

# An Introduction to Inclusive Practice

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#### LEARNING OBJECTIVES

At the end of this chapter, students will be able to:

- explain the development of inclusive practice in contemporary health care
- explain the relationships between exclusion and inclusive practice in the context of primary health care and the social determinants of health inequalities
- discuss how inclusive practices promote and sustain the well-being of people using health services
- discuss the structure of binary relationships that impact on the health and wellbeing of people using health services and people delivering health services.

#### **KEY TERMS**

binary relationships
exclusion
narrative/identity
identity politics
inclusion
primary health care
social determinants of health
social movements

I decided many years ago to invent myself. I had obviously been invented by someone else – by a whole society – and I didn't like their invention.

(Maya Angelou in Elliot, 1989).

### Introduction

Maya Angelou's quote opens Elliot's book *Conversations with Maya Angelou*. In this first chapter, Maya Angelou's words set the scene for the exploration of inclusive practice. Maya Angelou (1928–2014), civil rights activist, poet and author, draws attention to the importance of defining who we are first and foremost, rather than being defined by how others see us. Experiencing inclusion starts with knowing who you are – not being 'invented' by society. This book will explore the intersections and meeting points between self, other, relationship, trust and power, because it is how these concepts play out in healthcare relationships that can enable or constrain inclusive practices and healthcare outcomes for those who use healthcare services.

This chapter introduces the reader to inclusive practice in health care and offers an examination of why inclusive health care is a prerequisite for health and well-being for people using health services. It explores concepts and ideas that include or exclude health service users' access to safe, appropriate and acceptable health care. The first part of the chapter investigates concepts of inclusion/exclusion, primary health care and social determinants of health to illustrate underlying factors that inform the inclusive/exclusive practice. It then studies recent origins and interpretations of the terms. This helps to position inclusive practice in contemporary times. The second part of this chapter situates inclusive practice historically by examining power and identity, and the notion of the binary relationship, and inspects the power of this construct to shape current healthcare relationships, even though recent history has provided us with different lenses through which to see the term health care.

Inclusive practice is based on a belief that the health professional has the capacity to work effectively and safely in relationships of difference. Working inclusively is not simply a matter of taking people's differences into account when providing health care; it requires an ability and willingness to engage authentically and genuinely with people in any healthcare situation. Being inclusive means working effectively in relationships of difference at times characterised by ambiguity, contradiction, uncertainty and paradox. Spence (2005, p. 59) suggests that when we come in contact with people who are different from us we experience ourselves in relation to someone we see as 'other'; that is, not like us. At the same time we are also faced with the idea of similarity; that is, we may see ourselves as being different, or the other person as different while at the same

#### Inclusion

Actions and events that create the conditions necessary for populations to meet and go beyond their basic requirements in everyday living.

#### Exclusion

Also known as marginalisation, exclusion consists of dynamic, multidimensional processes driven by unequal power relationships interacting across four main dimensions: economic, political, social and cultural.

#### Primary health care

A holistic approach to health care, which recognises and seeks to address broader social and environmental influences on health outcomes.

## Social determinants of health

Societal structures, affected by the distribution of power and resources that result in the conditions in which people live. time identifying where we might be the same. Spence calls this experience a paradox – we 'simultaneously engage with similarity and difference' (Spence, 2005, p. 59). Spence also suggests that all healthcare encounters are relationships of difference, with some differences influencing health care more than others. Sibley et al. (2005) note that our differences distinguish us from one another; it is what makes us unique.

History, genes, culture, class, life experience and identity, along with geography, economic and socio-political factors shape our uniqueness. Our similarities connect us and suggest a shared relationship, while at the same time our difference indicates that we belong to different groups with whom we share other kinds of relationships (Sibley et al., 2005). Differences and similarities play out in every healthcare encounter and help shape health outcomes for people using health services. An inclusive practitioner can negotiate ambiguity, complexity, difference, and similarity within health settings, to maintain the delivery of culturally safe, secure and respectful care.

Contemporary healthcare settings are organised through multilevel and complex networks of relationships. They operate within powerful hierarchical relationships and are formed through the application of complex technologies, diverse treatments and interventions. Wherever health care is delivered, be it in a country, place, community agency, home or hospital setting, the health service user or recipient of care has to negotiate many different kinds of relationships in order to have their health needs met. While people bring their specific health needs to the healthcare relationship, they also bring their cultural identity and life experience.

Professional codes of ethics and health care standards provide for practice frameworks where people are treated with respect and dignity, where their differences are acknowledged by health professionals and the health service involved in their care. They should have an expectation that the health professional caring for them will be competent, knowledgeable in their field and be someone who can be trusted. Within these networks of complexity, potential for expectations to be compromised or diminished are ever present. When a person experiences any action that demeans, diminishes or disempowers (Wood & Schwass, 1993) their sense of identity and well-being, there is a risk that they will be excluded from participating fully in their care.

### Inclusion/exclusion

Codes of practice and ethical frameworks of care provide structures for ensuring that people using health services are treated with respect and dignity. The United Nations Declaration of Human Rights (1948) states: 'recognition of the inherent dignity and the equal and inalienable Rights of all members of the human family is the foundation of freedom, justice and peace in the world' (United Nations, 2008 p. 1).

#### REFLECT AND APPLY

Refer to codes of practice and ethical frameworks relevant to your professional discipline.

- How do they address the concept of inclusive practice?
- Is inclusive practice identified specifically as a framework for practice?
- Is inclusive practice implied in the language of the code?

Inclusive practice is concerned with the freedom to be, with justice and equity, with the right to fairness and peace and the right to be free from barriers that affect our sense of peace or well-being. Inclusiveness can take the form of a policy, a practice, an idea, a process or a relationship. The experience of exclusion/inclusion is dynamic, and moves along a continuum. To work inclusively means knowing what conditions, attitudes and practices exclude, in order to act to include.

The Social Exclusion Knowledge Network (SEKN) (Popay et al., 2008) positions exclusion/inclusion in the context of health inequalities. This chapter addresses exclusion and inclusion from a relational positioning, while policy is addressed in Chapter 2. A relational perspective positions exclusion in a 'dynamic, multidimensional process driven by unequal power relations' (Popay et al., 2008, p. 7).

### Primary health and social determinants of health

Healthcare institutions and health professionals are bound by codes of practice ensuring protection of consumer rights and the provision of safe, competent health care. The World Health Organization identifies that those most at risk of needing health services are those for whom mainstream values are not reflected in their lives, and yet these people are also at risk of being high end users of health services (Labonte, 2004; Ramsden, 2015). The Alma Ata Declaration on Primary Health Care (World Health Organization [WHO], 1978) aimed to shift the focus of healthcare services from large healthcare institutions, where the power to determine and control health care was invested in a few, to a reorienting of health services addressing empowerment and self-determination by the health service user in negotiation with health professionals. It is an attempt to shift hierarchal structures to a more participative and inclusive healthcare environment. The Alma-Ata Declaration (1978) and the subsequent Ottawa Charter (1986) for Health Promotion are key documents guiding the development of a healthcare system underpinned by interconnecting principles of equity, access, empowerment, community self-determination, social justice and collaboration between community sectors and services. Quality primary health care happens when a person or groups are enabled to access appropriate, affordable health care that is acceptable to them in the context of their cultural

needs and identity (WHO, 1978; 1986). While primary health care is often associated with community health and public health, the principles of justice, empowerment and equity apply across all healthcare settings. A criticism of primary health care is that there is a tendency for it to be seen as a first level of care. Rasanathan et al. (2010) suggest that this a limiting view, and that primary health care needs to be seen to work across all sectors (primary, secondary and tertiary health care), as well as beyond the health sector. The principles of primary health care go hand in hand with the social determinants of health. Together they contribute to how we understand inclusiveness in health care in the context of social justice, equity and empowerment. Working within an inclusive framework of practice means understanding the different forces that come into play in relationships of power. Some of these forces come under the banner 'social determinants of health'. They illustrate how power plays out in contexts of cultural, social and economic capital. Power is not an easy concept to define and to do so is beyond the scope of this chapter. Foucault (1972) and Bourdieu (1998) are used in this chapter to illustrate two different approaches to understanding concepts of power. Both are relevant for inclusive practice. They are only briefly discussed here as the ideas are complex and require deeper reading for a better understanding. Their concepts challenge 'top down' notions of power, or power exercised from outside of a person. They position power within a nexus of relationships and explore power as dynamic and constantly circulating in all encounters.

Bourdieu (1998) explains power as a field, or a social arena, in which power struggles and conflicts take place overtly and symbolically – through language, actions and behaviour. Power is social, cultural, political and economic. In our everyday encounters we jostle for positions of influence and success within these networks of power (Bourdieu, 1998). Understanding this approach to power helps explain why in some situations people are powerful, while in others they are not.

Foucault's construct of power (1972) is best described as energy that is everywhere. Within us it circulates, and is produced in discourses, conversations, language, and behaviour. Power can be presented as 'regimes of truth'. Regimes of truth are produced by scientific discourses embedded and reinforced as 'truth' through social institutions, for example, education and health. These 'truths' help produce language, attitudes and beliefs about certain social conditions and events. Unless challenged, critiqued or resisted, such 'truths', become 'taken for granted' and become 'the way things happen around here' or 'the norm' (Bourdieu, 1998). Over time, people forget what knowledge constructed a particular practice in the first place, and practices continue to be enacted with little thought or critique about why things are the way they or if such practices are safe or appropriate for the health and well-being of recipient of care. These concepts will be further explored in the section on binaries later in this chapter.

Yarwood and Betony (2009) and Marmot and Wilkinson (2005) identify social determinants as any circumstances that are beyond the control of individuals – they are

not of their making or necessarily their choice. They encompass the conditions of daily life where people live, work and age, and include biological and socially constructed factors. There are two elements to the social determinants of health: those that derive from the social and political structures and those that arise out of social mores, values, attitudes, beliefs, or the dominance of one value system over another. The first set of conditions includes education, income, employment, housing and transport. The second set of conditions includes the less obvious and at times invisible elements that limit access to health care. Any or a combination of these contribute to social exclusion. Can you name an invisible element? Often, it is through relating and communicating that the invisible elements affecting exclusion/inclusion are made visible.

Primary health care and the social determinants of health are not always well understood. While there are similarities between the two, there are also differences. Primary health care and the social determinants of health represent a shift away from a sole reliance on curative models of diagnosis, treatment and cure of illness and disease (Rasanathan et al., 2010). Reorientation of health services was designed to create health systems characterised by prevention, health promotion, equity and the empowerment of individuals and communities to participate in and determine their own needs to address their health care. Although there is a strong desire to organise health services away from the narrow health-illness continuum and hospital-based care, there is a powerful discourse (the medical model) that continues to promote a health-illness, diagnosis, treatment, cure process in healthcare systems. It is recognised that poverty, education, control, stress, racism and other factors drive poor health outcomes. These are often ignored, overlooked or considered too hard to address within current health care systems (Adrian, 2009; Rasanathan et al., 2010). Rasanathan et al. (2010) also suggest that health care systems can be a social determinant of health, and can perpetuate inequality by providing differential levels of health care in relation to quality and cost.

Before examining inclusion and exclusion and exploring why the dominance of the curative medical model maintains its power, the differences and similarities between primary health care and the social determinants of health will be made explicit in order for you to understand the relationship between the two concepts. First, both identify disempowerment and alienation of marginalised groups as major obstacles to achieving health equity. Second, both position inequity in the context of inequitable distribution of power and resources (Rasanathan et al., 2010). Primary health care is a broad concept with a focus on the need for health systems to respond to community needs and create opportunities for community participation. Social determinants of health are factors that impact on health, and are related to access, distribution of resources, empowerment, social inclusion/exclusion, social status, resiliency and social support. They are associated with, for example, poverty, education and stress (Rasanathan et al., 2010). Rasanathan et al. (2010) also identify similarities, they focus on health equity; are applicable in all

contexts across all levels of health care; embrace health as being more than the absence of illness or disease; promote intersectoral policy development and the role of empowered communities in different social environments.

We have laid out the role primary health care and social determinants play in creating inclusive health care. Now it is time to examine the dynamics of inclusion and exclusion a little more closely. Taket et al. (2009) note that exclusion arises from multiple deprivations and inequities that people experience across all sections of society leading to reduced participation in society, reduced consumption, mobility, access, integration, influence and recognition. The language of exclusion includes marginalisation, silencing, rejection, isolation, segregation and being disenfranchised. The language of inclusion embraces concepts of connectedness, recognition, acceptance, opportunity, equity, justice, citizenship, expression and validation (Taket et al., 2009). This chapter explores how this language plays out in the construction and provision of health care in individual, community and cultural contexts.

Healthcare environments are not socially, economically or politically neutral. Each interaction is value laden and embedded within relationships of uneven power; therefore, each relationship is one of difference. Differences between people may or may not be obvious at first; or if obvious, difference may be mediated through social attitudes or personal beliefs. Difference works in tandem with power, and like differences between people, it is not always easy to identify how power shapes and influences communication. The impact of power may become apparent when there is a conflict, miscommunication or misunderstanding, where there is the potential to exclude or where service might be compromised. Social inclusion/exclusion interweaves with all threads of society through the dynamics of social relationships and social structures. An understanding of how these relationships and structures interact is central to healthcare practice.

The presence or absence of health determinants can create continuums of inclusion and exclusion. They are the result of an unjust distribution of resources and/or unequal access to services. Inclusion is about creating conditions necessary for populations to meet and go beyond their basic requirements and includes:

enabling participatory and cohesive social systems recognising diversity guaranteeing peace and human rights sustaining environmental systems.

(adapted from Popay et al., 2008, p. 7).

Primary health care, the social determinants of health and the dynamics of inclusion and exclusion form the basis for building an inclusive healthcare system that will support inclusive healthcare practice. A key challenge for a beginning inclusive practitioner is to maintain a focus on these concepts in healthcare systems and structures that do not always support such thinking and may actively resist attempts to place an inclusive approach at

the centre of healthcare delivery. The next section provides an analysis about why this may be so. The following chapters provide you with knowledge and skills to work with resistance as well as work with enabling inclusive healthcare environments.

# Setting the scene for working toward inclusive practice

The term 'exclusion' originated in France (cited in Taket et al., 2009). It was used to refer to individuals who were not covered by a social security system which put them on the margins of society. Over time, the concept changed to include a wider range of citizens, until today, exclusion can be defined as a process that shuts people out from social, cultural and political systems, effectively excluding them from participating in society (Taket et al., 2009). Responses to exclusionary practices were notable in the 1970s when families of children with disabilities challenged exclusionary practices of segregating children with special educational needs into institutions and special schools. Martin et al. (1996) describe the history of special education from exclusionary practices to inclusionary practices in a North American context. A shift from exclusion to inclusion for this group of people was part of a wider worldwide movement that aimed to reduce discrimination based on disability. Schools were not always sensitive to the specific learning needs of children, especially those needs resulting from physical or intellectual functioning. Educators were challenged to identify exclusionary practices based on gender, learning styles, culture and background. Systems were historically designed for measuring and evaluating performance based on statistical norms (Gronna et al., 1998). These methods meant that for decades children were classified and categorised according to different behaviours or abilities. This branding meant that children who were deemed physically or intellectually less able were unable to function in mainstream classrooms and were thus excluded (Knowles, 2006). This movement was the forerunner of the development of inclusion policies across other social institutions.

Co-occurring with this movement, in the 1960s and 1970s, socially, culturally and politically disempowered groups organised and challenged the exclusionary power structures of the status quo or how things were. Children born post World War II grew up in a world that was very different from their parents' generation. There was a growing dissatisfaction and rejection of the older values and an embracing of values associated with rights, freedoms and inclusion. Increasing affluence in Western countries and a growing middle class opened up access to higher education opportunities for young people. This change provided a platform for students to organise and protest against social injustices and the exclusion of marginalised groups from fully participating in society. Alongside this growing affluence, colonised countries were gathering momentum to resist continuing

exploitation and control by foreign European powers. They were asserting their right to live their culture on their own terms. For the Vietnamese, it was about unification and ending decades of colonialism. For the US, it was about supporting the French colonial forces and halting the advance of communism in South East Asia, because communism represented a threat to the established order of the Western world. These events were symbolic of a wider social unrest. The Vietnam-US war was a flashpoint for protest, and became a rallying point for disparate groups wanting greater inclusion and social justice for people and groups marginalised or discriminated against in the dominant structures of society (Goodwin & Jasper, 2009; Kurlansky, 2005). Although organised according to different socio-political goals, various movements, including civil rights, black power, global indigenous rights, anti-war movements, feminist movements, the environmental movement, gay and lesbian rights, mental health and physical disability movements found they shared common goals (Gamsan, 2009; Kurlansky, 2005): greater social justice, decolonisation, fair treatment, the right to participate in the social and political decision-making processes of society and the right to enjoy the same levels of health and freedoms their 'mainstream' counterparts enjoyed.

The collective force of differing movements gave rise to intense national and international social conflict, mainly centred in Western societies. They came to determine and define a new reordering of society away from the values of the dominant, and their power to shape and control the structure of social and cultural institutions to work toward building institutions and systems that recognise and value group diversity, social and individual difference. These movements became the forerunners of inclusiveness. Appropriate antidiscrimination and anti-racism legislation affirms recognition of difference, through the application of the principles of social justice. Understanding social justice can provide a framework for guiding actions promoting equity and working towards the resolution of ongoing struggles and conflict associated with achieving sovereignty and self-determination. Laws on their own are not enough to ensure social justice and the protection of rights; there also needs to be a focus on attitude change at an individual and institutional level. While laws provide rules and regulations supporting inclusion, attitudes, relationships and behaviours measure the degree to which people experience inclusion. The pursuit of realising justice, tolerance and acceptance of difference is a challenge for contemporary health services.

#### Social movements

A group of people sharing a common goal and collectively seeking to address issues of social exclusion or injustice.

# Social movements, identity politics and contemporary health care

Values shaping the structure of 1960s and 1970s healthcare institutions were embedded in institutional healthcare values of mid-nineteenth century Europe where the need was to find treatments and interventions to control and reduce the spread of infectious diseases.

By virtue of their economic and social status the poor, or lower classes, were the main recipients of institutional health care. However, while effective care was provided, their status excluded them from fully participating in their own health care. Mid-twentieth century ideas related to identity and self-determination represented a 'mismatch' between different sets of values - past and present. Pressure from the marginalised and oppressed groups on mainstream health institutions sought to improve access to healthcare services. The goal was to ensure that care was appropriate and acceptable and that people could use services safely without risk to their identity and cultural well-being. There was a rejection of identities and labels ascribed to them by the dominant group who held the power to name and prescribe the behaviour of less powerful 'others'. What became known as identity politics gave rise to the emancipatory movements of the 1970s and 1980s (Friere, 1993), where, through the processes of consciousness raising and power analysis, people were freed to express who they were and not be silenced by the power of others saying they could not be who they were or could not fully participate in their own lives. Previously marginalised people and groups became visible in the wider society. Greater visibility presents a challenge to the dominant group and the way difference is perceived and judged. By claiming difference, a group or person is asserting their uniqueness in the world (Young, 2011). Identity politics changed ideas about difference constructed from positions of power and influence and difference expressed by people in the reality of their everyday lives.

A word of caution: there is a fine line between acknowledging difference in a respectful way that acknowledges and values a person's difference and highlighting a person's difference to the extent that their difference further excludes them. As human beings, we want our differences to be acknowledged and accepted. At the same time, we desire to be connected through similarities. This is the paradox of inclusive practice (Spence, 2005). It is this fine line that requires conscious reflection by the health professional in the context of everyday practice because it is here where power, values and attitude come into play and has the potential to include or exclude.

### Power and inclusion

Those who have power and are used to having power do not relinquish it easily, and the reality of healthcare services today is that there is a mixture of hierarchal relationships characterised by what Derrida (1978, cited in Caputo, 1997) calls binary relationships and more democratic participatory relationships, as defined by Friere (1993). Giroux (1991) notes that to overcome the binary we need to deconstruct, analyse, unpack or take apart the way social relationships are constructed or built and explore who benefits from the binary. Giroux suggests that those who benefit from power are the people who have the power to define, name and ascribe certain characteristics to the less privileged 'other'.

#### Identity politics

An approach to asserting identity politically to foreground individual and social difference. A popular movement beginning with the civil rights protests of the 1960s and continuing today. Identity politics originates from people and groups who share common experiences of being marginalised within mainstream social and political institutions such as health, government and social welfare. Examples of identity politics are feminism, addressing equity for women, indigenous recognition for sovereignty and self-determination.

#### Binary relationships

Social relationships organised around a set of binding characteristics that define the roles and behaviour of two people, or groups, social, cultural or political. The binary is based on opposition with one position privileged or advantaged over the other. The privileged position has the greater power. For example, husband-wife, blackwhite, big-small, girl-boy, north-south.

Relationships built on these assumptions are embedded deep in history and are difficult, but not impossible, to shift. Changing social structures means having an ability to critique forms of power by identifying who has access to power and asking why some people do not have access to power (1991). Inclusive healthcare practice is about changing the conditions that prevent people from speaking in places where those who are privileged by their power and culture have the power to name, define and describe the other from their positions of influence. Any profession (including the healthcare profession) has this power to name and describe, by virtue of their specialised area of health care. Working inclusively means being present and negotiating at the boundaries of different kinds of relationships. This requires skill in negotiating difference and learning to manage tensions, but there is uncertainty inherent in working in such spaces. At times, we go into a situation not knowing what the outcome might be. This may only be known through a process of engagement and exchange of information. Openness to what might be or can be will ensure that the principles of inclusive healthcare practice are upheld. The healthcare professional works to provide quality health care and create environments that protect the dignity, identity and well-being of the person using health services. To create an inclusive environment, the potentially harmful effects of some binary relationships have to be overcome. The dominance of the binary will differ from setting to setting – as will the shape of the relationship in hospital, community or cultural settings.

Inclusive practice is concerned with practices that move away from the traditional binary relationship, where the health professional 'knows what is best' because of their professional knowledge. This kind of relationship is sometimes referred to as 'the expert model of care'. In the mid-nineteenth century, a forerunner to modern philosophies underpinning nursing and health care, a well-meaning but exclusionary approach treated people regardless of race and creed or difference (Nightingale, 1898). Similar thinking guided the development of social work. Nursing and social work were central to the social reforms of the nineteenth century. The reforms aimed to reduce disease and poverty, not only through hygiene movements and improved sanitation, but also through establishing codes of moral behaviour and responsibility in the poor and the working class to improve their health. Such thinking was based on Western enlightenment ideas of history as progressive and evolving along rational lines that would eventually rid the world of disease and poverty (Herdman, 2001). Those charged with instilling moral behaviour were those in the growing professions of medicine, nursing, social services and the growing middle classes (Richardson & MacGibbon, 2010). While there is not a problem with this kind of approach, and the health of people and communities did improve, such models of care excluded people who were not from the professional classes or because of skin colour, language or some other quality that made them different from the dominant group, and these were excluded as 'other' or marginalised. It is clear that disease and poverty continue to be issues impacting health care in the twenty-first century, and it is also clear that a

participatory relational approach brings difference to the forefront of care where people are treated regardful of who they are culturally and socially (Ramsden, 2015). The latter relationship is characterised by mutual negotiation and participation between the health professional and the health service user, where life experience and cultural knowledge become an important part of care. Inclusive health care calls for a rethink of the way health relationships are mediated in an equitable manner.

Labonte (2004, p. 117) asks 'How does one go about including individuals and groups in a set of structured social relationships responsible for excluding them in the first place?' Do attempts at social inclusion help people accommodate to their relative powerlessness? (Labonte, 2004) That is, do we adopt a 'tick box' by saying 'we have done this or that' according to the policy and consider this as being inclusive, or do we take the more challenging path by developing knowledge and skills to change the structures and hierarchies that established exclusionary practices in the first place? Our concern should be, according to Labonte, not with the groups or conditions that are excluded, but with the social rules and political influences creating the conditions of exclusion (Labonte, 2004).

This section has identified the contribution that primary health care, social determinants of health and the principles of social justice, equity and identity make to developing an inclusive practice approach. We have explored how, over time, the landscape of health care has changed by a reframing of health service using a more participatory approach. Such an approach can counter the more traditional hierarchal power relationships. The next section further explores structures, relationships, ideas and practice contributing to a greater understanding of inclusion.

### Identity and social structures

Identity underpins our sense of belonging in various groups and social settings. It is a personal, individual or biographical construct, or a personality constructed over time by a person or group. This suggests that identity is fixed and stable over time. However, this view does not take account of the way other factors such as relationships have in shaping identity. As we have already seen, the 1960s and 1970s saw how socio-political events gave rise to dramatic shifts in the social order and a reshaping of identity – identity politics. Our identities are defined, negotiated and expressed narratively through stories, according to different contexts and the expression of different roles (Phibbs, 2008; Somers, 1994). For example, a person who is a patient in a hospital setting will be classified as a 'patient' because of the setting. Each time they interact with someone they will be telling a story about themselves in the context of who they are. The personal story will also contain information about public narratives. Public narratives are narratives we share with one another (Somers, 1994). They may be cultural, social, or familial, and they add to our shared understanding of our world and the world of others. Different public narratives

carry different weight in social environments. Consider public narratives of family, what kinds of family structures are valued over other kinds of family structures? People will express different aspects of their identity depending on the qualities and behaviour of the person with whom they are interacting. The same person using health services in the community will express their identity in other ways. We go to them as people first; in hospital they come to us as patients. The different public spaces – hospital and community – carry with them different historical and contemporary values. These values will construct our identities according to the kinds of stories we tell about these spaces. The power dynamics are different in each setting. In hospital we have less control over who we are than in the community. At work we may have more control over who we are than we have at home. When we are with people who are the same as us, we may experience a greater sense of belonging. We convey these aspects through the way we interact with people, hence the idea of narrative identity.

#### Identity/Narrative

Unique identity expressed in narratives and contexts, as shaped by our life's social, historical and cultural experiences and relationships. Identity is fluid, changes over time and according to the spaces we are in. The only way we can express our identity is through story. Our identity changes according to the qualities of the listener. Identities rarely conform to a single category of gender, age, ethnicity or some other marker of difference. A person will express different aspects of their identity according to the context they are in.

This chapter explores how identities are expressed or acted out relationally across boundaries of social inclusion and exclusion. Our identities are shaped by history, personal experience and by master or grand narratives, ideologies or worldviews (Lyotard, 1979 as cited in Jones, 2003). Colonisation is an example of an ideology, a grand/public narrative. A public narrative describes knowledge that is shared socially, but may be understood differently by different people. Understanding how a colonising narrative works in our everyday lives can help us deconstruct the way binary relationships keep us locked into certain sets of behaviours and relationships that are acted out according to predetermined ideas or assumptions. The binary plays are key roles in the inclusion/exclusion continuum.

#### REFLECT AND APPLY

- Undertake this narrative activity with a partner. Share your story with a partner using the outline below. The other partner is to listen and use encouragement, but not ask questions.
  - How long have you or your family lived in, for example, Australia or New Zealand?
  - Where did you or your family come from originally? (This could mean from another country or a geographical area within Australia/New Zealand.)
  - Why did you or your family move here?

- Identify two values that are important to you and say why.
- Briefly talk about how you might (or have) responded when you have been in a situation where you have been unable to express those values.
- Conclude with a summary of what you have shared and in three short sentences tell your partner who you are and what is important to you in your life.
- 2. Join up with two other people and discuss what this activity was like for each of you. This is the time to ask questions of one another about one another. Can you make links between the sharing of a narrative of self through story and how this shapes who you are?

It is now time to step back to an earlier time, to the seventeenth and eighteenth centuries. With the invention of modern science and its power to name an 'other' in the seventeenth and eighteenth centuries, scientists claimed the power to categorise, measure, define, name and label human characteristics against what they considered to be the normal or expected behaviour of citizens. Ardill (2009) draws on the idea of socio-biology to provide an understanding of the way seventeenth and eighteenth century ideas of race were constructed to justify processes and practices of colonisation.

Colonisation positions some people with desirable qualities at the top of a hierarchy, descending down to people or groups of people who have the least desirable qualities, hence a hierarchy of difference based originally on racial characteristics determined by scientific observation, measurement, classification and categorisation. The same mechanisms used to classify plants and the natural world were applied to human beings. Colonising practices enabled social life, behaviour, culture and experience to be filtered through the lens of the dominant, a privileged few who held the power to prescribe social and cultural behaviour according to people's position in the power hierarchy (Ardrill, 2009); hence, the invention of the constructs of class, race and gender. These power relations continue to be reproduced today and are a feature of contemporary social life, including health care.

While hierarchies bring about order in a society, they constrain the expression of identities that do not conform to that order, or accommodate people moving easily away from their fixed binary position in the established order. Expressing who we are is bound up with our different identities, our cultural, personal, micro and macro worldviews. We express who we are relationally through narratives. It is through relating that we come to know one another and construct our identities (Somers, 1994). The impact of the binary on identify through the construction of hierarchies, and biological, racial and social public narratives of difference, are difficult to overcome. These narratives are deeply

embedded in the social fabric of our everyday lives and we are often unaware of the effect they have on our daily interactions.

Binary constructions are embedded in scientific racism and a colonising ideology. A binary is a strategy designed to dispossess Indigenous people within countries colonised by eighteenth to twentieth century European powers of their rights, language and land in order to assimilate, exploit and dominate. Colonisation enabled the export of natural economic resources to sustain and advance the social, economic and political development of European societies. Any discussion about difference and inclusivity begins with this primary relationship originating from a colonising ideology. Care needs to be taken not to integrate cultural (racialised) difference with other forms of difference, because although connected, these stand alone. It is important to note that 'racialised' is used with the proviso that it is positioned within the construct of scientific racism, and is used by the dominant to categorise the dominated. Race itself is a cultural construct arising out of a colonial discourse, and while open to critique, serves as marker of difference between Indigenous and non-Indigenous people who fall into a constructed category of ethnicity.

Ethnicity is often reserved for people and groups who are not part of the white settler population and are not Indigenous or First Nations people. Missing in this grouping of difference is the dominant or privileged group. Pease (2009) notes that privilege is not always recognised. Rosenblum and Travis (1996, cited in Pease, 2009) suggest that 'members of privileged groups occupy an 'unmarked status' (p. 39); that is, they do 'not require any special comment' (p. 39), and are able to say what can be taken for granted. It is important to note while members of dominant groups may oppress others, not all people from dominant groups behave in oppressive ways. Yet the dominant also 'gain privileges through subordination ... of, in this example, people of colour, even if she or he is not personally exploiting or taking advantage of any person of colour' (Free et al., 1999, cited in Pease, 2009). The impact of the binary relationship on the health and well-being of Aboriginal or First Nations people is addressed late in this chapter.

### **Binaries**

Where once the power lay at the top, with the medical personal and the biomedical model driving the underpinning values of the health care institution, and the patient at the bottom with little power, there is now a more relational approach to health care, where power is shared and negotiated between the health professional and the recipient of care. While binary no longer has the power it once had to determine and influence health outcomes, binary still permeates everyday healthcare relationships and is a powerful force in everyday health care.

A binary positions people in fixed roles; they are designed to maintain order and hierarchy (Richardson & MacGibbon, 2010). Each participant in a binary relationship has an opposite, and each opposite is expressed in language and thought. For example, this person is black, that person is white. The binary is operating when the white person, the social norm, is set up in opposition to the black person who is 'outside' the predetermined social norm and therefore excluded. Each opposite is expressed through different characteristics, attitudes and behaviours. These qualities are not neutral, and are constructed over time by history, place, values and beliefs. Within any binary relationship language is used to describe the values society puts on different words to identify the status of each person or idea; for example, good/bad, black/white. Derrida (1979, cited in Caputo, 1997) describes a binary as a set of predefined positive qualities set against a predetermined negative quality. In a binary relationship one person or idea is dominant and one is subordinate. In the context of a negotiated relationship, which is through the exchange of historical, personal or cultural narratives, this binary position can shift and different identities made visible through the moving back and forward of different information between the people involved.

While it is difficult to overcome a binary, an inclusive framework does provide a way for working with people in a more empowering way. An inclusive framework is informed by the values, attitudes and beliefs of the health provider and recipient of health care. It is characterised by a willingness of the health professional to be present, flexible and open in their communication with people or groups. Inherent in an effective inclusive relationship is a preparedness to participate in shared and negotiated decision-making with clients. The health professional needs to be in touch with their own values and attitudes that may impact on this process, and be aware of the power they hold within the inclusive relationship.

#### CASE ACTIVITY 1.1

You are working in the community as a new health professional. You work as an outreach worker assessing health needs and planning health promotion activities with and for people in a low socioeconomic area. You have been meeting with a group from this area for some time, so a level of trust has been established. Three of the group of twelve approach you one day and suggest that they look to establishing a weekly health clinic in an empty room in one of the area's block of flats. This room has been vacant for some months. The group has been thinking about it for some time, they have some ideas about how it could happen and see you as being able to support them.

- 1. What is your first reaction to the idea?
- 2. What will you do next?
- 3. How would you employ an inclusive framework to progress action on this idea?
- 4. What are your fears and concerns?
- 5. How will you create an empowering environment?
- 6. What factors might enable or constrain the development of the idea?
- 7. What public narratives related to health care might shape this process?

### Conclusion

This chapter has provided a backdrop to inclusive practice. It has explored concepts that explain why health care settings and relationships are the way they are, and how they might influence the development of inclusion values. People and groups previously marginalised or excluded from participating in their own health care are now in a better position to do so than they have been in the past. With policies in place that address the need for inclusive health care, modern healthcare organisations (which in the past had unfettered power to organise health systems) are now reorienting their healthcare relationships and services to better meet the health needs of people in an increasingly diverse and complex health environment. Policies are designed and implemented to guide the development, application and evaluation of inclusive practices. No matter the kind of policy, it is at the point of contact between the recipient of care and the provider of care that the worth of policy is upheld. A discussion of inclusive practice cannot occur in a vacuum. If we talk about what constitutes inclusive practice and the binary opposite, exclusion will be addressed. An exclusionary discourse is driven by narratives of difference informed by binaries of race, gender, class and age, to name a few; or racism, sexism, classism and ageism. It is discriminatory and excludes. An inclusive framework embraces the importance of social justice, equity and self-determination (individual or group) in healthcare service and delivery.

#### SUMMARY POINTS

- Primary health care, partnered with the social determinants of health, form the foundation for the building of inclusive relationships.
- Primary health care aims to reorient health care away from a single focus on a curative bio-medical model to a more inclusive approach that takes into account the role that equity, social justice and empowerment play in providing appropriate health care.

- Social determinants of health are a subset of factors positioned under the umbrellas
  of primary health care and form the drivers of ill-health or good health. Social
  determinants influence the degree to which health care systems and services include
  or exclude people based on social, cultural or economic conditions of living.
- Current understandings of inclusiveness grew out of the social and cultural resistance to traditional social agencies and structures that exclude people on the basis of cultural or social difference.
- An outcome of the social upheaval of the latter part of the twentieth century gave rise
  to a newfound consciousness by previously marginalised individuals and groups who
  were excluded from participating in the decision-making processes of society.
- Identity is about who we are, and gives us a sense of belonging in society. Any threat
  to identity increases our vulnerability in day-to-day living and influences the degree of
  control we have over our lives. This is especially important when we experience illness,
  change or life crises.
- Creating inclusive health systems and practices requires health practitioners to work
  to reduce the power of the historical binary relationship that creates health inequity
  based on either/or criteria (exclusive/inclusive), into systems and practices that
  embrace 'and/and' (inclusive) approaches to health care.

#### CRITICAL THINKING QUESTIONS

- Consider the values and beliefs underlying colonisation and binary relationships. Do
  you think they do or do not impact on health care delivery today? If so, how? If you
  don't agree, explain why.
- 2. Identify key factors that act as barriers or facilitators to implementing a comprehensive approach to primary health care across broader health care systems.

#### **WEBLINKS**

Scientific Racism. The Eugenics of Social Darwinism:

https://www.youtube.com/watch?v=3FmEjDaWqA4

UN Declaration on the Rights of Indigenous Peoples:

https://www.youtube.com/watch?v=bB2uZxekt-k

Community Guide to the UN Declaration on the Rights of Indigenous Peoples:

https://www.humanrights.gov.au/publications/community-guide-un-declaration-rights-indigenous-peoples

- The Free Speech Movement: civil disobedience in Berkeley 1964: https://www.youtube.com/watch?v=28aPyBrP0Yc
- Major events of the Civil Rights Movement: https://www.youtube.com/watch?v=spXlsQKHKXM

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