness that their expressions are dehumanising (Bastian et al 2011). Examples can be found in cases of stereotyping 'people of difference' (Bastian et al 2011).

An instructive example of the infrahumanisation of people is the dehumanising, stereotypical depiction, by the media and politicians, of refugees and asylum seekers

# BOX 7.7 Explicit Expressions of 'Othered' People being Described as Non-Human

- Nazi characterisations of Jews and Gypsies as 'rats' and 'vermin'
- Hutu characterisation of Tutsis as 'cockroaches' during the Rwandan civil conflict<sup>2</sup>
- · Africans being called 'apes'
- Indigenous Australians being called 'monkeys'
- Migrants stranded in Calais camps attempting to reach Britain described as 'swarms'

(Sources: Bain et al 2013; Bar-Tal 1990; Costello & Hodson 2009; Elgot 2016; Haslam 2013)

as 'queue jumpers' and 'cheats not willing to follow fair procedures' (Esses et al 2008: 5; see also Chouliaraki & Stolic 2017). They are relentlessly portrayed as having 'less capacity' for complex emotions and moral values ('be like us'), and as being primarily motivated by only the 'basic emotions' that animals share (e.g. fear and pleasure) (see also Utych 2017). The subliminal message here is that 'these people' ostensibly lack the moral motivations and personal control that a more 'civilised' and 'cultured' people ('us') would otherwise exhibit. A useful example of this can be found in the Australian 'Children overboard' incident. This incident involved the public misrepresentation of photographic images and false claims by Federal government politicians that asylum seekers who were attempting to enter Australian territory 'illegally' by sea had 'deliberately' thrown their children overboard from the boat they were on so they would be rescued. It was later revealed and subsequently verified by a Senate inquiry into the matter that no children had, in fact, been thrown overboard. This, however, did not stop politicians or the media from portraying them ('demonising them') as 'faceless, violent queue jumpers' and as people of poor moral character, as was widely quipped at the time 'the kinds of people who would throw their children overboard' (Senate Select Committee on a Certain Maritime Incident 2002: xxi).

In addition to being either explicit or subtle, researchers contend that expressions of dehumanisation may also be relative or absolute, a feature that must also be assessed when attempting to mitigate its effects. In the case of *relative expressions*, the target individual or group (usually an outgroup or individual) is portrayed as being less than human 'relative' to another (usually the in-group or individual) (Haslam 2013). In contrast, *absolute expressions* of dehumanisation are explicit: the target individuals or groups are characterised unequivocally as being animalistic, or devilish or monstrous in and of themselves *independent of* 

comparisons that might otherwise be made with other beings or entities (Haslam 2013).

It is important to clarify that, although the various ways in which dehumanisation can be expressed have been described in dichotomous terms (e.g. humanness/non-humanness, object/animal, explicit/subtle, conscious/unconscious, relative/absolute), as Haslam (2013) concedes, in practice its expression probably occurs along a continuum that encompasses subtle variations of all the dimensions identified. What these categorisations enable, however, is a better understanding of the phenomena at issue and whether the diverse forms that human denial can take are to qualify as cases of 'dehumanisation' (Haslam 2013: 42).

### Why Dehumanisation Occurs

The causes of dehumanisation, the possible neural mechanisms involved and the psychological motivations for people to engage in harmful dehumanising behaviours are extremely complex, with some suggesting that the human brain has been 'hard wired' through evolutionary processes to favour in-groups ('us') over out-groups ('them') (Greene 2013; Lee & Harris 2013). Although research on the subject is inconclusive, one thing is clear: everyone has the capacity to dehumanise others - especially those identified as being outliers to one's own 'in-group' and hence labelled (often unconsciously) as 'other'. Research also strongly suggests that when an in-group perceives that its resources and/or identity are threatened by an out-group, this often leads to a 'rejection response' and the dehumanisation of those deemed to pose the 'resource threat' or the 'identity threat' to members of the in-group (Costello & Hodson 2009; Hodson & Costello 2007; Leyens et al 2000). Given this, it would be a grave mistake to assume that it is only the ignorant, the misguided, or the manifestly psychopathic individuals who are capable of denying 'others' their humanness and the moral protections and entitlements that come with this status. This is not to deny, however, that some people are more predisposed than others to perpetrate acts of dehumanisation, or that some are more motivated than others to expose and mitigate this predisposition.

Research to date suggests that people who see animals as inferior to humans, who have a 'social dominance orientation' and who subscribe to 'right-wing authoritarianism' are more likely to engage in the dehumanisation of people outside of their in-group than are those who do not have such ideological orientations (Haslam 2013; Hodson & Costello 2007; Leyens et al 2000). This is because people who hold these ideologies tend to see themselves as 'superior' to others and to value social hierarchies and group dominance. The world is seen as a competitive jungle, with 'intergroup interactions perceived as zero-sum competitions over finite

resources' (Haslam 2013: 6) and over their social and political identities (Bar-Tal 1990; Tajfel & Turner 1979). When out-groups are perceived as a threat, depending on the severity of the threat (whether real or imagined) this perception tends to be accompanied by fear, stress and feelings of uncertainty and vulnerability by the in-group (Bar-Tal 1990; see also Becker 1973; Crimston et al 2018). This helps to explain why people with these orientations and dispositions tend to be associated with 'prejudice towards a variety of outgroups, particularly subordinate and competitor outgroups' (Haslam 2013: 6), for example immigrants and asylum seekers (Esses et al 2008; Hodson & Costello 2007).

In contrast, people who have 'inter-species' empathy and concern (e.g. value and even anthropomorphise animals, and encourage perceptions of the similarities between animals and human beings), who emphasise inter-group similarities and who have a low preference for and tolerance of social hierarchies and dominance tend to be less associated with prejudice and intolerance of out-groups and people otherwise deemed 'different to us'.

In sum, there seems to be a link between a perception that 'humans are different from and superior to animals' and a disposition to dehumanise others, and especially people who are perceived as belonging to out-groups and as posing a threat to the in-group's resources, identity and social–political standing. Conversely, those who hold beliefs about animal–human similarities are less predisposed towards and are less likely to dehumanise others – and indeed may actually foster *out-group humanisation* and the *rehumanisation* of those who have already been dehumanised – for example, immigrants (termed 'immigrant humanisation') (Costello & Hodson 2009: 17).

### **Consequences of Dehumanisation**

Some researchers contend controversially that not all instances of dehumanisation are harmful and, indeed, may even be adaptive and necessary (Lee & Harris 2013). For example, a surgeon may not be able to perform effectively unless focused on the 'mechanics' of the human body and its constitutive parts that lie beneath his scalpel blade. Such instances tend to be the exception not the norm, however. Although unlikely to exacerbate an entity's vulnerability per se, such instances of 'benevolent' mechanistic dehumanisation may nevertheless result in what some have termed human 'dignity violations', a form of dehumanisation that encompasses the humiliation and degradation of human beings (Kaufmann et al 2011b). Thus, the diligent surgeon may well have performed a perfect surgical procedure and prolonged the life of his patient, yet may still have committed a dignity violation - albeit one that was unintended: the patient, stripped of her body part (a limb, a breast, a sex organ, the side of her face), although grateful for her life-prolonging treatment, may nevertheless feel degraded and 'less than human' on account of losing the part that has been amputated and the function it once afforded.

Putting aside what might be termed 'benevolent mechanistic dehumanisation', dehumanisation remains morally problematic. The main reason for this, as suggested in the opening paragraphs to this discussion, is that it justifies what Staub (1990) and Opotow (1990a, 1990b) call 'moral exclusion' and the related moral harms that would otherwise be considered unconscionable. As noted earlier, moral exclusion occurs when:

individuals or groups are perceived as outside the boundary in which moral values, rules, and considerations of fairness apply. Those who are morally excluded are perceived as nonentities, expendable, or undeserving; consequently harming them appears acceptable, appropriate, or just. [emphasis original]

(Opotow 1990a: 1)

Opotow (1990b: 174) explains that moral exclusion emerges when 'group differences (or "we-they" distinctions) are salient and when difficult life conditions (such as harsh social circumstances, destructive conflict, or threat) exist' [emphasis original]. It can also emerge where there are perceived conflicts of interests that give rise to group categorisations, which in turn 'contribute to moral justifications for unjust procedures, which can themselves be injurious and which permit other harmful outcomes to ensue' [emphasis original] (p 174).

Opotow concludes that what primarily makes moral exclusion problematic is not only that it enables the unjust and even brutal treatment of others considered 'less than human' and inferior, but also that it is insidious and difficult to detect. This is because its justifications are largely unspoken on account of being based on shared social perceptions that are 'institutionalized, invisible, and accepted as if inevitable' (Fine 1990: 111). Opotow (1990a: 13) cautions, however, that:

moral exclusion is neither an isolated nor inexplicable event, but occurs with great frequency, depends on ordinary social and psychological processes to license previously unacceptable attitudes and behaviour, and can cause great harm, from personal suffering to widespread atrocities.

### **Deterring Dehumanisation**

Dehumanisation is a malevolent process: it unjustifiably denies the humanness of 'others' and, by virtue of this denial, justifies harming or at least failing to protect the significant moral interests of those targeted. Targeted

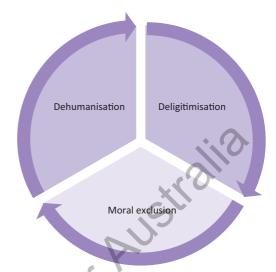


FIGURE 7.1 Self-perpetuating cycle of dehumanisation.

individuals and groups are not the only 'victims', however. Research has shown that when people dehumanise others they also dehumanise themselves (Bastian et al 2011, 2012); likewise, in harming others, perpetrators harm themselves (Rodriguez 2017). Thus denial of humanness is a double-edged sword that cuts both ways: not only does it risk the self-perpetuation of the *dehumanisation-delegitimisation-moral exclusion cycle* (Fig 7.1) that ultimately will harm the moral interests of us all, but it also risks the corruption and decline of our moral systems generally and their capacity to cultivate peaceable bonds between people in the interests of promoting human welfare and wellbeing.

As examples to be given in this chapter and the following chapters will demonstrate, dehumanisation and the moral exclusion it justifies needs to be detected and deterred (Opotow 1990b). This is particularly so in health care domains where the processes of dehumanisation and moral exclusion have resulted in disparities in access to and the beneficial outcomes of quality health care. The question remains, however, how might dehumanisation be detected and deterred, if at all? In attempting to answer this question, attention will be given to four key strategies (Box 7.8).

# BOX 7.8 Strategies for Addressing **Dehumanisation**

- Address the root causes of dehumanisation
- Foster the moral inclusion of 'out-groups' and individuals
- Detect and expose instances of dehumanisation
- · Energise dissent

Addressing the root causes of dehumanisation. Little is known about the mechanisms that might help to reduce and deter dehumanisation, with some authors acknowledging that the problem is 'a knotty one' owing to the interrelated complexities that drive it (Haslam & Loughnan 2014: 417). Even so, evidence is growing that various mechanisms can be used to help reduce the incidence and negative impact of dehumanisation (Haslam & Loughnan 2014: 417-18) and that addressing the 'root cause' of dehumanisation is an important starting point. Endeavours could begin, first, by redressing the 'hierarchal divide between humans and animals', which has enabled the 'justified' oppression and subjugation of people deemed to be 'animal-like' (Costello & Hodson 2009: 5). Processes by which this hierarchy could be redressed might include emphasising empathic attitudes towards the similarities (e.g. sentience, cognitive abilities and relative moral intelligence) as opposed to the differences between humans and animals. Research has revealed, for instance, that some social mammals (e.g. gorillas, elephants, wolves, rats, bats and others) exhibit a range of cooperative 'moral' behaviours akin to those exhibited by humans (Balcombe 2016; Bekoff & Pierce 2009). Examples are given in Box 7.9. Far from being a case of anthropomorphising animals, scholars in the field remind us that 'humans are animals too', so it should not come as any surprise that animals and humans exhibit a similar range of moral behaviours. They have gone on to conclude that many animals have moral intelligence and are in essence 'moral beings', which means that human beings 'are not alone in the moral arena' (Bekoff & Pierce 2009: 152; see also Balcombe 2016).

In light of the above insights and observations, there is room to conclude that the moral gap between humans and other species – if it exists at all – has been overstated. By emphasising animal-to-human similarities, a humanisation process can be activated and engaged, which, as one Canadian study has found, can prompt heightened empathy and stronger inclinations to perceive members of both an ingroup and an out-group (e.g. immigrants) 'as belonging to the same inclusive ingroup' (Costello & Hodson 2009: 17).

# BOX 7.9 Moral Behaviours Exhibited by Animals

- Justice
- Empathy
- Forgiveness
- Care
- Trust
- Reciprocity (including helping each other when in trouble)

# BOX 7.10 Attitudes for Fostering Moral Inclusion

- Believing that considerations of fairness apply to another
- Willingness to allocate a share of community resources to another
- Willingness to make sacrifices to foster another's wellbeing

**Fostering moral inclusion.** Commensurate with the above, a second strategy to deter dehumanisation is to consciously and actively foster *moral inclusion* and the *rehumanisation* of dehumanised individuals and groups. According to Opotow (1990a: 4) moral inclusion may be taken as comprising a 'coherent cluster of attitudes' (Box 7.10).

How best to cultivate these and related attitudes, however, remains the subject of ongoing debate. Even so, there are a number of processes that are germane to fostering in people a disposition towards the virtue of moral inclusion and to expanding people's 'moral circles' to be more inclusive of entities that otherwise lie outside their 'in-group' (Crimston et al 2016, 2018); these are outlined in Box 7.11.

**Detecting and exposing instances of dehumanisation and moral exclusion.** As suggested earlier in this discussion, dehumanisation (especially its subtle form) can be difficult to detect. Even those who have been the targets of dehumanising processes may not always recognise it as such and, instead, through a process of internalised dehumanisation (whereby they internalise the very norms and beliefs systems that victimise them), blame themselves for the way they are treated (Opotow 1990b: 176). Because of this and also because of their felt vulnerability at the hands of the perpetrators, victims of dehumanisation might not always be able and/or willing to give voice to and expose their plight. For example, asylum seekers and detainees awaiting the outcome of their visa applications to stay in a

# BOX 7.11 Processes for Fostering Moral Inclusion

- Making a commitment and actively seeking opportunities to become more familiar with the life-ways and world views of those who have been 'othered'<sup>3</sup>
- Searching for similarities and shared human experiences
- Adopting a pluralistic perspective<sup>4</sup>
- Engaging in mindful practice aimed at fostering a sense of compassion for those who are vulnerable to dehumanisation<sup>5</sup>

host country, or charitable organisations supporting marginalised people that are dependent on government funding, may understandably be reluctant to speak out and expose their situation. There is, however, another category of persons who can take a proactive stance in detecting and exposing instances of dehumanisation and moral exclusion, notably *bystanders*.

A 'bystander' may be defined as any member of society who is neither a victim nor a perpetrator, and who witnesses the injustice of dehumanisation and moral exclusion but is not directly affected by it (Opotow 1990b). Bystanders can be individuals, groups, professions and even whole nations. Opotow (1990b: 176) argues that among the actions that bystanders can (and ought) to take is: first and foremost to detect the problem, define it and provide an early response to it (this is crucial to the process of 'reinstating victims in the moral realm'). Following this, bystanders then need to 'call attention' to the injustices witnessed and assert the inhumanity of the actions promulgated by the perpetrators – whether these are individuals, groups, governments or entire nations.

According to Opotow (1990b) bystanders are in an ideal position to take such a proactive stance as, from their vantage point, the injustice that victims of dehumanisation and moral exclusion experience 'is less personally threatening to them' and hence more easy to recognise (Opotow 1990b: 176). Bystanders, however, must do more than just 'passively observe', recognise and expose the injustices of dehumanisation and moral exclusion; they also need to actively combat it. This is because merely exposing dehumanisation might not be sufficient to generate the public outrage otherwise necessary to demand reform of the societal and political structures and processes that otherwise enable and sustain the whole sophisticated dynamic of dehumanisation and moral exclusion of 'othered' people.

Energising dissent. Those who do not agree with conventional ideologies that underpin the dehumanisation and moral exclusion of 'othered' people need to 'energise dissent' (Martin 2007) and strategically resist pressures to conform to the status quo (Opotow 1990b). This can be done by dissenters using unofficial channels to share with likeminded people the information they have and their interpretations of 'what is going on', something that is now relatively easy to achieve via the use of social media. As their actions and views gain traction, it will become increasingly difficult for them to be credibly ignored, notwithstanding the tactics that might otherwise be used by opponents intent on spreading misinformation ('fake news') and disrupting and discrediting them.

Information sharing, exposing injustices to the public and providing credible explanations for 'what is going on here' will not, however, be sufficient to energise dissent. This is because perpetrators of injustice use powerful methods to reduce and even suppress public outrage (Hamilton & Maddison 2007; Martin 2007) or, conversely, provoke extreme right-wing authoritarian populism to energise dissent in the 'wrong direction', as has occurred via the activities of groups such as Cambridge Analytica (see Persily 2017). As Martin (2007: 63) reveals:

They cover up evidence and information about the event, devalue the target, reinterpret what happened, use official channels to give an appearance of fairness, and intimidate or bribe participants and observers.

Martin (2007) goes on to argue that dissenters must combat these powerful methods, which are cleverly used by perpetrators to reduce public outrage. To this end, he proposes five corresponding approaches (Box 7.12).

These and other strategies will be considered further later when discussing specific individuals and groups whose dehumanisation and moral exclusion give rise to special responsibilities for members of the nursing profession.

# Stigma

Stigma (from Latin via Greek meaning 'brand' or 'bodily sign') is literally a distinguishing mark of social disgrace. It presupposes the acquisition of an attribute or attributes that others (usually those who are dominant members of a mainstream culture or group) find or regard as deeply discrediting (personally, socially and morally) and, importantly, who have the power to discredit those deemed 'marked' as socially disgraced (Goffman 1963; Link et al

# BOX 7.12 Five Strategies for Energising Dissent

- 'Expose the actions' (this is essential to enable people to be as well informed as is possible).
- 'Affirm the value of the targets' (this is essential to counter the denigration of targets).
- 'Interpret the situation as unfair' (the damaging consequences of what has been done and the vested self-interests and denial of responsibility, ultimately, cannot be kept hidden 'truth will out').
- 'Mobilise support and avoid or discredit official channels' (be aware that 'official channels' can be cumbersome, take time and can distort the issues in favour of maintaining the status quo).
- 'Resist and expose intimidation and bribery' (every time a progressive bystander speaks out, it makes it easier for others to do the same).

(Source: Martin 2007: 63)

## **BOX 7.13 Five Dimensions of Stigma**

- 'Concealability' refers to how obvious a characteristic is and the degree to which it can be concealed from others.
- 'Disruptiveness' refers to 'the extent to which a mark strains or obstructs interpersonal interactions'.
- 'Aesthetics' refers to the extent to which a mark elicits an 'affective reaction of disgust'.
- 'Origin' refers to 'how the condition came into being' and particularly whether the marked person was responsible for the condition (e.g. whether genetic, accidental or self-caused).
- 'Peril' refers to 'feelings of danger or threat that the mark indicates in others'.

(Source: cited in Link et al 2004: 512)

2004; Link & Phelan 2006). What is regarded as a 'distinguishing mark of social disgrace', however, and what impact it will ultimately have on people, will depend on the culture from which it has originated and what that culture deems as being 'deviant' (Eliasson et al 2021; Fan et al 2021; Link et al 2004).

According to Jones and colleagues (1984) the incidence and impact of a given stigmatised 'characteristic' or 'condition' will depend on five dimensions (Box 7.13). The process of stigmatisation becomes problematic when it evolves into a situation in which an individual is disqualified from full social and cultural acceptance on the basis of his/her carrying a given 'distinguishing mark of social disgrace' (e.g. being immigrant, disabled, homosexual, mentally ill, old, etc.) (Goffman 1963). Inevitably this means that stigma almost always carries with it commensurate processes of discrimination - that is, the unfair treatment of persons on the basis of their 'distinguishing mark(s)'. This treatment is unfair as judgments are made on the somewhat arbitrary basis of morally irrelevant distinguishing marks, rather than on moral considerations per se, hence the notion that stigma and stigmatisation are unjustly discriminatory. This outcome is unethical as, by focusing on one (or more) arbitrary characteristic(s) of a person (e.g. the marks that may 'distinguish them'), stigma and discrimination undermine the moral worth (dignity) of a person (results in them 'losing face') and thus dehumanise the person. The stigmatising and (negative) discriminatory treatment of persons thus stands in contradistinction to the respectful treatment of persons – that is, responses to persons that are guided by moral considerations, not merely arbitrary ones.

It is important to note that stigma can involve both 'public' (public-stigma) and 'self ' (self-stigma) reactions (Box 7.14). *Public stigma* has been described as comprising

# BOX 7.14 Reactions and Elements of Stigma

Public stigma – entails reactions by the public:

- stereotypes
- prejudice
- discrimination

Self-stigma – entails reactions of individuals stigmatised; internalised public reactions of:

- stereotypes
- prejudice
- discrimination

'reactions of the general public towards a group based on stigma about that group, and as consisting of three elements - stereotypes, prejudice and discrimination - that occur in 'the context of power differences and leads to reactions of the general public towards the stigmatized groups as a result of stigma' (Rüsch et al 2005: 530, 531). Selfstigma, in contrast, refers to 'reactions of individuals who belong to a stigmatized group and turn the stigmatizing attitudes against themselves' (Rüsch et al 2005: 531). Like public stigma, self-stigma also consists of three elements: stereotypes, prejudice and discrimination, but with the notable distinction that all three tend to be strongly aligned with public stigmatisation, with individuals internalising the negative public attitudes against themselves - for example 'That's right; I am weak and unable to care for myself' (Rüsch et al 2005: 531).

### **Prejudice and Discrimination**

The term *prejudice* (literally to 'prejudge' without adequate facts) may be defined as 'any belief (especially an unfavourable one), whether correct or incorrect, held without proper consideration of, or sometimes in defiance of, the evidence' (Flew & Priest 2002: 326). The counterpart of prejudice is *discrimination*. Discrimination, in turn, may be broadly defined as 'the unfair treatment of a person, racial group, minority, etc., based on prejudice' (*Collins Australian dictionary* 2011: 478).

Within the concept of discrimination, two forms are distinguished: direct discrimination and indirect discrimination, which may be either intentional or unintentional (Fig. 7.2). In Australian and New Zealand jurisdictions (as well as in others, e.g. Canada, EU, Hong Kong, South Africa, USA), direct discrimination may be held to have occurred when a person (or group of people) with certain characteristics protected by law (e.g. their race, sex, pregnancy, marital status, family responsibilities, breastfeeding, age, disability, sexual orientation, gender identity or intersex status) is 'treated less favourably than another

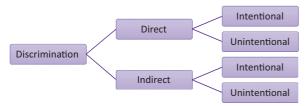


FIGURE 7.2 Forms of discrimination.

person or group' based on their personal characteristics noting that some limited exceptions and exemptions may apply (Australian Human Rights Commission (AHRC) nda; New Zealand Human Rights Commission nd). It needs to be understood that one does not have to have acted intentionally or to believe that one's actions were not discriminatory for a complaint of discrimination to be upheld. Indirect discrimination (which is controversial in some jurisdictions) may be held to have occurred 'when there is an unreasonable rule or policy that is the same for everyone but has an unfair effect on people who share a particular attribute' (e.g. a public building that has only stairway access will disadvantage those who are wheelchair dependent for their mobility) (AHRC ndb; New Zealand Human Rights Commission nd). In short, although seemingly neutral, a policy or practice (e.g. stairway-only entry to a public building) may nevertheless indirectly discriminate against a person insofar as it has a 'disparate impact' on and causes 'disproportionate disadvantage' to that person compared with other cognate groups (Collins & Khaitan 2018; Khaitan 2018). As in the case of direct discrimination, indirect discrimination can be established without reference to whether it was intentional or known; instead it is established by demonstrating a 'disparate adverse impact' (Collins & Khaitan 2018) - for example, a wheelchairdependent person being unable to access a public building because it has only stairway access.

# Disadvantage

Before concluding this section, a brief comment about the notion of *disadvantage* is warranted. Disadvantage, in its most basic sense, may be taken to mean a deprivation that is unfavourable or detrimental to a person's interests. The notions of vulnerability, dehumanisation, delegitimisation, moral exclusion, stigma, prejudice and discrimination as discussed in this chapter are all correlated in important ways with the notion of disadvantage. In this instance, disadvantage correlates with the notion of equal opportunity and the ways and extent to which this is denied when people are dehumanised, marginalised and excluded from the moral community. Disadvantage, in this case, can result regardless of whether the processes of dehumanisation, delegitimisation and moral exclusion

are covert or overt. This is because these processes disrupt what would otherwise be a level playing field and result in privileged groups (i.e. those with a social dominance orientation) accruing unearned advantages over those they have subordinated.

People who are subjected to dehumanisation, delegitimisation, moral exclusion, stigma, discrimination and prejudice are all vulnerable to being disadvantaged in terms of realising the health benefits commonly associated with having equitable access to the social, cultural and political conditions that promote safe and high-quality health care. It is for this reason that identification of and emphasis on the special responsibilities that others might have towards vulnerable populations are warranted. The problem of disadvantage and its co-relationship with vulnerability, dehumanisation, moral exclusion, stigma, prejudice and discrimination has been laid bare during the COVID-19 pandemic, an issue which will be explored further in Chapter 14 of this book.

# IDENTIFYING VULNERABLE INDIVIDUALS AND GROUPS

It is well established locally and internationally that people who are old (especially those who are frail, cognitively impaired and socially isolated), who suffer from a mental illness or who are disabled are among the most stigmatised, discriminated against and marginalised in society. Also vulnerable to be treated in prejudicial and discriminatory ways are: indigenous peoples (i.e. peoples of the world's First Nations); ethnic minorities; refugees, asylum seekers, displaced people and stateless people; the unemployed, 'deserving' poor and homeless people; and those who are perceived to have deviated from or breached society's accepted norms - illicit drug users and addicts, sex workers, people living with sexually transmitted disease (e.g. HIV/AIDS) and people imprisoned for criminal offences. If sharing membership of more than one of these demographic groups (e.g. if old, disabled and suffering from a mental illness), an individual may face a 'double jeopardy' or even 'triple jeopardy' of being stigmatised, discriminated against and ultimately abandoned by society and left languishing on its margins.

The issue of vulnerability and dehumanisation has particular resonance for nurses, particularly when encountering people who are disadvantaged by their vulnerability and who may require the intervention of nurses (individually and collectively) to rehumanise and destigmatise them and foster their re-inclusion in the moral realm of health care. Of particular note, some of whom are also the subject of position statements by the International Council of Nurses (ICN), are those listed in Box 7.15.

# BOX 7.15 Individuals and Groups Commonly Regarded as Vulnerable

- Older people
- · People with mental health problems and illnesses
- Immigrants and ethnic minorities
- Refugees, asylum seekers, displaced people and stateless people
- · People with disabilities
- Indigenous peoples
- · Prisoners and detainees
- Homeless people
- Sexual minorities (lesbian, gay, bisexual, transgender, intersex, queer/questioning, asexual (LGBTIQA+))

People who require and are dependent on medical treatment and nursing care might also be characterised as being vulnerable and hence as giving rise to 'special responsibilities' in the moral realm. As the ethical issues associated with this population group are extensive and also inclusive of the vulnerable population groups identified above, they will be considered separately in Chapter 8.

# Older People<sup>6</sup>

The world's population is ageing in an unprecedented manner. According to the United Nations Department of Economic and Social Affairs (UN DESA 2019) and the World Health Organization (WHO 2017a), by the year 2050, 1 in 6 people will be over the age of 65 years. It has been further estimated that the number of people over the age of 80 years will triple over the next three decades.

For many, the world's ageing population is a triumph of human and social development and one that deserves to be celebrated (United Nations Population Fund (UNFPA) and HelpAge International 2012). For others, however, a more circumspect view is held – particularly when consideration is given to the significant 'social, economic and cultural challenges to individuals, families, societies and the global community' that population ageing poses (UNFPA and HelpAge International 2012: 11). One particular challenge confronting all societies globally is the problem of ageism.

Today, older people are amongst the most discriminated against, marginalised and vulnerable groups of people in the world. Although there is now a much greater awareness about the nature and negative impact of ageism, it remains highly prevalent, insidious and, as the Australian Human Rights Commission observes, 'remains an accepted and normalised prejudice, underpinned by powerful stereotypes and assumptions which lead to exclusion, marginalisation and inequality' (AHRC 2021: 13).

Officer and de la Fuente-Núñez (2018: 295) likewise contend that, unlike other forms of discrimination (e.g. sexism, racism), ageism is 'socially accepted' and thus rarely challenged. What is particularly troubling about ageism is the impact that ageist attitudes can have on public policy, as HelpAge International (HAI) explains:

all societies discriminate against people on grounds of age. Ageism and stereotyping influence attitudes, which in turn affect the way decisions are taken and resources are allocated at household, community, national and international levels.

(HAI 2001: 1)

Here the questions remain: 'What is ageism?' and 'How ought the nursing profession respond to it?'

### **Ageism**

The notion of 'ageism' was first coined in 1968 by Dr Robert Butler, founding director of the US National Institute on Ageing, who originally defined the term as a:

systematic stereotyping of and discrimination against people because they are old, just as racism and sexism accomplish this with skin color and gender. Old people are categorized as senile, rigid in thought and manner, old-fashioned in morality and skills [...] Ageism allows the younger generation to see older people as different from themselves; thus they subtly cease to identify with their elders as human beings.

(Butler 1989: 139)

Contemporary definitions reflect the elements of this original definition. For example, the World Health Organization (WHO 2021a: 2) defines ageism as referring to the 'stereotypes (how we think), prejudice (how we feel) and discrimination (how we act) directed towards people on the basis of their age. The WHO (2021a: 2) goes on to clarify that ageism can be:

- institutional (i.e. the 'laws, rules, social norms, policies and practices of institutions that unfairly restrict opportunities or disadvantage people because of their age')
- interpersonal ('arises in interactions between two or more individuals'), or
- *self-directed* (i.e. internalised ageism, where ageist attitudes are turned against oneself).

Ageism can occur in any socio-cultural context including health care, which can be hostile to the needs and interests of older people. Ageism in health care (also called 'medical ageism') can be expressed in a variety of ways, including 'stereotypes about the recuperative abilities of elderly patients, or value judgments about the quality or

worth of elderly lives, or misconceptions about the desires of elderly people for certain forms of treatments' (Williams 2009: 11). The use of chronological age as decisional criteria (irrespective of a patient's medical condition) and dehumanising age-based language (e.g. 'bed blockers,' 'train wrecks,' 'disaster waiting to happen,' 'nightmare on a stretcher,' etc.) to refer to older people/patients are also examples of ageism in health care.

Arguably one of the most insidious forms of ageism can be found in the highly politicised scapegoating of older people in public debates on the public affordability of pensions and health care. These debates (which tend to emphasise 'demographic crisis thinking', 'apocalyptic demography' and 'apocalyptic economics') are primarily shaped by prejudice, politics, ideology and social organisation, and not by demography as the public is often led to believe (Ebrahim 2002; Evans 2002; Fine 2014; Howe & Healy 2005; Spies-Butcher & Stebbing 2018). What the 'crisisisation' of population ageing does is promulgate a spurious portrayal of older people as a perpetual 'costly burden on society' and a threat to the social wellbeing of future generations (commonly framed as 'threatening generational equity' and ipso facto causing 'intergenerational conflict') (Fine 2014; Spies-Butcher & Stebbing 2018). This portrayal is spurious for at least three key reasons: first, it arbitrarily ignores that older people throughout the world (including those who are disadvantaged and poor) actually make positive and substantial contributions to society (in economic, social capital and cultural capital terms) as paid and unpaid workers, as consumers, as volunteers and as contributors to the wellbeing of their children and grandchildren (noting that analyses across the globe have shown that private wealth tends to flow more strongly downwards - i.e. from old to young) (Fine 2014; Spies-Butcher & Stebbing 2018); second, it overlooks the inadequacies of current inter-generational frameworks in terms of their capacity to provide 'a reliable picture of the future economic costs and benefits of population ageing' (Fine 2014: 224); finally, it ignores the fact that the future burdensome costs of health care are more probably due to changes in technology and not demography per se (Spies-Butcher & Stebbing 2019).

The ACHR notes that some people may believe that ageism has nothing to do with the narratives on the supposed cost-burden of an ageing population on society. The AHRC points out, however, that the evidence suggests otherwise, noting with reference to the cultural context of Australia, that ageism:

has much to do with people's choices and rights, expressed through exclusion, stereotyping and inequality. It drives discrimination. It is mobilised to spur narratives of intergenerational conflict and competition for resources, particularly through media narratives of scarcity and greed, at the expense of the shared values and connections that unite most Australians across age groups.

(AHRC 2021: 14)

### **Role of Nurses**

In keeping with their advocacy role and responsibilities, nurses and their professional associations have an obligation to safeguard the safety of older people. This includes influencing debates on global ageing and policies addressing the problems of ageism, stigma, dehumanisation and the moral exclusion of older people, and the possible harmful impact these processes can have on the health and wellbeing of older people. How nurses might best mitigate the prejudice, discrimination and stigma that germinate from these processes will require considered attention as well as close and coordinated collaboration with other organisations and groups committed to combating ageism locally and globally (see, for example, Officer & de la Fuente-Núñez 2018). If nurses are to be able to uphold their professional obligations to safeguard vulnerable older people, they first need to understand what ageism is and how it works to dehumanise older people and ultimately lead to their being 'soft targets' for the 'understandable' and 'justified' exclusion from some of society's limited health resources.

Protection of the safety, welfare and wellbeing of older people is going to require more than knowledge and understanding of the impact of ageism, however. Nurses must also actively engage in a campaign of 'detection and deterrence' of ageism and its negative impact on older people in health care. This includes their engaging in what Butler has termed the 'New Ageism', which seeks to: foster respect for age diversity, debunk the gerontophobic 'decline and failure' model of ageing (Whitton 1997), dispel the myths around the costs of caring for older people and dying (as Butler correctly notes, an honest accounting of the 'cost of life' would examine all sources of expenditure for all people - young and old - not just the health care of older people), and counter negative ageist attitudes, generally in the interests of promoting inter-generational solidarity – of generations working together - in recognition that 'there is a continuity and unity to human life' (Butler 1989: 145). By taking such a stance, nurses will help restore the boundaries of moral inclusion and reinstate older people as moral entities deserving our respect and recognition as fellow human beings.

Older people continue to remain vulnerable to not having their health rights recognised. Moreover, there is growing recognition that the current system of health rights is not sufficient to protect the rights and interests of older people. In response to this situation, in 2011 a Global Alliance for the Rights of Older People (GAROP) was established (https://rightsofolderpeople.org/). The Alliance is using its network of over 390 members worldwide to spearhead a global movement for recognising the rights of older people (https://rightsofolderpeople.org/about/). Together with a growing number of other campaigners, including non-governmental organisations (NGOs), academics, lawyers and UN member states and individuals, HelpAge International and GAROP have been calling for the development of a convention on the rights of older people together with the creation of 'a new special rapporteur on older people's rights' who would report to the Human Rights Council (https://www.helpage.org/what-we-do/ un-convention/). HelpAge International suggests that, in addition to enabling the rights of older people to be protected under international law, such a convention is necessary to:

- establish legal standards that challenge and replace stigmatising and dehumanising ageist attitudes and behaviour
- · clarify how human rights apply in older age
- ensure that states understand their human rights obligations to us in our older age
- better understand and assert our rights in our older age
- improve accountability of states for their human rights obligations towards us in older age
- provide a framework for policy and decision-making (https://www.helpage.org/what-we-do/un-convention). Insofar as what *specific human rights* are relevant to the experience of ageing and should be protected for older people, GAROP and HelpAge International have respectively identified the following general principles:
- non-discrimination
- respect
- dignity
- autonomy
- equality
- self-fulfilment and personal development
- full and effective participation and inclusion in society
- · respect for difference and diversity
- accessibility
- inter-generational solidarity
- recognition of intrinsic value and worth as a human being (GAROP 2015: 6; HelpAge International 2015: 3).

Nurses are in a good position to actively engage with the processes of championing the development and adoption of a convention on the rights of older people and the creation of new special rapporteur on older people's rights. A first step to engage in these processes would be for nurses to join GAROP and to participate in the various advocacy campaigns it organises. In addition, where able, nurses have a valuable role to play in encouraging eligible organisations to likewise join and participate in GAROP's advocacy campaigns (http://www.helpage.org/get-involved/).

# People with Mental Health Problems and Mental Illness

It is well documented that people suffering from mental illness (including severe and complex mental illnesses)<sup>7</sup> are among the most stigmatised, discriminated against, marginalised, disadvantaged and hence vulnerable individuals in the world. As the World Health Organization noted in its 2012 background paper for the development of a comprehensive mental health action plan:

Persons with a mental disorder have their own set of vulnerabilities and risks, including an increased likelihood of experiencing disability and premature mortality, stigma and discrimination, social exclusion and impoverishment.

(WHO 2012a: 2)

Moreover, despite the efforts of mental health consumer groups and other mental health activists across the globe, people with mental and psychosocial disabilities continue to experience the violation of many of their basic human rights. One of the main reasons for this, as explained by the WHO, is that:

There is a commonly held, yet false, assumption that people with mental health conditions lack the capacity to assume responsibility, manage their affairs and make decisions about their lives. These misconceptions contribute to the ongoing marginalization, disenfranchisement and invisibility of this group of people in their communities.

(WHO 2012a: 2)

The WHO (2012a) has characterised the continual stigmatisation of the mentally ill as 'a hidden human rights emergency'. In an attempt to re-address this emergency, in 2011 the WHO initiated the QualityRights initiative, the aim of which is to 'unite and empower people to improve the quality of care and promote human rights in mental health and social care facilities' (WHO 2012b: 2). It was anticipated that this project will leave a 'lasting legacy of respect for human rights' (WHO 2012b: 2). An important component of the QualityRights initiative has been the development of the 'WHO quality rights tool kit' (WHO 2012b). This kit has since been used in countries around the world and has demonstrated that 'change is possible' and that 'better outcomes' can be achieved for people using

mental health services, health service providers, policy makers and communities (Funk & Bold 2020). Even so, there remains much more work to be done.

In the past it has been difficult to provide reliable national and global estimates of the prevalence, incidence, remission and mortality in mental illness (Baxter et al 2013). Today, however, a more reliable picture is available. Comparative epidemiological studies of the incidence and impact of mental illness in different countries have now been undertaken, enabling improved understanding of the prevalence and impact of mental illness across the globe (WHO 2017b, 2019). These studies have affirmed earlier estimates that high-prevalence illnesses and conditions (e.g. depression, anxiety) and low-prevalence illnesses (e.g. bipolar disorder, schizophrenia, eating disorders) occur to varying degrees in all societies and contribute significantly to the global burden of disease (Baxter et al 2013; WHO 2017b, 2021b).

According to some international authorities, one of the key issues facing people with mental health problems is being able to access quality mental health services, the singularly most significant barrier to the effective treatment of mental illness being *stigmatisation*. A notable proponent of this view is Professor Norman Sartorius, former director of the WHO's Division of Mental Health and a former president of the World Psychiatric Association. Sartorius (who has been described as one of the most prominent and influential psychiatrists of his generation) contends that stigmatisation is 'often buried deep within governments, public health agencies, health services and the general public' (Sartorius 2014: 2). Stigma, in turn, leads to discrimination against the mentally ill, as well as their families and others who provide them with care. Discrimination, as indicated earlier, can take several forms - not least the failure in the case of mental health to develop appropriate policies and allocate appropriate resources to ensure the delivery of quality mental health care to those who need it. On this point, Sartorius asks rhetorically, 'Who wants to help a person with schizophrenia? If he dies sooner, that's a decrease in cost' (Sartorius 2014: 8).

Taken together, stigmatisation and discrimination can lead to an insidious and generally underrecognised form of the dehumanisation of people with mental health-related problems.

In order to redress this problem, people who work in the field of mental health promotion have to be 'indefatigable' (change can sometimes take decades) and need to embark on a strategy of what Sartorius calls 'enlightened opportunism'. By this, he means that people must keep themselves:

in a state of watchful preparation and look for opportunities. Understand [their] local surroundings and their needs, and stand ready with the best tools. Opportunities will arise; luck will come. And then ... you pounce [on that opportunity]!

(Sartorius 2014: 9)

### **Role of Nurses**

Mental health is everybody's business. Accordingly, nurses share with others the collective responsibility to promote mental health, to promote the prevention of mental illness, to challenge the stigmatisation and dehumanisation of people with mental health problems and to champion improved access to mental health care and services for all who need it.

More specific ethical issues arising in the context of mental health, such as the capacity to decide, advance psychiatric directives and preventing the moral harms of suicide, will be considered separately in Chapter 9.

# **Immigrants and Ethnic Minorities**

Culture and ethnicity are recognised predictors of disparities in the safety and quality of health care and related health outcomes. In its landmark report *Unequal treatment: confronting racial and ethnic disparities in health care*, the US Institute of Medicine (IOM) (Smedley et al 2003) presented evidence suggesting that immigrants and ethnic minorities<sup>8</sup> tended to receive a lower quality of health care than did their non-minority counterparts, and experienced greater morbidity and mortality rates (Smedley et al 2003: 1). The IOM also found that, with few exceptions, the ethnic disparities noted were 'remarkably consistent across a range of illnesses and health care services' (Smedley et al 2003: 5).

It was further noted that some of the ethnic disparities revealed were associated with socio-economic differences and that these diminished significantly when socio-economic factors were controlled. It was further observed, however, that the vast majority of the disparities noted remained even after adjustments had been made for socio-economic differences and other health care access-related factors. Defining *ethnic disparities* in health care as 'racial or ethnic differences in the quality of health care that are *not* due to access-related factors or clinical needs, preferences, and the appropriateness of interventions' [emphasis added], the IOM concluded that the disparities revealed were 'not acceptable' and that action needed to be taken to address this situation (Smedley et al 2003: 4–5).

Although originating in the USA, the IOM report had relevance for health services around the world and provided an important catalyst for health service providers and policy makers alike to reflect on ethnic disparities in their own local health care services and what must be done to redress the inequities that are found to exist. Since this

report was published, there has been a plethora of articles published on the subject (too numerous to list here) and the implications of racial and ethnic disparities for patient safety in general (see systematic review by Chauhan et al 2020) and for other health care scenarios in particular (e.g. the COVID-19 pandemic) (Mackey et al 2021). Arguably one of the most important developments in the field, however, has been the establishment in 2014 of the *Journal of Racial and Ethnic Health Disparities*, described by the publisher as 'the first journal of its kind dedicated to examining and eliminating racial and ethnic [health] disparities' (https://www.springer.com/medicine/journal/40615).

As noted previously in Chapter 6, there are probably thousands of different ethnic groups in the world and that most nations are comprised of people from diverse cultural and language backgrounds.

In order to ensure that people of immigrant and ethnic minority backgrounds get equal access to the safe and high-quality care otherwise enjoyed by non-minority patients, health service organisations and some governments (e.g. in Australia, Canada, New Zealand, UK, USA) have initiated what might be termed 'cultural diversity plans'. The purpose of such plans is to provide a framework for embedding cultural diversity considerations into a health service's policies and programs. These plans require health care services to have in place processes that will ensure and increase their capacity to be appropriately responsive to the needs of their culturally and linguistically diverse communities, and to provide 'culturally competent' care.

Despite the initiatives taken by governments and other bodies (e.g. health professional associations), patients of diverse cultural and language backgrounds ('ethnic minorities') nonetheless continue to suffer discrimination based on their personal characteristics such as race, ethnicity and culture, encompassing forms of both 'old' and 'new' racism. Underpinning what Came and Griffith (2018) have termed this "wicked" public health problem is a reluctance by those in the field (practitioners, researchers, policy makers, and bioethicists alike) to specifically name and redress the problem of racism in health care. This reticence to 'talk openly about racism' in health care has also been identified in nursing, with growing calls for the 'culture of silence' surrounding the issue to be broken and for an 'authentic dialogue' about racism be progressed (Hilario et al 2018; Iheduru-Anderson et al 2021; Thorne 2017). Similar calls have been made in the medical literature. For example, in an editorial in the JAMA Network, medical journals were identified as having a responsibility to address racism in health care (Ogedegbe 2020), and likewise in the field of bioethics, with the lead journal Bioethical Inquiry hosting a symposium on 'Institutional racism, whiteness and bioethics'. The aim of the symposium was 'to examine how racism

has been institutionalized in healthcare' and 'what bioethics can contribute to antiracism' (Mayes et al 2021: 9).

### Cultural Racism9

This section would not be complete without some attention being given to 'cultural racism' (also called new racism, neo-racism, postmodern racism), which refers to the application of prejudice and discrimination based on the cultural differences of different ethnic or racial groups (Johnstone & Kanitsaki 2008a, 2009b).

The term *racism* is defined by the *Oxford English dictionary* (2021) as 'prejudice, discrimination, or antagonism directed against someone of a different race based on the belief that one's own race is superior'. In reality, however, racism refers to a highly complex and hotly contested notion that is often misused and misunderstood (Alim et al 2020; Corlett 2003; Fredrickson 2002; Miles & Brown 2003; Miles & Torres 1999; Solomos 2020). Premised on (the now) debunked scientific theories of 'race', racism is principally a classificatory term that has been (mis)used to imply, establish and sustain a hierarchical racial order in human society (Goldberg D 1993).

Historically, racial ordering has been used to collectively produce and fallaciously justify the structured subordination, exclusion and disadvantage of those deemed racially inferior ('other'), and the structured hegemony, inclusion and advantage of those deemed racially superior ('the dominant') (Corlett 2003; Goldberg D 1993; Miles & Brown 2003). Thus, although ostensibly a *principle of gradation*, as Goldberg posits, racism is also at once 'a principle of degradation' (Goldberg D 1993: 51).

Despite being utterly discredited and shown to have no genetic or scientific basis, *race* as a concept and its implied inferior/superior racial gradation of people continues to have considerable currency and practical influence in contemporary life and thought. Many people continue to believe and act 'as if' race is a scientifically warranted category and continue to differentiate and discriminate against people on racialised grounds (Miles & Torres 1999: 20; see also Fredrickson 2002).

As scientific theories and related concepts of race have been attacked, debunked and rejected 'as a package of irrational beliefs; prejudices' (Barker 1981: 1), a new conceptualisation of race has emerged, notably, *race as culture*. Whereas the 'old' concept of race was used almost exclusively to refer to *skin colour*, the 'new' concept of race is strongly identified with 'language groups, religion, group habits, norms and customs: including typical style of dress, behaviour, cuisine, music and literature, etc.' (Goldberg D 1993: 70; see also the notion of 'linguistic racism' apropos the racialisation of language, in Alim et al 2020). As in the case of 'old racism', however, this new conceptualisation of

race continues to use 'racial otherness' to service the rhetoric of racial ordering (Goldberg D 1993). As Bekerman (2020: 1) asserts:

'culture' in its present use is a proxy for 'race' and supports views, which ignore diversity and suggest, purposely or not, an homogeneity which can easily spread into a sphere of biological resemblance and differences.

Termed 'new racism' (after Martin Barker's classic 1981 work: The new racism: conservatives and the ideology of the tribe), racial ordering along cultural lines is portrayed in a manner 'that at once rationalise(s) and recreate(s) racialised exclusions, that are expressed in (terms of) and through the claims and chains of rationality' (Goldberg D 1993: 208). Moreover, as research over the past several decades has shown, by presenting their views as 'unprejudiced and factual' and by appealing to emotive arguments spuriously presented as morally principled arguments, proponents of the new racism are able to advance their negative views in a manner that enables them to avoid any threat to their status as 'normal' and 'respectable persons', or of being accused of 'racism' and hence as being 'unethical' people (Dovidio & Gaertner 2000; Verkuyten 1998). As Verkuyten (1998) explains, the persuasiveness of new-racist thinking largely lies in its contentions that (pp 155, 159):

Principled considerations can always be countered by practical ones, and vice versa. Things may be desirable in principle, but one also has to be realistic. Hence applying moral principles stereotypically and rigidly to reality can lead to accusations of being unrealistic and moralistic. [...] There is a natural limit to one's tolerance and responsibilities [in regard to foreigners]. People should control their emotions and behaviors, but when they are driven to the limit, a temporary outburst is inevitable and understandable.

Regardless of how racism may be defined (and whether expressive or 'new' or 'old' racism), there is a notable common feature that binds them together, notably: the lived reality of racism involving harmful and/or offensive acts and omissions that are based on the *perceived racialised characteristics of a person*, and that are committed against that person *just because* he/she is a member, or perceived to be a member, of a certain ethnic group.

It is important to clarify here that racism involves much more than merely harbouring a *negative belief* about or *negative attitude* towards someone because he/she is, or is perceived to be, a member of a certain ethnic group. Racism fundamentally involves also *acting* on that negative belief/attitude – that is, acting (or deliberately refraining from acting) in such a way that results in 'real discriminatory treatment' (e.g. exclusions and/or threats to and/or violations of genuine welfare interests) of targeted people, and where the target of the discrimination 'is wronged in a way that amounts to a harm and/or an offence' (Corlett 2003: 66, after Feinberg 1984).

Although racism is recognised internationally as a modifiable determinant of health (Came et al 2018), its preventable and unjust harmful impact on the health and wellbeing of 'racialised others' continues. Even so, as Came and Griffith (2018) point out, systems can and do change. If efforts to eradicate racism and remedy the unjust harms it causes are to succeed, attention must first be given to understanding the complex nature of racism, the various levels on which it operates and the concerted and cumulative negative impact it has on those affected. To this end, Came and Griffith (2018) contend that much more than mere 'consciousness raising' is required; rather, what is required is working with allies and operationalising a substantive 'anti-racism praxis'.

### **Role of Nurses**

There is a genuine belief among nurses and allied health professionals that 'racism no longer exists' in health care and that, if racialised practices do exist, they cause little or no harm. This stance has been termed elsewhere as 'the healthcare illusion of non-racism', which is defined as 'an illusion that rests on the frequently articulated belief that "there is no racism here" and "racism is not an issue anymore" (Johnstone & Kanitsaki 2008b: 178; see also Johnstone & Kanitsaki 2010). The basis of this illusion and the reasons for its durability are complex, and regrettably beyond the scope of this present chapter to discuss. What is plain, however, is that maintaining the illusion of non-racism in health care is untenable and that, if the ideals of safe, egalitarian and evidence-based health care are to be upheld, racialised health care practices need to be unmasked.

The ICN has made explicit in a position statement that both it and its affiliated national nurses' associations (NNAs) have particular responsibilities for the immediate and long-term health and nursing care needs of immigrants, refugees and displaced people (ICN 2018). To this end the ICN encourages NNAs to examine the extent of the problem in their countries and to undertake cooperative action to ensure the provision of safe and appropriate health services for immigrants and ethnic minority groups. The ICN has also taken the stance that NNAs and their members have a responsibility, through collaborative action, to 'strengthen public awareness of the health vulnerabilities and healthcare-related challenges' faced by these cognate groups (ICN 2018: 3).

It is important to note that, although the ICN has merged consideration of 'migrants' with 'refugees and displaced people, these entities are not synonymous, as the United Nations High Commission for Refugees (UNHCR) working definitions of these entities (discussed in the following subsection) clarifies. Moreover, although each of these entities faces similar issues, there are also significant differences in the kind and degree of experiences that refugees, asylum seekers, displaced people and stateless people have compared with migrants. For example, the plight of a stateless person or a refugee forced to live for years in a resource-depleted refugee camp cannot be meaningfully compared with an immigrant who has moved to a new host country by choice or a person who is a second-generation citizen (i.e. born of migrant/immigrant parents), even though both these entities might experience the hardships and health consequences of being vilified or discriminated against by their fellow citizens on the basis of their race, ethnicity or culture.

# Refugees, Asylum Seekers, Displaced People, Stateless People and Returnees

In its *Global report 2020*, the UNHCR confirmed that 82.4 million people had been forcibly displaced worldwide as a result of 'persecution, conflict, violence, human rights violation or events seriously disturbing public order' (UNHCR 2020, 2021). Children and adolescents have been particularly vulnerable in this global scenario.

Throughout recorded human history, people have been forced to leave their homes, become displaced and/or been forced to seek refuge within and outside the borders of their own countries. What is unprecedented today is the drivers of displacement, the sheer number of people seeking refuge and the sometimes-brutal dehumanisation of asylum seekers by politicians perpetrated solely for political gain.

The world's troubled history of 'forced migration' has given rise to the following various categorisations of people deemed to be of concern to the UNHCR: refugees, asylum seekers, stateless persons, internally displaced people and returnees. Sometimes the terms 'refugee' and 'asylum seeker' are used interchangeably. The terms 'migrants', 'refugees' and 'displaced people' are also sometimes conflated as referring to the same or at least a comparable thing in organisational policy and position statements. This usage is, however, incorrect and care should be taken not to confuse the terms at issue. To help clarify what each of these categorisations refers to, the UNHCR has developed an online 'Master glossary of terms (https://www. unhcr.org/master-glossary.html). A summative definition of each of the key terms pertinent to this discussion is given in Table 7.1.

As examples already given in this chapter have shown, refugees and asylum seekers are extremely vulnerable to being vilified and dehumanised and, accordingly, denied the moral protections and entitlements that would otherwise be owed them (see also the penetrating analyses by Every and Augoustinos (2007) and Leach (2003) respectively, which reveal the disturbing vilification and racist practices supported by Australian politicians and which were squarely aimed at dehumanising refugees and asylum seekers in Australia; see also Antony 2017; Canetti 2016; Czymara 2021; Pedersen & Hartley 2015; Tucker 2021). The vulnerability of these cognate groups has been exacerbated during the COVID-19 pandemic (*Lancet* 2021; Manirambona et al 2021; Van Hout et al 2021).

During the past century the international community has worked together to assemble various guidelines, laws and conventions aimed at protecting the human rights of refugees and also to ensure that those who have refugee status receive 'adequate treatment' by their hosts. Notable among the works progressed has been the development and adoption of The Convention and Protocol relating to the Status of Refugees ('1951 Convention'). Initiated by the League of Nations in 1921, the Convention was later adopted by a diplomatic conference in Geneva and later amended by the 1967 Protocol (UNHCR 2011a: 1). These landmark documents (which can be viewed at http://www.unhcr. org/protect/PROTECTION/3b66c2aa10.pdf) defined who qualified for refugee status, the legal protections they were entitled to receive upon being deemed refugees and who were not entitled to qualify for refugee status (e.g. war criminals) (UNHCR 2011a: 2). The Convention also clarified the obligations that refugees had towards their host country, which rested on its cornerstone principle of nonrefoulement contained in Article 33 (Box 7.16). According to this principle,

a refugee should not be returned to a country where he or she faces serious threats to his or her life or freedom. This protection may not be claimed by refugees who are reasonably regarded as a danger to the security of the country, or having been convicted of a particularly serious crime, are considered a danger to the community.

(UNHCR 2011a: 2)

### **Role of Nurses**

An often-overlooked issue for refugees, asylum seekers, stateless persons, internally displaced people and returnees is their precarious health status, which is often poor and frequently aggravated by deprivation, physical hardship, stress, human rights violations and a lack

TABLE 7.1 UNHCR Definitions	
Term	Definition
Asylum seekers	The grant, by a State, of protection on its territory to persons outside their country of nationality or habitual residence who are fleeing persecution or serious harm or for other reasons.
Illegal migrant	Migrant in an irregular situation, i.e. a migrant who, owing to unauthorized entry, breach of a condition of entry, expiry of a visa or stay permit, or failure to comply with an expulsion order, has no legal permission to stay in a host country.
Internally displaced people	Persons who have been forced or obliged to flee from their home or place of habitual residence, in particular as a result of or in order to avoid the effects of armed conflicts, situations of generalized violence, violations of human rights or natural or human-made disasters, and who have not crossed an internationally recognized State border.
Migrant	There is no universally accepted definition of the term migrant, and the term is not defined by international law. Nevertheless, the word migrant is used by some actors as an umbrella term to refer to any person who moves within a country or across a border, temporarily or permanently, and for a variety of reasons.
Refugees	Under international law and UNHCR's mandate, refugees are persons outside their countries of origin who are in need of international protection because of feared persecution, or a serious threat to their life, physical integrity or freedom in their country of origin as a result of persecution, armed conflict, violence or serious public disorder.
Returnees	A former refugee who has returned from a host country to their country of origin or former habitual residence, spontaneously or in an organized fashion, with the intention of remaining there permanently and who is yet to be fully integrated.
Stateless persons	A person who is not considered as a national by any State under the operation of its law, either because they never had a nationality, or because they lost it without acquiring a new one.

(Source: UNHCR Master glossary of terms: https://www.unhcr.org/glossary/)

of resources by host countries to adequately meet even their fundamental needs for food, shelter and clean water. Nurses have a moral responsibility and an important role to play in ensuring that the health and human rights of refugees, asylum seekers, displaced people and stateless people do not 'fly under the radar' (Carrigan 2014). One way to ensure this is to join with others in 'energising dissent' and rehumanising this highly vilified and dehumanised population.

# **People with Disabilities**

People with disabilities may be described as persons:

with long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

(UN 2006a: Article 1)

The WHO estimates that more than 1 billion people (or around 15% of the world's population) live with some form of disability. Of these, almost 200 million experience 'considerable difficulties with functioning' (WHO 2011: 5). Although not all people with disabilities are vulnerable, research suggests that some people with disabilities are more vulnerable than others on account of being at a higher risk of abuse because of being dependent on a high number of caregivers and difficulties in communication (WHO 2011: 147).

In its first (and now much-cited) *World report on disability*, the WHO highlights that people with disabilities tend to have 'poorer health outcomes, lower education achievements, less economic participation, and higher rates of poverty than do people without disabilities' (WHO 2011: 5). One reason for this is that people with disabilities experience many barriers to accessing services (including health care) that people without disabilities often take for granted.

# BOX 7.16 Rights contained in the 1951 Convention

- The right not to be expelled, except under certain, strictly defined conditions (Article 32)
- The right not to be punished for illegal entry into the territory of a contracting State (Article 31)
- The right to work (Articles 17 to 19)
- The right to housing (Article 21)
- The right to education (Article 22)
- The right to public relief and assistance (Article 23)
- The right to freedom of religion (Article 4)
- The right to access the courts (Article 16)
- The right to freedom of movement within the territory (Article 26)
- The right to be issued identity and travel documents (Articles 27 and 28)

(Adapted from UNHCR Glossary of Terms: https://www.unhcr.org/glossary/)

In 2006, the United Nations adopted the *Convention* on the Rights of Persons with Disabilities (CRPD) (www. un.org/disabilities/documents/convention/convoptprot-e. pdf), the key aim of which is to:

Promote, protect and ensure that full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for human dignity.

(UN 2006a: Article 1)

Despite these and other mechanisms designed to protect the moral entitlements of people with disabilities, discrimination on the basis of disability still occurs – that is, people with disabilities are still vulnerable to being distinguished by and excluded from social participation on the basis of their disability. Once 'marked' on the basis of disability, people with disabilities may experience the impairment, nullification or negation of the enjoyment and exercise of their 'human rights and fundamental freedoms in the political, economic, social, cultural, civil, or any other field' (UN 2006a: Article 2). The flow-on effect of this can also work to undermine the possibility for people with disabilities to 'make friends, express their sexuality, and achieve the family life that non-disabled people take for granted' (WHO 2011: 147).

The CRPD has identified eight key barriers that are instrumental in restricting participation by people with disabilities; these barriers are summarised in Box 7.17.

People's experiences of disability vary across conditions, contexts and cultures. Nevertheless, stereotypical images of

being blind, deaf or confined to a wheelchair prevail, even though in reality disability can be associated with a range of health conditions and can depend on the personalities of the people affected, the level of support they have and the socio-cultural environments in which they live (WHO 2011: 8).

As previously noted, not all people who have a disability are equally vulnerable; however, vulnerable populations are disproportionately affected by disability and those with severe disabilities tend to be more disadvantaged than are others. As Cohon (2003: 658) notes:

People with disabilities tend to be looked down on, ignored, discriminated against, and otherwise badly treated. Sometimes they are denied education or medical care or excluded from employment. Sometimes they are institutionalized or sterilized against

# BOX 7.17 Barriers Faced by People with Disabilities

- 'Inadequate policies and standards' (which do not always take into account the needs of people with disabilities)
- 'Negative attitudes' (encompassing negative beliefs about and prejudices against people with disabilities – e.g. school-age children seeking admission to mainstream schools)
- 'Lack of provision of services' (people with disabilities are particularly vulnerable to inadequacies in services including health care and rehabilitation)
- 'Inadequate service delivery' (e.g. poor coordination of services, inadequate staffing and skill mix and so forth)
- 'Inadequate funding' (it has been suggested that, even in high-income countries, between 20% and 40% of people with disabilities do not receive adequate assistance with everyday activities)
- 'Lack of accessibility' (this can include difficulties in accessing buildings as well as basic information and communication technologies such as telephones, the internet and television)
- 'Lack of consultation and involvement' (people with disabilities are often excluded from decision-making on matters that stand to directly affect their lives)
- 'Lack of data and evidence' (owing to a lack of robust comparative data, there is only limited understanding of the enablers and disablers affecting the capacity of people with disabilities to be active participants in social processes).

(Source: WHO 2011: 9-10)

their will. Sometimes they are subjected to violence or other forms of abuse. Often, especially but not only in poor countries, their needs for food and shelter are not met. Many nondisabled individuals are uncomfortable in the presence of the disabled and therefore exclude them from social life. Thus, at times the attitudes of their fellow citizens bar disabled people from carrying out the social roles of students, employees, spouses, and parents.

The vulnerability of people with disabilities was highlighted during the COVID-19 pandemic, which, according to the COVID-19 Disability Rights Monitor (COVID-DRM), resulted in wide-scale violations of their rights to health and life, and 'policy makers at many levels treating people with disabilities as "objects of care or control" (https://www.covid-drm.org). Violations included breakdowns in essential services, 'multiplication of intersectoral harms', and being denied access to healthcare (Mladenov & Brennan 2021a: 1356). The failings of 'the system' during the pandemic (many of which pre-dated the pandemic) led researchers to call for a shift in focus from 'individual vulnerability' to 'social vulnerability' vis-à-vis the social determinants of vulnerability (Mladenov & Brennan 2021a, 2021b).

#### **Role of Nurses**

As is the case with other vulnerable populations, nurses have a moral responsibility and an important role to play in ensuring that the health and human rights of people with disabilities are upheld. It is also incumbent on nurses to fulfil these responsibilities in their capacity as 'good citizens'. On this point, as Professor Steven Hawking (2011: 3) reminds us,

we [all] have a moral duty to remove the barriers to participation, and to invest sufficient funding and expertise to unlock the vast potential of people with disabilities. Governments throughout the world can no longer overlook the hundreds of millions of people with disabilities who are denied access to health, rehabilitation, support, education and employment, and never get the chance to shine.

Just as governments can no longer credibly overlook the vulnerabilities and disadvantages experienced by people with disabilities, neither can the nursing profession. Nurses need to collaborate with other community advocates and energise dissent aimed at improving the status quo.

# **Indigenous Peoples**

According to the advocacy group *Cultural Survival* (https://www.culturalsurvival.org/issues), there are over 476 million

indigenous peoples<sup>10</sup> in the world, belonging to more than 5000 different groups worldwide and speaking more than 4000 languages (WHO 2007a). Taken together, these peoples represent a rich diversity of cultures, religions, traditions, languages and histories. Historically, indigenous peoples have suffered unconscionable disenfranchisement and the abrogation of their rights by colonisers who saw fit to construct them as 'savages', 'barbarians', 'backward', and 'inferior and uncivilised' – all dehumanising constructions that were ultimately used by colonisers to justify their subjugation, domination, exploitation, moral exclusion, random killing and genocide of indigenous peoples (International Work Group for Indigenous Affairs (IWGIA) 2013: 452). The legacy of this history continues to affect prejudicially the health and wellbeing of indigenous peoples the world over.

The disadvantage that has historically been experienced by indigenous peoples has been unequivocally exposed and re-lived during the COVID-19 pandemic. As noted in the 35th edition of *The indigenous world 2021* (IWGIA 2021: 8):

History has demonstrated that diseases like COVID-19 can wreak havoc on Indigenous Peoples due to a variety of factors, from poor access to infrastructure to a lack of basic health services, including vaccination. Indigenous Peoples already face marginalisation and inadequate medical services and health information, including insufficient information in their languages, making it difficult for them to receive the proper information and care they need to either test and identify cases of infection or treat those who may become infected. Additionally, many communities often don't have access to clean or sufficient water sources either due to improper or non-existent infrastructure, drought or pollution, meaning that one of the main measures in preventing the spread of the disease washing one's hands with soap - is a difficult preventative step for communities to take (IWGIA 2021: 8)

In 2007 the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) was adopted by the General Assembly. Although 144 states voted in favour of the declaration, 4 voted against it, notably Australia, Canada, New Zealand and the United States; these four countries later reversed their position, however, and now support the declaration (United Nations (UN) nd). It is acknowledged that, since the UNDRIP was adopted, progress has been made in terms of formally recognising indigenous peoples, the devastating history and negative health impact that colonisation has had on their lives and cultures, and the need for reconciliation. Despite the progress that has been made, indigenous peoples 'continue to face discrimination, marginalization and major challenges in enjoying their basic rights' (UN nd)

and face ongoing and deep challenges with regard to the lack of domestic remedies to address their concerns.

Epidemiological data show that there are continuing disparities in the morbidity and mortality (including lower life expectancy) rates among indigenous peoples compared with non-indigenous populations. The health disparities noted in the world's indigenous populations are reflected in the health status of Australia's indigenous (Aboriginal and Torres Strait Islander) peoples and the New Zealand Māori people (Disney et al 2017; Phillips et al 2017). Moreover, as with other indigenous populations, much of the health disadvantages experienced by Australia's indigenous peoples and Māori 'can be considered historical in origin' (MacRae et al 2013: 13). However, as MacRae and colleagues (2013: 6) correctly point out, this is only part of the story: 'the perpetuation of the disadvantages owes much to contemporary structural and social factors, embodied in what have been termed the "social determinants" of health' [emphasis added as it does to historical influences.

### **Health Status of Australia's Indigenous Peoples**

The health of Aboriginal and Torres Strait Islander people is improving and progress is slowly being made in 'closing the gap' in their health relative to non-indigenous persons (Australian Indigenous HealthInfoNet 2021). Even so, disparities remain, with morbidity and mortality rates remaining unacceptable. The known disparities that persist in indigenous health give weight to Morgan and Allen's (1998) call, made over three decades ago, for indigenous health in and of itself to be treated as 'a special moral imperative' for which all citizens share collective responsibility. Morgan and Allen (1998: 732) persuasively argue that, in relation to the health of Australian Aboriginal peoples, health stands as an 'appropriate site for restitutional action, which accordingly needs to be situated as a primary locus of action encompassing the complex, interwoven and 'enmeshed' processes of recognition (of past wrongs), restorative justice (to repay some of the 'accrued moral debts' owing to Aboriginal peoples) and ultimately reconciliation (see also Johnstone 2007a).

#### **Health Status of New Zealand Māori**

Māori health continues to improve although, as is the case in Australia, progress is slow, with Māori continuing to experience significant disparities in health and disadvantage (Houkamau et al 2017; McIntosh et al 2021; Phillips et al 2017; Rolleston et al 2020). Inequalities in Māori health are widely acknowledged as posing significant and ongoing challenges to the New Zealand government, which the government itself acknowledges. To this end, the Government has developed its *Māori health strategy*, He Korowai Oranga, which stands as an overarching

document to guide both it and the health and disability sector to achieve the best health outcomes for Māori (https://www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga).

### **Global Call to Redress Indigenous Health Disparities**

In May 2001, deeply concerned about the disparities in the health conditions of indigenous peoples, the Fifty-Fourth World Health Assembly urged its member states (WHA 2001: 1–2):

- 1. to recognise and protect the right of indigenous people to enjoyment of the highest attainable standard of health as set out in the Constitution of the World Health Organization, within overall national development policies;
- 2. to make adequate provisions for indigenous health needs in their national health systems, including through improved collection and reporting of statistics and health data;
- 3. to respect, preserve and maintain traditional healing practices and remedies, consistent with nationally and internationally accepted standards, and to seek to ensure that indigenous people retain this traditional knowledge and its benefits.

It is over two decades since this resolution was passed, yet the disparities in indigenous health stubbornly persist. The persistent nature of disparities in the health status of indigenous peoples serves as a potent reminder of the challenges involved in trying to redress past wrongs and the enduring and accumulative negative effects that the processes of dehumanisation, discrimination, moral exclusions and marginalisation can have on the health and wellbeing of a vulnerable population.

#### **Role of Nurses**

Reduction of health disparities in Australian Aboriginal and Torres Straight Islanders, Māori and other indigenous peoples is going to require more than political rhetoric. As Tobias and colleagues (2009: 1712) contend, it will require sustained political commitment to 'pro-equity health and social policies'. To help foster this commitment, timely monitoring of ethnic health disparities based on high-quality data will be required. In addition, changes in *both* the distribution of the social determinants of health *and* a responsive health care system will also be required (Tobias et al 2009). This is an area in which nurses can meaningfully contribute.

#### **Prisoners and Detainees**

According to the *World prison trends* (https://www.prisoninsider.com/en/articles/global-prison-trends-2020) there

are more than 11 million people held in penal institutions worldwide, with many facing substandard detention conditions (see also Penal Reform International 2021). The incarceration of people in penal institutions is one of the main forms of punishment for the commissions of crimes and other offences. It is often forgotten, however, that 'prisoners are part of society' and that, under various declarations and oaths, while in prison (and upon being released from their custodial sentence) they are entitled to the same quality of health care as is the general population (Gatherer 2013: 1).

What may be surprising to many is that the majority of primary health care provided to people in prison is given by nurses. However, what is variously termed 'custodial nursing', 'prison nursing' and 'correctional nursing' (to be distinguished from 'forensic nursing'11) has tended not to have a high profile in the nursing profession despite the important work that has been and continues to be done in this 'silent' field (Dhaliwal & Hirst 2016; La Cerra et al 2017; Maruca & Shelton 2016; Schoenly & Knox 2013; Shelton et al 2020; Starr & Newman 2020; Woods & Peternelj-Taylor 2021). The importance and (often overlooked) evolution of this work is reflected in various ways such as via the establishment of correctional nursing as a specialty area, publication of foundational texts in the field - for example, Essentials of correctional nursing (by Schoenly & Knox 2013) - the publication of research studies and systematic reviews on the subject (e.g. Dhaliwal & Hirst 2016; La Cerra et al 2017) and publications generally in the nursing literature which have grown substantially since around 2017.

Many prisoners warrant and even need incarceration for the crimes they have committed, particularly those who are extremely dangerous offenders. And members of the public probably agree that most people who are committed to serve a prison sentence for their offences 'deserve what they get'. They may also have little if any sympathy for prisoners who, upon being incarcerated, face the stress of losing the everyday freedoms that most people take for granted and in some cases even losing their civil liberties - such as the right to vote, the right to the same health care as if one were not a prisoner (e.g. in Australian jurisdictions, upon their entry to prison, prisoners lose access to Medicare - the universal health cover scheme – and the pharmaceutical benefits scheme (PBS)) (Plueckhahn et al 2015); their medical care is determined and provided by the state or territory in which they are imprisoned (AIHW 2019: 6); their right to privacy is curtailed, and the right to write letters to family and friends without this being monitored. Some might go even further and contend that prisoners not only deserve to lose their freedoms but, because of violating the rights of their victims, they have also forfeited their rights to these

freedoms as well as the right to be treated with respect as a member of society.

Prisons contain some of the most vulnerable, marginalised and disadvantaged people in society. Compared with the general public, prisoners are more likely to have been in social care as a child, unemployed or homeless and to have a low level of educational attainment (AIHW 2019; Plueckhahn et al 2015; Shelton et al 2020; Woods & Peternelj-Taylor 2021; WHO 2014a). Some ethnic minority groups and indigenous groups also tend to be overrepresented (noting that indigenous Australians and New Zealand Māori are significantly overrepresented in the respective Australian and New Zealand prison systems). Positioned as 'social outcasts' and already deprived of moral status, prisoners (especially those who have committed heinous crimes) are highly vulnerable to being dehumanised - that is, described and treated as 'animals' or 'monsters' - and thus 'justifiably' excluded from the moral entitlements and protections that would otherwise be afforded them. This may help to explain why, until relatively recently, prison and prisoner health has not attracted the level of attention that is otherwise warranted (see, for example, the ongoing global controversy over what is called 'the health-promoting prison' (Baybutt et al 2019; Woodall 2016; Woodall & Dixey 2015; Woodall & Freeman 2021)).

Over the past few years it has been increasingly recognised that prisoners tend to have poorer health than the average population and that penal institutions are not the best places to address poor prisoner health (Baybutt et al 2019; Ginn & Robinson 2013; Plueckhahn et al 2015; Woodall 2016; Woodall & Dixey 2015; WHO 2014a). Not only this, because of the bullying cultures often found in penal institutions, overcrowding, shared facilities, confined and poorly ventilated spaces, and high staff, prisoner and visitor turnover, prisons are a significant source and 'cause' of poor prisoner health (especially mental illness and infectious disease). Prisoner poor health in this situation is often compounded by a lack of appropriate health care services and inadequate medical attention. This has led some to argue that, as prisoners come from and are usually returned to the community, taking a proactive stance towards promoting prisoner health is warranted. Taking such a stance stands to benefit not just the prisoners but also the broader community since health promotion in this instance has the capacity to reduce a country's burden of disease (WHO 2014a).

It is now widely recognised that, compared with the general public, prisoners have far greater health needs. Prisoners often enter prison with several pre-existing health problems including mental health problems, certain chronic diseases, communicable diseases, risky drug and alcohol consumption and tobacco smoking; conversely, others who enter prison healthy are at considerable risk of leaving prison with an acquired health condition such as

poor mental health, an illicit drug problem, HIV or tuberculosis (WHO 2014a). In the Australian prison population, there is a high prevalence of mental health problems and mental illness (e.g. depression and psychosis), illicit substance use, chronic disease (e.g. asthma, arthritis, cardiovascular disease, diabetes and cancer), communicable diseases (e.g. sexually transmitted infections, hepatitis B, hepatitis C and HIV) and disability (Starr & Newman 2020). Mental health problems and harmful drug use are particularly prevalent (Starr & Newman 2020).

The health vulnerability of incarcerated people has been underscored during the COVID-19 pandemic, which has had a devasting impact on prisoners (Rorvig & Williams 2021; Suhomlinova et al 2022). Due to the prison environment, prisoners were at a high risk of contracting the virus, with global data showing that prison inmates suffered higher morbidity and mortality rates compared with the general population (Suhomlinova et al 2022). Compounding the prisoners' plight were the unintended negative consequences of mitigation strategies on their living conditions.

# The Rights of Prisoners

There are various declarations and oaths protecting the rights of prisoners to appropriate and equivalent health services to those available in the general community (Coyle 2007). Notable among the measures and instruments advocating this stance are those presented in Box 7.18. Although these and other instruments (including national measures) affirm that health services available in prison should be appropriate and equivalent to that available in the general community, in reality the 'prison environment may make the goal of equivalence and continuity of care between the community and prison difficult to achieve, especially upon entry' (AIHW 2015: 4). In an attempt to redress this situation, the WHO has championed the idea of fostering the 'health-promoting prison' (referred to earlier), a term which is taken as denoting prisons in which:

the risks to health are reduced to a minimum; essential prison duties such as the maintenance of security are undertaken in a caring atmosphere that recognizes the inherent dignity of every prisoner and their human rights; health services are provided to the level and in a professional manner equivalent to what is provided in the country as a whole; and a whole-prison approach to promoting health and welfare is the norm.

(WHO 2007b: xvi)

#### **Role of Nurses**

Nurses are at the forefront of providing prisoner health care in Australia, New Zealand and elsewhere. In Australian jurisdictions, for example, registered nurses (RNs) are the

# BOX 7.18 Instruments Protecting the Rights of Prisoners to Appropriate Health Services

- United Nations Universal Declaration of Human Rights 1948 (UN 1949):
  - https://www.un.org/en/universal-declaration-human-rights/
- United Nations standard minimum rules for the treatment of prisoners and procedures for the effective implementation of the standard minimum rules (UN 1955):
  - https://www.unodc.org/pdf/criminal\_justice/UN\_ Standard\_Minimum\_Rules\_for\_the\_Treatment\_of\_ Prisoners.pdf
- United Nations International Covenant on Economic, Social and Cultural Rights (UN 1966) Article 12: https://www.ohchr.org/EN/ProfessionalInterest/ Pages/CESCR.aspx
- The Oath of Athens (International Council of Prison Medical Services 1979):
  - https://www.medekspert.az/ru/chapter1/resources/ The\_Oath\_of\_Athens.pdf
- Principles of medical ethics relevant to the role of health personnel, particularly physicians, in the protection of prisoners and detainees against torture and other cruel, inhuman or degrading treatment or punishment (UN 1982):
  - https://www.ohchr.org/EN/ProfessionalInterest/ Pages/MedicalEthics.aspx
- United Nations General Assembly basic principles for the treatment of prisoners (UN 1990):
  - https://www.ohchr.org/en/instruments-mechanisms/instruments/basic-principles-treatment-prisoners
- United Nations Office of the High Commissioner for Human Rights Istanbul protocol: manual on the effective investigation and documentation of torture and other cruel, inhuman or degrading treatment or punishment. (UNOHCHR 2004):
  - https://www.ohchr.org/Documents/Publications/training8Rev1en.pdf
- United Nations Office on Drugs and Crime (UNODC)
   The United Nations standard minimum rules for the treatment of prisoners (the Nelson Mandela rules) (UNODC 2015):
  - https://www.unodc.org/documents/justice-and-prison-reform/GA-RESOLUTION/E\_ebook.pdf

most commonly consulted (more than 2 in 3 (68%)) health professionals in prison clinics, followed by general medical practitioners (14%) and mental health care providers (10%)

(AIHW 2019: 132). Prison discharge self-reports suggested that more than 4 in 5 (82%) saw a nurse at the prison clinic (AIHW 2019: 131).

Nurses working in prisons face significant challenges in their work, not least being the challenge of battling the health-injurious effects of the dehumanisation and delegitimisation of their clientele. They also face the challenges that come with requirements to provide ethical care in a correctional context. Issues include, but are not limited to, the ethics of: body cavity searches, DNA testing, medical restraint, the administration of treatments during hunger strikes, involvement in inmate discipline, preventing transmission of disease (e.g. HIV), vulnerability, privacy and confidentiality, end-of-life care and access to and equity in preventive health care (Faiver & Heiserman 2017; González-Gálvez et al 2018; Schoenly nd). The challenges posed by correctional nursing do not - and should not be the domain of prison nurses alone, however, and rightly stand as the province of *all* nurses.

In *The ICN code of ethics for nurses* (ICN 2021a: 7), nurses are reminded that their primary responsibility is to those 'people who require nursing care'. In its position statement on *Nurses' role in the care of detainees and prisoners*, the ICN (2011a: 1) makes clear that 'prisoners are people' and, accordingly, are just as deserving of the professional advocacy of nurses as is the general public. To this end, the ICN (p 1) stipulates that prisoners 'have the right to health care and humane treatment regardless of their legal status' and that, when caring for detainees and prisoners, nurses are expected to adhere to the human rights and ethical principles (such as outlined in the declarations, measures and oaths cited in Box 7.18). Nurses are also expected to uphold the standards prescribed by the ICN (2011a) (Box 7.19).

Several years ago a forensic psychiatrist, who worked in a large high-security prison housing long-term male prisoners who had committed extremely violent crimes, was asked the question: 'Why do you do this work?', 'How can you work with those "animals"?' To this question, the psychiatrist replied calmly, 'Well someone has to treat those men as human beings, and it might as well be me' (personal communication).

# **Homeless People**

It has been conservatively estimated that approximately 1.6 billion people world-wide live in inadequate housing conditions in urban areas alone (Homeless World Cup Foundation nd). Based on the last global survey conducted by the UN, it is further estimated that more than 100 million people have no housing whatsoever, with almost one-quarter of these being children (Homeless World Cup Foundation nd). Although severe housing deprivation can affect anyone, those who tend to be disproportionately affected

# **BOX 7.19 ICN Standards of Care for Prisoners and Detainees**

- Nurses who are aware of abuse and maltreatment take appropriate action to safeguard the rights of detainees and prisoners.
- Nurses employed in prison health services do not assume functions of prison security personnel, such as restraint or body searches for the purpose of prison security.
- Nursing/health research should be based on ethical standards and respect for human subjects and protection of their health and rights. Nurses participate in clinical research on prisoners and detainees only with the prisoner or detainee's informed consent.
- Nurses collaborate with other health professionals and prison authorities to reduce the impact of crowded and unhealthy prison environments on transmission of infectious diseases such as HIV, hepatitis and tuberculosis and improve their care and management.
- Nurses abstain from using their nursing knowledge and skills or health information specific to individuals in any manner that violates the rights of detainees and prisoners.
- Nurses advocate for safe humane treatment of detainees and prisoners including dignity, respect, the provision of clean water, adequate food and other basic necessities of life.

(Source: ICN 2011a: 1)

are children and young adults, ethnic minorities and indigenous peoples, women, sole-parent families and people without families. This situation is not confined to individual countries and is replicated across the globe – even in well-resourced OECD nations like Australia, Canada, New Zealand, the UK and the USA (Willison & Mauri 2021).

The idea of homelessness often conjures up stereotypical images of 'dishevelled vagrants wandering the streets' – people on 'skid row'. The reality of homelessness, however, is far more complex. Moreover, as a team of New Zealand researchers has suggested, since the term *homelessness* is 'burdened by stereotype', a more appropriate term should be used such as 'severe housing deprivation' (Amore et al 2013: 7). This view has been reiterated by Busch-Geertsema and colleagues (2016) in their attempts to develop a global framework for conceptualising and enabling meaningful comparative measurements of homelessness.<sup>12</sup>

The negative impact of stereotypical views about homeless people should not be underestimated. One reason for this is that homeless people are particularly vulnerable to being treated as 'less than human' (*viz* dehumanised) and

discriminated against (Bower et al 2018; Harris & Fiske 2006). This is because homeless people are often stereotypically perceived as having 'caused their own plight' and hence as moral failures. Once dehumanised, homeless people are at particular risk of being treated prejudicially with disgust and contempt, and denied the moral entitlements and protections that being human would otherwise afford them (Harris & Fiske 2006). This, in turn, leaves them vulnerable to the harms of stigma and discrimination – often without remedy – and even the subjects of unwarranted criminalisation, for example, when arrested for begging or sleeping rough on the streets (Ploszka 2020; Watts et al 2018).

#### What is Homelessness?

It is important to state at the outset that there is no *one* definition of homelessness (Busch-Geertsema et al 2016). Even so, it is generally recognised that homelessness may fall into one of several categories depending on the country, individual situation and needs of the people concerned. Notable among the categories that have commonly been used are:

- Primary homelessness people who are literally 'roofless' and without shelter (e.g. living on the streets, in parks, in subways or in deserted buildings); this is arguably the most visible form of homelessness.
- Secondary homelessness people with no place of usual residence or 'fixed abode' i.e. people of 'no fixed address'; they move frequently between various types of accommodation (including transient accommodation with family or friends, or living temporarily in refuges, hostels or boarding houses with shared amenities and without security of tenure) (Chamberlain & MacKenzie 2009).

In Australia, homelessness has been defined under Australian federal law as 'inadequate access to safe and secure housing' (*Supported Accommodation Assistance Act 1994*: Preliminary Part 1, Section 4: Definition of *homeless* (p 5)) (Box 7.20). In New Zealand, homelessness is officially defined in terms similar to that used in Australia, that is:

living situations where people with no other options to acquire safe and secure housing are: without shelter, in temporary accommodation, sharing accommodation with a household or living in uninhabitable housing.

(Statistics New Zealand 2015)

#### Causes of Homelessness

The causes of homelessness are complex and varied and can range from poverty and financial difficulties (exacerbated by unemployment) to personal and family problems such as domestic violence, family breakdown, family rejection

# BOX 7.20 **Definition of Homelessness in Australian Federal Law**

In Australia, homelessness has been defined under Australian federal law as 'inadequate access to safe and secure housing' (*Supported Accommodation Assistance Act 1994*: Preliminary Part 1, Section 4: Definition of *homeless* (p 5)). For the purposes of the Act, 'inadequate access to safe and secure housing' is taken to mean housing to which the person has access:

- 1. damages, or is likely to damage, the person's health; or
- 2. threatens the person's safety; or
- marginalises the person through failing to provide access to:
  - (i) adequate personal amenities; or
  - (ii) the economic and social supports that a home normally affords; or
- places the person in circumstances which threaten or adversely affect the adequacy, safety, security and affordability of that housing.

(Source: Supported Accommodation Assistance Act 1994 [Cth]: 5)

(notably of LGBTIQA+ youths), poor physical and mental health, substance use and other addictions leading to an inability to cope (AHRC 2008). These situations are compounded in the case of people who already live on the margins of society (e.g. ex-prisoners, refugees and asylum seekers), have few or no social support networks with either family, friends or the community and are socially isolated (AHRC 2008). When these situations are examined in depth, it can be readily seen that when life circumstances beyond a person's control 'strike' then homelessness is a frighteningly real possibility. The lesson here for anyone contemplating making moralising judgments about homeless people is recognising that another's misfortune could so easily be our own – that is, 'there but for the grace of God go I'.

# Homelessness and the Right to Health

Research has shown a strong correlation between homeless and health disadvantage, with homeless people experiencing a disproportionately higher rate of morbidity (disability and chronic illness) and premature mortality compared with the general population (Fazel et al 2014; Jego et al 2018; Moledina et al 2021; Rhoades et al 2018; Stafford & Wood 2017). Moreover, as Gerber (2013: 37) notes, the persistently homeless also live in:

constant chaos, confusion, and fear. Trauma from head injuries, gunshot wounds, stab wounds, lacerations,

and/or fractures is a significant cause of death and disability. Hypothermia in the winter and dehydration in the summer are of particular concern.

Homelessness is not just a 'housing' issue; it is also fundamentally a human rights issue (AHRC 2008). This view has led some observers to call for a more comprehensive approach to the rights of homeless people (Eisenmann & Origanti 2021) including the development of a *Homeless bill of rights* as 'a new instrument to protect the rights of homeless people' in countries otherwise devoid of human rights protections for the homeless (Ploszka 2020: 601).

#### **Role of Nurses**

Given that every person (young and old alike) has a fundamental right to the highest attainable standard of health and health care, homelessness thus stands as a potent threat to the right to health. It is this risk that imposes correlative responsibilities onto others – including nurses – to take action.

Significantly, homelessness can be both a cause and a consequence of ill health. Because of a lack of resources (e.g. the means of transport and the capacity to attend and pay for appointments, the lack of identification and a Medicare card or health insurance card, a lack of facilities to store and administer medications (e.g. refrigeration of insulin, thyroxine)) and a lack of access to appropriate health services generally, it can also exacerbate existing health problems and complicated care and treatment regimens.

As even a cursory search of the nursing literature will show (too numerous to list here), nurses (particularly those working in community and primary care) have a long history of advocating for and caring about people who are homeless and delivering harm reduction outreach programs. Their work continues to this day through the efforts of community nurses and nurse-led primary health care clinics operating in liaison with other sectors of the health care system (Crock 2016; Roche et al 2017; Savage et al 2006; Su et al 2015). The practical and advocacy role of nurses in caring for people who are homeless has been emphatically highlighted during the COVID-19 pandemic, which has seen nurses assert testing and vaccination outreach services to help minimise community transmission among this vulnerable group (see, for example, Australian nurse Julie Martin's account of the impact of the COVID-19 pandemic on people experiencing homelessness (Martin 2020)).

Like prison nursing, nurse-led care of the homeless has tended not to have a high profile in the nursing profession. Despite the dedicated efforts of nurses working in this 'silent' field, to date the vulnerability and health rights of homeless people have not featured significantly in the nursing ethics literature or nursing policies and position statements. This stands as an area requiring attention and action.

# Sexual Minorities (LGBTIQA+ People)

People who identify as lesbian (L), gay (G), bisexual (B), transgender (T), intersex (I), queer/questioning (Q), asexual (A) and 'other descriptors' (+) (commonly referred to by the acronym LGBTIQA+ or variations thereof)13 constitute a significant sexual minority of the world's population. The demographics of LGBTIQA+ people are difficult to quantify accurately owing to a variety of reasons (e.g. flaws in research methodologies and population surveys, reluctance by people to either self-identify or disclose their sexual orientation and gender identities in response to surveys or requests for personal details (e.g. when being admitted to hospital, completing an application for health insurance, etc.), underreporting and a lack of reliable data generally). Nevertheless, it is conservatively estimated that a significant minority, of around 3% (between 1.5% and 5.5%) of people surveyed, identify as being 'other' than heterosexual (Wikipedia Contributors 2021a).

Sexual orientation and gender identities are 'essential elements of identity' and inform how people plan, organise and generally live their lives (Callahan et al 2014: S48). People who are heterosexual often take for granted the 'normalcy' of their sexuality and gender identities and the 'heteronormative' world in which they can openly live. In contrast, people who are not heterosexual and who do not have a 'fit' within a heteronormative world (i.e. a world in which heterosexism is regarded as the norm) have historically been characterised as 'unnatural' and 'deviant'. This (mis)characterisation of non-heterosexual people has seen LGBTIQA+ people stigmatised and subjected to unmitigated prejudice, discrimination and hate crimes (many of which have resulted in serious injury and even death). In addition, LGBTIQA+ people have had their identities ignored, their sexuality pathologised (homosexuality was classified as a mental illness in the Diagnostic and statistical manual of mental disorders until 1973) and their sexual behaviour criminalised (noting here that homosexuality remains a criminal offence in some countries, punishable by incarceration and even death) (McGill 2014; Powell & Foglia 2014; Voss 2018). More fundamentally, upon disclosing their sexual orientation and/or gender identities, many LGBTIQA+ people have been treated as outcasts by their own families and have remained permanently estranged from them even when seriously ill or dying. As noted earlier, estrangement by families is also a major cause of homelessness (with associated risks of mental health issues and suicidality) among LGBTIQA+ youth (Fulginiti et al 2021).

In considering the vulnerability of LGBTIQA+ people, it is important to place in context the protracted history of stigma, prejudice, discrimination and psychological trauma that many have experienced - especially during their formative years - and the lasting impact that these negative experiences have had on their lives and world views. The US literature identifies at least three distinctive generations of LGBTIQA+ people and the formative cultural contexts and social periods in which they lived (Box 7.21). Although derived from the cultural context of the USA, the generations and social periods identified equally apply to other common-law jurisdictions (e.g. those of Australia, Canada, New Zealand and the UK), which have been similarly affected by the events and socio-cultural norms of the periods in question and who share similar histories regarding the dehumanisation and degradation of LGBTIQA+ people.

Over the past five decades, progressive liberal democratic countries around the world have enacted many positive social and legal reforms which have resulted in greater social recognition and public acceptance of LGB-TIQA+ people locally and globally. The 'rapid progress' of marriage equality laws (e.g. in Europe, the USA, New Zealand, Australia and elsewhere) is an example. However, as Voss (2018: 1) points out, with rapid progress has come 'harsh backlashes and deterioration of rights'. Despite the many reforms that have been made, LGBTIQA+ people nevertheless continue to experience prejudice, stigma, discrimination and marginalisation in their everyday lives. Moreover, with the rise of authoritarian (right-wing) populism (whose proponents regard LGBTIQA+ people as 'eschewing traditional values' and as 'the antithesis of morality'), violence against members of the LGBTIQA+ community continues despite the enactment of protective laws (Voss 2018: 2). In addition, health inequalities (particularly with regard to mental health issues) remain paramount (Carman et al 2020; Health4LGBTI State-of-the-Art

# BOX 7.21 Three Generations of LGBTIQA+ People

- 'Greatest Generation' (born between 1901 and 1924) affected by deprivations of the Great Depression
- 'Silent Generation' (born between 1925 and 1945) affected by the laws and medical doctrine that criminalised and pathologised same-sex behaviours and identities
- 'Baby Boom Generation' (born between 1946 and 1964) – influenced by the civil rights era (1960s) and the Stonewall riots (1969)

(Source: Foglia & Fredriksen-Goldsen 2014: S40)

Synthesis Report 2017). As noted by the Australian State of Victoria Better Health Channel, many LGBTIQA+ people continue to harbour uncertainties about 'whether they will receive acceptance from families, friends, colleagues and services' should they decide to disclose their sexual orientation or gender identities (i.e. 'come out') (Better Health Channel 2018: 1–2). The pressure of these uncertainties, together with both anticipated and actual daily experiences of stigma, prejudice and discrimination, continue to have a significant negative impact on the health and wellbeing of LGBTIQA+ people, a burden that others who are heterosexual do not have to carry.

It is easy to become complacent about the political gains made by sexual minorities and to assume that equality and justice for this population are 'inevitable' (Powell & Foglia 2014). In light of the growing legitimisation of same-sex marriage, and law reforms permitting LGBTIQA+ people to adopt children and have access to in vitro fertilisation (IVF) treatments and surrogacy services in order to start a family, it would also be easy think that homophobia in modern societies is 'not an issue anymore' and that LGB-TIQA+ people are no longer a vulnerable minority. As a growing body of social and public health research is showing, however, justice is neither 'inevitable' nor 'done' for LGBTIQA+ people, who continue to experience what Meyer (2003: 3) has classically termed 'minority stress', which he defines as 'the excess stress to which individuals from stigmatized social categories are exposed as a result of their social, often minority, position. This stress is experienced on account of both anticipated and actual prejudicial and discriminatory behaviours towards them and the related isolation and marginalisation that often follows (see, for example, the study by Synnes & Malterud 2018). In the case of LGBTIQA+ people who have other stigmatising characteristics (e.g. are of culturally and linguistically diverse backgrounds, live with a disability, are old, suffer from a mental illness, or have been diagnosed with a highly stigmatised disease such as HIV/AIDS or hepatitis C), their vulnerability and risk of minority stress are compounded i.e. they face a 'double jeopardy'.

Health care contexts have not been immune from the dominant influences of a heteronormative world view and, historically, have even been overtly hostile to the health needs and interests of LGBTIQA+ people. This has included 'labeling, judging and forcing wrongful, cruel treatment' upon LGBTIQA+ people (Powell & Foglia 2014: S2), ignoring their identities, denying them and their partners respect as human beings, and providing inappropriate and less than competent care (Callahan et al 2014). In light of this, it is not surprising that many 'older generations' of LGBTIQA+ people, who have spent the majority of their lives concealing their sexual orientation and gender identities, are suspicious

of 'the system' and may find it difficult to trust health care providers and institutions. Accordingly, they may continue to conceal their sexual orientation from their health service providers and may avoid altogether seeking needed medical treatment and health care (including nursing care) even if the health consequences of such avoidance might be dire.

Although many of the 'old prejudices' against LGB-TIQA+ people have shifted, their heritage has lasted such that both conscious and non-conscious biases (the activation of negative stereotypes outside of conscious awareness) persist in modern social contexts (Foglia & Fredriksen-Goldsen 2014). These are particularly problematic in health care settings since, as Foglia and Fredriksen-Goldsen (2014) point out, they can threaten the clinical encounter by undermining patient engagement and shared decision-making, which in turn might (and does) result in patients withholding information that is otherwise essential to correct patient assessment and diagnosis. In either case, the quality and safety of patient care are placed at risk.

It is acknowledged that most LGBTIQA+ people lead fulfilling and healthy lives. Nevertheless, research is increasingly showing that, as a demographic group, such people have poorer health and wellbeing (particularly in regards to their mental health) compared with the total population (Carman et al 2020; Cronin et al 2021; Haas et al 2011; Health4LGBTI State-of-the-Art Synthesis Report 2017; Hughes 2018; Perales 2019). A key variable contributing to this disparity is the continuing stigma and discrimination that LGBTIQA+ people can experience in their everyday lives and the minority stress and health-injurious distress that this may engender in them.

Despite the widespread acceptance of patient rights bills and charters in hospital settings and the promulgation of patient engagement and patient-centred care as core principles and standards of the global patient safety movement, biases and prejudices against LGBTIQA+ people in health care persist (Ayhan et al 2020; Health4LGBTI State-of-the-Art Synthesis Report 2017). These biases and prejudices can be individual or institutional, subtle or overt, conscious or unconscious, intentional or unintentional (Box 7.22). For example, an explicit institutional bias can be found in cases of aged-care facilities that do not allow same-sex partners to room-share when admitted for residential care. Other examples of institutional biases (which may be unintended but discriminate just the same) include the use of 'standard' demographic forms that do not include provisions enabling a patient to indicate that he/she is in a same-sex relationship (e.g. do not contain options for use of terms such as 'lifelong partner, or contain options that allow patients only to refer to their life-long partner as a 'friend') and of 'standard' demographic forms that fail to contain provisions enabling patients to indicate that they are transgender or intersex in

# BOX 7.22 Expressions of Unconscious Bias

Examples of individual and unconscious biases that can be expressed ('leaked out') include:

- declining/refusing to care for LGBTIQA+ people on grounds of conscientious (religious) beliefs
- · averting eye contact
- turning away
- avoiding physical contact e.g. refusing to shake hands, or declining 'ordinary' acts of comfort, care and kindness
- conveying frank dislike or repugnance either verbally or non-verbally
- · ignoring the presence of a partner
- limiting attendance time when caring for or treating LGBTIQA+ patients
- using derogatory, dehumanising terms when referring to or caring for LGBTIQA+ patients
- snickering and joking about the patient or his/her partner to others (including staff)

(Source: adapted from Foglia & Fredriksen-Goldsen 2014)

sexual identity/orientation (e.g. includes options only for indicating whether the patient is male *or* female). Another institutional bias can be found in hospital policies which do not recognise same-sex partners as 'next-of-kin', which in turn enables staff to restrict their visiting rights, to withhold vital information about a partner's health status or medical condition and to deny partners a legitimate role in surrogate decision-making concerning the care and treatment of their loved one, including at the end of life.

It is only in recent years that the human rights of people whose 'sexual orientation and gender identity' (SOGI) differs from the heteronormative population has become the subject of advocacy at the United Nations Human Rights Council (Daigle & Myrttinen 2018; McGill 2014; Voss 2018). As Voss (2018: 3) contends, however, SOGI is a 'highly contested normative space' and the time being taken to pass resolutions in favour of recognising the human rights of LGBTIQA+ people is taking an abnormally long time, largely because of the delaying tactics of populist 'counter-SOGI' entities. This delay, he warns, risks not only sending a negative message to LGBTIQA+ people and SOGI rights advocates, but also 'killing momentum' and withering the resources that would otherwise be allocated to progressing the SOGI rights cause (McGill 2014; Voss 2018).

#### **Role of Nurses**

Nurses, like others in society, have an ethical responsibility to contribute to the positive project of preventing the dehumanisation, discrimination and degradation of LGBTIQA+ people in health care contexts. They also have a responsibility to contribute to the positive project of improving the safety and quality of health care for LGBTIQA+ people and redressing their health disparities. This, however, is going to require a multifaceted response encompassing education, research, leadership and ethical practice and making visible the critical (missing) link between sexuality biases and prejudices and patient safety and quality of care.

### CONCLUSION

It is often said that we can judge a nation or a society 'by the way it treats its most vulnerable citizens' (attributed to Aristotle, 384–22 BC) or, similarly, 'by how it treats its weakest members' (attributed to Mahatma Gandhi, 1869–1948). The same might be said of the health care professions: these too can be judged by the way they treat the most vulnerable and weakest members of society. How well the nursing profession will ultimately be viewed against this measure remains to be seen.



### **CASE SCENARIO 1**

A 89-year-old woman of non-English speaking background, who lived alone, was admitted to the emergency department (ED) of a metropolitan hospital with suspected fractures of her wrist, ribs and knee after falling while pruning some trees in her backyard 3 days earlier. Upon admission she initially refused all diagnostic procedures, including x-rays, on the basis of her belief 'that everything will heal naturally'. The woman's elderly sister who had brought her to the ED was eventually able to persuade her to 'have an x-ray of her wrist at least', as it was 'obvious' it was broken. The x-ray confirmed a displaced distal radius fracture - a known common injury in the 'super-elderly'. While waiting for the reduction of her fracture and her arm plastered, the woman developed a cardiac arrhythmia for which she was already on medication prescribed by her general practitioner (GP). Concerned by the pain she was experiencing and the onset of the cardiac arrhythmia, the attending doctor decided to admit her 'for monitoring'. Unfortunately, due to COVID restrictions that were in place at the time, none of her family members were able to be with her or to visit following her admission to the ward. Phone calls over the next 3 days started to perplex her family as they revealed the woman was becoming increasing agitated and it was clear to them that she was 'deteriorating' (they had noted that her voice had become 'frail and weak' and she seemed disorientated). On the third day of her admission, the woman's NOK (next of kin) received a phone call from a nurse during which it was revealed the woman had become 'distraught' by her hospitalisation. On the basis of their assessment, the family decided that 'she needed to come home immediately'. A phone meeting was arranged with the attending doctors who confirmed that the woman 'had the right to discharge herself' but that 'it was against their medical opinion'. They explained that 'provided she signed the self-discharge form, she was free to go'. The

spokesperson for the family explained, however, that the woman 'would not sign such a form since she had a profound distrust of the system'. It was ultimately agreed that a note would be made in the woman's hospital records that she 'wished to discharge herself home', that 'she had declined to sign the relevant form' and that a referral to the orthopaedic outpatients clinic for a follow-up review would be sent to her. The family confirmed that they were available to pick her up from the hospital once the discharge procedures had been completed. Assuming they would call the ward once they had arrived at the hospital, they were shocked to find the woman (supported only by her walking stick) disorientated and wandering aimlessly from the hospital entrance towards a busy main road (a matter they intended to follow up). Once home, it seemed to the family that their loved one's disorientation and frailty had been drug induced, probably by the strong analgesic medication she had been given while in hospital (they suspected it might have been an opioid, to which the woman had a known intolerance). After 3 days at home in the care of her family and sleeping peacefully in her own bed, the woman's heart rate settled, the colour in her face returned and she was beginning to be 'her old self' again. Two weeks after her discharge, the family noted that they had not received the referral for the woman's outpatient clinic appointment. A call to the clinic confirmed that they 'had not received a referral' and that, until they did, an appointment could not be made. After several failed attempts at trying to phone through to the ward (the phone would just 'ring out'), a ward clerk eventually answered the phone. After refusing a request by the family's spokesperson to arrange an appointment to speak directly to the Nurse Unit Manager about the situation, the clerk advised (incorrectly) that 'as the patient had discharged herself, it was "against the rules" to arrange a follow-up appointment'.

# **CRITICAL QUESTIONS**

- 1. What ethical issues are raised by this case?
- 2. What are the contextual/cultural considerations relevant to moral decision making in this case?
- 3. Should the woman's 'right to discharge herself from hospital' have been respected?
- 4. Is it morally acceptable that patients who have discharged themselves from hospital be denied followup care?
- **5.** What moral obligations did the staff have in this case?

### **ENDNOTES**

- Excerpts taken from Johnstone M-J. (2009). Ethics and human vulnerability. *Australian Nursing Journal*, 16(10), 23. Reproduced with permission.
- This conflict saw the genocidal mass slaughter of between 500 000 and 1 million Rwandans (70% of whom were Tutsis).
- 3. See, for example, the Australian television series 'Go back to where you came from', which sought to give Australians from various walks of life an opportunity to challenge their preconceived notions about refugees and to gain insight into what it is 'really' like to be a refugee or asylum seeker fleeing a troubled land; this series can be viewed via https://www.sbs.com.au/programs/go-back-to-where-you-came-from. See also Ai Weiwei's 2018 epic film 'Human flow', which documents the plight of the world's 65 million people displaced since World War II; this film provides an opportunity to challenge the prejudices and biases held against refugees and asylum seekers, and the cruel and spiteful treatment they are too often exposed to. Information about this film can be viewed at: https://www.humanflow.com/.
- 4. See Opotow 1990: 176-7.
- 5. See, for example, the Compassion Cultivation Training (CCT) program founded in 2008 and developed by the Center for Compassion and Altruism Research and Education (CCARE) at Stanford University School of Medicine; this can be viewed at: http://ccare.stanford.edu/education/aboutcompassion-cultivation-training-cct/; see also the use of mindfulness to cultivate compassion (DeValve & Adkinson 2008) and to reduce stress and anger (Bergman et al 2016) in members of the US Police force.
- Excerpts taken from Johnstone M-J (2013). Ageism and the moral exclusion of older people. Australian Nursing and Midwifery Journal, 21(3), 27. Reproduced with permission.
- 7. Many different terms are commonly used to describe people's mental health status. Sometimes the terms are used interchangeably, which may be not only incorrect (e.g. a person could have a mental health problem, but not have a mental illness per se) but also confusing. The wrong use of terminology can also be highly stigmatising particularly if the terms used are perceived as having a negative connotation for example, 'being disturbed' versus 'being mentally ill' (https://www.mentalhealth.org.uk/a-to-z/t/terminology). In an attempt to dispel some of the myths around mental illness and to improve public perception and understanding

- of mental health problems, the following key terms have been increasingly defined in the various glossaries included in updated mental health advocacy group and government information and policy documents: 'mental health', 'mental health problem, 'mental illness', 'severe mental illness' and 'severe and complex mental illness' (Australian Government Department Department of Health 2017). The terms 'mental disorder', 'psychiatric disorder' and 'psychiatrically disturbed' have tended to be abandoned and are now more appropriately referred to in information documents and guidelines as 'mental illness' or 'severe mental illness' depending on the symptoms being manifest (Australian Government Department Department of Health 2017). The terms 'mental disorder' incorporating meanings of 'disturbance' and 'defect' continue to be defined and used in mental health legislation, however (see, for example, summaries of Australian State and Territory mental health legislation in Chapter 11 of Staunton & Chiarella 2020). The following is an example of how the key terms have tended to be defined (NB although taken from the Australian Government Department Department of Health (2017) Fifth national mental health and suicide prevention plan, these definitions are consistent with those used in other OECD countries):
- Mental health problem diminished cognitive, emotional or social abilities but not to the extent that the diagnostic criteria for a mental illness are met.
- Mental illness a clinically diagnosable disorder that significantly interferes with a person's cognitive emotional or social abilities. Examples include anxiety disorders, depression, bipolar disorders, eating disorders and schizophrenia.
- Severe mental illness characterised by a severe level of clinical symptoms and often some degree of disruption to social, personal, family and occupational functioning (there are three subcategories: severe and episodic mental illness, severe and persistent mental illness and severe and persistent illness with complex multi-agency needs).
- Severe and complex mental illness mental illness that is not directly aligned to any of [the three] subcategories of severe mental illness. Rather, it is broader and may include episodic or chronic (persistent) conditions that are not confined to specific diagnostic categories (Australian Government Department of Health 2017: 67, 69).
- 8. The notion of 'minorities' is essentially political in nature and is used to identify groups distinguished by common

ties – e.g. of 'descent, race, gender, physical appearance, language, culture or religion, by virtue of which they feel or are regarded as different from the majority of the population in society' (Bullock & Trombley 1999: 533). As explained by Bullock and Trombley (1999: 533), 'In modern usage the term tends to connote real, threatened or perceived discrimination against minorities, although in exceptional cases (e.g. South Africa under Apartheid) a minority may hold power over a majority.' The notion 'minority group' also connotes a group of people with political claims for 'equality of treatment with that accorded the majority' (Bullock & Trombley 1999: 533).

- Excerpts from Johnstone MJ, Kanitsaki, O. (2009). The spectrum of 'new racism' and discrimination in hospital contexts: a reappraisal. *Collegian*, 16(2), 63–69. Revised for its inclusion in this section; reprinted with permission.
- 10. Although the term 'indigenous' is used here, its use is by no means universal. In some regions, terms such as 'tribes', 'First Peoples/Nations', 'Aboriginals' or 'ethnic groups' are preferred (WHO 2007a). The United Nations and the WHO, however, understand the term 'indigenous' to include peoples who:
  - Identify themselves and are recognized and accepted by their community as Indigenous.
  - Demonstrate historical continuity with pre-colonial and/or pre-settler societies.
  - Have strong links to territories and surrounding natural resources.
  - · Have distinct social, economic or political systems.
  - Maintain distinct languages, cultures and beliefs.

- Form non-dominant groups of society.
- Resolve to maintain and reproduce their ancestral environments and systems as distinctive peoples and communities (WHO 2007a; 1).
- 11. Forensic nursing has as its focus the application of forensic aspects to nursing practice *viz* the 'scientific investigation and treatment of trauma, and/or death of victims and perpetrators of violence, criminal activity, and traumatic accidents' (Schoenly nd). Forensic nursing work involves working with the principles and processes of criminal justice; correctional nursing, in contrast, concerns the provision of care to those incarcerated in the justice system. Although distinct specialty areas, the roles of correctional nurses and forensic nurses can overlap e.g. as reflected in the role of 'correctional forensic nurses' (International Association of Forensic Nurses 2017).
- 12. With reference to ETHOS (the European Typology of Homelessness and Housing Exclusion), Busch-Geertsema et al (2016: 125) follow the following three domains for assessing whether a standard of housing is adequate: security domain (refers primary to security and affordability of tenure), physical domain (pertains to the quality and quantity of accommodation and its capacity to meet the needs of inhabitants) and social domain (refers to opportunities to enjoy social relations as are culturally appropriate for the community).
- Acronym 'LGBTIQA+ Communities', Glossary of terms.
   (2019). Australian Institute of Family Studies. Commonwealth of Australia. Online. Available. https://aifs.gov.au/cfca/publications/lgbtiq-communities.