CHAPTER 3

INCLUSION: BEYOND A SENSE OF BELONGING

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Abstract

The social model of disability was first created in the mid-1970s to challenge and disrupt the prevailing medical model of disability. The social model made a distinction between disability and impairment. Impairment is considered to be the medical diagnosis, whereas disability refers to the barriers that an individual faces in an inaccessible society. The focus switches from a perceived 'problem' existing within the individual to the 'problems' or barriers existing with the broader community. Over the past decades, legislation, policies and frameworks have now clearly outlined the ways in which young people with disability are entitled to protection from discrimination and to have their human rights upheld. While physical access is being addressed in some areas across the community, stigma and attitudinal and communication barriers continue to exist for young people with disability. Historically, specialist disability services have been the default for young people with disability, as schooling and recreational opportunities have both been segregated. There are legal and ethical obligations for youth services to improve accessibility and enable all young people to feel included. The YACVic Code of Ethical Practice includes principles of empowerment and participation of young people. This chapter explores the ways in which community structures continue to exclude young people with disability and the role of youth workers as advocates to eliminate the systemic and social barriers to an inclusive society.

*** Note from the author:** The use of 'person with disability' as a term within this chapter does not make a distinction between singular (disability) or plural (disabilities). The singular is used simply to draw attention to the social construction of disability as a barrier facing an individual in society.

Introduction

Disability and impairment exist in all societies throughout the world. In the broadest context, a disability is defined by the World Health Organization (2019) as any 'condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restriction)'. In 2018, 17.7% of the Australian population identified as having 'a disability' (ABS 2018). This percentage has remained relatively steady over the past seven years, with a relatively even gender split. The vast majority (78%) of people with disability report having a physical impairment, such as arthritis or a musculoskeletal back condition. In contrast, only 21.5% of people report having a non-physical impairment defined as a 'mental' or 'behavioural' condition. It is important to note that older Australians with impairments directly related to advancing age are included in these statistics.

The Australian landscape is painstakingly slow at times in adapting to the diverse needs of the community (Deane 2005). There is a general recognition of the needs of people with physical disability in ensuring that physical access is available in most facilities and services in the community. If a facility is considered an inclusive setting, then the building regulations including ramps, railings, accessible lifts and toilets are clearly marked in order to ensure ease of access. These building regulations have a fundamental aim of preventing exclusion. However, despite these environmental improvements in creating an inclusive landscape, exclusion continues to occur. This is especially the case for people whose impairment is not easily identified by others. This chapter explores different types of access and the many subsequent barriers facing young people with disability.

Historical context

Braddock and Parish (2001:11) describe disability throughout Western recorded history as 'existing at the intersection between the particular demands of a given impairment, society's interpretation of that impairment and the larger political and economic context of disability'. In an attempt to understand why babies were born with impairments, different explanations were given under the traditional model of disability. There were religious faith influences in these societies that claimed demon possession, a spell of witchcraft, divine punishment for wrongdoing by the child or their parents, or moral failing (Shakespeare 2010) to be the causes of these impairments. Children and young people with impairments were often excluded from society or shunned on the outskirts of the community, for fear of spreading the impairment and other children in the community 'catching' the impairment or perceived 'misfortune'. An unfortunate consequence of this exclusion was that many children died from neglect and lack of access to health care in infancy and early childhood.

During the Enlightenment period, the traditional model of disability began to be rejected in favour of the medical model of disability. The medical model of disability was a product of the advancements in science and medical fields of study. It was the medical model of disability that focused on the deficit within the individual's body, stating that there was a 'problem' with the individual, who needed to be cured or treated (Kiernan 1999). Research during this period of history discovered the extra copy of chromosome 21 in individuals with Down syndrome (Patterson & Costa 2005), created medication to alleviate the symptoms and characteristics of attention deficit hyperactivity disorder (ADHD) and made advancements in the technology now included in the hearing aid. The focus at this time was to understand the origin of the impairment in order to 'fix' the loss and fit the individual into a society that was seeking perfection.

The social model of disability was formed during the civil rights movement. The social model of disability radically challenged the way that society viewed and valued people with impairments or medical diagnoses, as it directly contradicted the deficit view of disability that the medical model of disability offered. It was Mike Oliver (1996:32) who argued that an 'impairment is simply a description of the physical body' and that 'a disability in fact had nothing to do with the body'. Oliver and others such as Kiernan (1999) and Siminski (2003) further argue that the term 'disability' was socially constructed by society and it was the lack of opportunity, societal ableist attitudes, lack of access to physical environments and stigma that led to an individual being 'disabled'. The social model of disability therefore had underpinning human rights principles as it sought to eliminate the discrimination facing people with disability in the community.

Blaska (1993:25) notes that 'Language is a reflection on how people in society see each other'. There are ongoing debates in the community regarding the use of people-first language ('people with disability') versus identity-first language ('disabled people'). In recent history, there was a move towards people-first language in order to recognise the 'humanity' of the individual. Person-first language was introduced to refocus society's attention away from the impairment back to the person (Michalko 2002) as people with disability were valued less by society. However, many advocates in the sector now promote identity-first language, as they say that disability is central to their 'being', not just something that they 'have'. For example, identity-first language is most commonly used in the autistic community, as many autistic individuals see their diagnosis as an essential element of their being that cannot be separated from their personhood (Collier 2012). In saying this, not everyone who has an impairment considers themselves to 'be' disabled. As a result, both terms have validity and importance in broader discussions and it is always vital to use the preferred language of the individual.

A call for the discontinuation of terms such as 'handicap' evidences this shift in language. The inference that people with disability must come begging with a 'cap in hand' to receive charity does little to empower or affirm individuals. Rather, terms such as these seek to perpetuate notions of disempowerment and inability, rather than ability and strength (Oliver 1996). People with disability who are referred to in positive and strengths-based terms are more likely to see themselves as contributing members of the community (Blaska 1993). This helps to prevent feelings of alienation and hopelessness.

French and Swain (2000) later introduced the affirmation model of disability as a critical alternative to the social model. The affirmation model rejects the tragic view of disability, which can lead to pity and disempowerment, and instead makes the claim that rather than feeling a desire to be 'normal', people with disability view themselves in celebration as opposed to tragedy. French and Swain argue that the social model of disability did not go far enough to empower people with impairments and that there are in fact benefits to having an impairment. These include building one's identity outside of the pressures faced by non-disabled people and the perceived freedom from society's expectations regarding relationships (Cameron 2008; French & Swain 2000).

Tregaskis (2004) describes the way in which service providers continue to hold stereotyped and belittling attitudes towards people with disability which influence their words and behaviours. Cameron (2008) disagrees with the notion that the social model of disability has become outdated. He suggests that both the affirmation model and the social model of disability attempt to address the disadvantage and structural inequality that people with disability face. In addition, providing an alternative narrative to the traditional and medical models of disability assists in removing the barriers for people with disability to being active members of the community.

Questions for reflection and action

- Consider a youth work context that you are familiar with – do the policies and procedures of the organisation reflect the medical model of disability or the social model of disability?
- How might you advocate for change in this area?

Legislation and policy in Australia

People with disability experience violations of their human rights on a regular basis all around the world. These violations continue to occur despite numerous pieces of federal legislation and international frameworks put in place that are designed to have a positive impact on the lives of people with disability in Australia.

These pieces of legislation and frameworks include:

UN Convention on the Rights of the Child (CRoC), 1990

The CRoC is the most widely ratified international agreement throughout history and makes a commitment to ensuring that the rights of children (including young people up to the age of 18 years) are upheld. The guiding principles of the charter include: the best interest of the child driving all actions related to that child; non-discrimination; a child's inherent right to life; a government's responsibility to ensure the survival and development of the child (as much as possible); and the right of the child to express their views and have those views considered in decision-making processes.

Disability Discrimination Act 1992

This is an Australian piece of national legislation which aims to protect all individuals with disability across Australia from when direct and indirect discrimination occurs. Direct discrimination occurs when an individual is singled out and treated less favourably because of their disability or impairment. Indirect discrimination occurs when a rule or policy designed to cover everyone equally instead means that an individual with disability or impairment is excluded or treated less favourably.

Disability Standards for Education, 2005

The Disability Standards for Education 2005 were formulated out of the Disability Discrimination Act of 1992. The initial intention of the Disability Standards for Education was to ensure that students with disability have access to participate in all education and training opportunities alongside their peers, from foundational learning in kindergarten all the way through to tertiary education at university and TAFE. The Standards outline the responsibilities of the education provider to ensure that the learning environment and activities are accessible through a series of 'accommodations' and 'reasonable adjustments'.

UN Convention on the Rights of persons with Disabilities (CRPD), 2006

Australia was one of the first countries to ratify the CRPD. Ratifying is the process of a country confirming and giving formal consent through signing an agreement to follow a convention. This Convention has a global purpose to promote the rights and opportunities for people with disability to have choice and decision-making power in their own lives, as well as eliminating barriers to participation in all areas of political, social and community life.

***National Disability Insurance Scheme (NDIS) Act* 2013**

The NDIS Act is an Australian piece of legislation that covers all of the states and territories of Australia. The NDIS Act outlines the role of the National Disability Insurance Agency and establishes the funding scheme that supports people with disability in everyday life. This legislation outlines eligibility criteria for a person with disability to become a recipient of the fund, the process of establishing support plans and the role of the support agencies.

National Standards for Disability Services (NSDS), 2014

The National Standards for Disability Services were adopted by the Australian Government in 2014 and these Standards apply to all disability service providers to ensure that the rights of people with disability are upheld when they access a community service. The six Standards are: Rights; Participation and inclusion; Individual outcomes; Feedback and complaints; Service access; and Service management.

National Disability Strategy 2010–2020

The National Disability Strategy is an Australia-wide plan that looks at practical ways to implement the CRPD. The National Disability Strategy covers six outcome areas: Inclusive and accessible communities; Rights protection; Justice and legislation; Economic security; Personal and community support, learning and skills; and Health and wellbeing.

The Disability Discrimination Commissioner and the Australian Human Rights Commission work together to address complaints and work with organisations, businesses and the wider community to ensure compliance with all of the pieces of legislation outlined above and that the rights of young people with disability are upheld.

Questions for reflection and action

Scenario:

A young person with disability approaches their youth worker and says that they are not receiving shifts at work since they asked for the lightbulbs that had been flickering in the staffroom to be replaced (flickering light can be a trigger for a seizure) and complained about a joke email that was sent to all staff making fun of a person with disability.

- Are these examples of direct or indirect discrimination?
- What process should the youth worker follow to best support this young person?

Barriers to access in the community

Despite the current Australian legislation and international conventions, there are many additional barriers that young people with disability continue to face when attempting to live everyday life in the community. Some of the common barriers are listed below:

- **Access to information** – Young people need to be able to access information in a variety of formats including Easy English, braille, closed captions on videos and TV, and written materials with accessible fonts.
- **Access to communication** – Young people need a range of communication tools that assist in decision-making and ensure their voices are heard. These communication tools facilitate and complement verbal speech. Augmentative and alternative means for communication include sign language (Auslan and Makaton), speech-generating devices and PECS (Picture Exchange Communication System).
- **Physical access to spaces** – Young people need to be able to enter buildings and facilities to access services using the same entrance spaces as others. Young people should be able to occupy and enjoy public spaces without encountering physical barriers such as steps and narrow doorways. Venues cannot deny access to a young person with a guide dog wanting to participate in an activity. Section 23 of the Disability Discrimination Act covers access to premises.
- **Access to education** – Young people have the right to access public education in their local community. Segregated, specialised education should not be the first and only option for children and young people with disability. More than 1 in 10 students with disability are currently being refused enrolment at their school of choice and over a third of students with disability are being excluded from school activities and events. Restraint and seclusion continue to be practised in Australian schools, which further restricts a student's access to education.

- **Access to justice** – Young people continue to be overrepresented in the criminal justice system and people with disability have been incarcerated for extended periods of time without being found guilty of any crime. Young people with disability face barriers when attempting to report a crime and accessing justice as a victim of crime. Education is limited for law enforcement officers and assumptions are made based on young people's appearance and behaviour without taking into account any impairment that may exist.
- **Access to employment** – Young people have a right to employment alongside their peers and workplaces are mandated to provide 'reasonable adjustments' to ensure that employees' needs are met.
- **Access to voting** – The right to vote is considered to be one of the most important rights in a democratic nation. Currently, there is a provision in the Australian *Commonwealth Electoral Act 1918* s93(8) that can exclude people from voting based on being of 'unsound mind'. This is an unclear and archaic term that appears to be referring to people with an intellectual or psychosocial disability. This provision is enshrined in medical model of disability thinking, as it allows a medical practitioner to make a determination of a person's inability to understand the voting process without requiring reasoning for making that determination.

Questions for reflection and action

- What steps should be taken to ensure that a young person's voice is heard in a group setting if the young person uses other forms of communication than speech?

Ableism and attitudinal barriers

Ableism is a pervasive barrier to inclusion in our society. The term 'ableism' can be defined as a prejudice against people with disability based on the false belief that people without disability have more value and are superior. Ableism can be displayed in subtle ways through a lack of empathy or ignorance towards young people with disability, through to overt examples of abuse and neglect experienced by young people with disability. In the media, we see examples of actors without disability inaccurately portraying characters with disability. These portrayals continue to perpetuate ableist attitudes and stereotypes of young people with disability. While physical, communication and information barriers can be challenged and addressed with tangible outcomes such as ramps, railings, alternative formats and communication devices, attitudinal barriers can be more difficult to call out and challenge. Youth workers have a responsibility to critically analyse their own beliefs and values towards young people with disability in order to eliminate their own attitudinal barriers, and to encourage others to do the same.

Questions for reflection and action

Scenario:

Rosie has been sent to the youth worker at her high school by the English teacher, who has referred to Rosie as being 'at risk'. Teachers have said: 'Rosie is non-compliant, she refuses to do any work, she won't speak in class, won't use eye contact, and this is disrespectful to the teachers'. 'She is not very smart and she has Down syndrome, so she probably won't finish high school anyway'. As a result, the youth worker has been asked to work with Rosie, as the teachers are frustrated at having her in the classroom.

- Are the teachers using the medical model of disability approach or the social model of disability approach with Rosie?
- What rights should be upheld when working with Rosie?

Universal instructional design

Universal instructional design (UID) principles are a practical example, originating from universal design in architectural design, where physical spaces are designed from the outset to be used by everyone and thus promote inclusivity, rather than making adaptions or modifications for individuals or groups after the space has been created. The universal design principles have then been adapted to education and learning environments with UID. Universal design principles benefit everyone in the community while still promoting the rights of people with disability to occupy and utilise community spaces. The UID principles are:

1. **Equitable use** – Learning materials and activities should be accessible and fair.
2. **Flexible in use** – Learning materials and activities should provide flexibility in use, participation and presentation.
3. **Simple and intuitive** – Learning materials and activities should be straightforward and consistent.
4. **Perceptible information** – Learning materials and activities should be explicitly presented and readily perceived.
5. **Tolerance for error** – Learning materials and activities should provide a supportive learning environment.
6. **Low physical effort** – Learning materials and activities should minimise unnecessary physical effort and requirements.
7. **Size and space for approach and use** – Learning materials and activities should ensure a learning space that accommodates both students and instructional methods.

Source: University of Guelph (2016)

What is inclusion?

Often the terms 'access' and 'inclusion' are seen as synonymous and therefore used interchangeably. These terms, in fact, although interconnected, have important distinctions. This chapter outlines the importance of access for young people with disability in our community. Inclusion, however, is more than the ability to enter a premises or receive information in an alternative format. Inclusion begins with a sense of belonging and being part of the group or community, and the group seeing the young person's contribution as valid and valued within that group. Inclusion benefits the whole group, not just the young person with disability, as young people without disability learn how to appreciate and celebrate diversity and everyone's contribution is accepted.

There is both a broad and a narrow understanding of the term 'inclusive education'. The narrow understanding of inclusive education looks at the extent to which a specific individual or group is currently accessing education; their level of active participation in educational activities is also aligned with this term. In contrast, the broad understanding of inclusive education refers to 'education for all'. This broader understanding brings together all members of an educational community and the role that each member of the community plays in the educational process. Armstrong, Armstrong and Spandagou (2011:31) explain that 'Inclusion can be descriptive and prescriptive – meaning how inclusion is put into practice vs how it should happen'. Each member of the educational community is able to contribute to the development and implementation of inclusive teaching and learning practices.

Questions for reflection and action

Scenario:

Jeff is a part of the afterschool homework club. The homework tutors are complaining that Jeff cannot sit still and is disrupting the other young people, as he always wants to talk about the Richmond Football Club. The tutors have said: 'Jeff is full of useless information, he is hyper and can't concentrate, Jeff is obsessed with football and doesn't belong in this homework club because he is only doing VCAL and won't be doing exams, so he shouldn't be in the homework club'. The youth worker has been asked to work one on one with Jeff, who is autistic and has ADHD.

- What are Jeff's strengths?
- What strategies could be used to work effectively with Jeff?

Codes of practice as underpinning frameworks for inclusive practice

A youth work code of practice is a necessary tool that is used to underpin the work and should align with the beliefs and values of the youth worker. In order for a young person to be fully included in their community, they must be supported by a youth worker who has a fundamental belief in the human rights of all young people and is willing to advocate with and for that young person.

The Youth Affairs Council of Victoria (YACVic) Code of Ethical Practice is underpinned by human rights frameworks and it outlines the principles and practice responsibilities of a youth worker and other people working with young people in community settings. This framework can be aligned with other pieces of legislation such as the UNDHR and the CRoC. Although young people with disability are not specifically mentioned in the YacVic Code of Ethical Practice, this framework relates to work with all young people. In terms of the barriers and exclusion that young people with disability continue to experience in society, the principles and practice responsibilities of empowerment, participation, social justice and anti-opressive practice are particularly relevant for the youth worker here. The challenge with any framework of practice is to keep the document from sitting on a shelf and not being implemented in youth work practice. Therefore, it is the responsibility of all youth workers to be involved in critical conversations with colleagues, to analyse and unpack workplace ethical dilemmas, to undertake evaluation processes for change and to participate in ongoing individual and collective reflective practices to ensure that the Code of Ethical Practice remains a living document embedded in youth work practice.

Questions for reflection and action

- How does a youth work code of ethics promote the rights of young people with disability?
- Do you have a youth work code of ethics in your community? If yes, is this document implemented well in youth work practice? If no, what can youth workers do to promote the rights of young people with disability?

Role of youth worker

The defined roles of a youth worker in the community are varied; however, the central focus of every youth worker role is the young person. A young person with disability has the right to actively participate in all areas of life. The youth worker can proactively work with individuals and groups of young people in their own social contexts to promote and uphold the rights of young people with disability. The youth worker will also work collaboratively with other practitioners and professionals in the community who also work with young people, for example, social workers, allied health workers, teachers and housing workers. These practitioners may have competing priorities and limitations to their job roles, so the youth worker must always ensure that the young person remains the primary focus and consideration.

Advocacy is a process of 'walking beside' that a youth worker can use to create meaningful and longlasting change in the community. Advocacy can take many forms. These can include:

- **self-advocacy** – where the young person speaks for themselves
- **individual advocacy** – where the youth worker works alongside a young person and speaks on behalf of the young person, and their interests are at the forefront
- **family advocacy** – where a family member acts on the behalf of the young person
- **group advocacy** – where the youth worker supports the interests of a whole group of young people who have experienced the same discrimination or barriers to participation
- **systemic advocacy** – where the youth worker campaigns to change the structures, policies and systems that disadvantage young people with disability

Advocates ensure that the voices of the young people with disability are heard and central to any campaign that is undertaken. Self-advocacy is an important skill for all young people to learn. The ability to communicate your needs as an individual is not only empowering, but also builds a strong sense of self-worth. A youth worker can utilise several models of advocacy at the same time, for example, individual advocacy to support a young person and ensure their rights are upheld and their needs are met, and systemic advocacy to promote changes in a systemic structure that may have contributed to the discrimination faced by the individual young person.

It is essential for young people to be actively involved in every stage of decision-making and service delivery. Until that happens, young people with disability will continue to face discrimination and exclusion. Youth workers play an essential role in dismantling the barriers created by the community. All young people have the right to participate in all areas of social and political life.

Conclusion

The role of a youth worker is strategically placed for them to be active contributors to the ongoing campaign with young people with disability for an inclusive community. There have been significant progressive moves forward with the development of key legislation and international conventions that dictate the elimination of discrimination and recognise the importance of protecting all human rights. However, a truly inclusive community where every young person's contribution is recognised and valued is still not today's reality, but it is the tomorrow that we wish to see.

References

Armstrong, D., Armstrong, A.C., & Spandagou, I. (2011). Inclusion: By choice or by chance? *International Journal of Inclusive Education*, 15(1), 29–39.

Australian Bureau of Statistics. (2018). *Survey of Disability ageing and carers*, Australian Bureau of Statistics, Canberra, viewed 7 July 2020. <abs.gov.au/ausstats/abs@.nsf Latestproducts/4430.0Main%20 Features12015?opendocument&tabname=Summary&prodno=4430.0&issue=2015& num=view=>.

Blaska, J. (1993). The power of language: Speak and write using 'person first'. *Perspectives on disability*, pp. 25–32.

Braddock, D., & Parish, S. (2001). An institutional history of disability. In G.L. Albrecht, K.D. Selman & M. Bury (Eds), *Handbook of disability studies* (pp. 11–21). CA: Sage.

Cameron, C. (2008). Further towards an affirmation model. In C. Barnes & G. Mercer (Eds), *Disability studies: Emerging insights and perspectives* (pp. 20–36). London: Disability Press.

Collier, R. (2012). Person-first language: Noble intent but to what effect? *CMAJ*, 184(18), 1977–1978.

Deane, K. (2009). *Shut out: The experience of people with disabilities and their families in Australia*. CanPrint Communications, Flagstaff Print and Mail.

French, S., & Swain, J. (2000). Towards an affirmation model of disability. *Disability and Society*, 15(4), 569–582.

Kiernan, C. (1999). Participation in research by people with learning disability: Origins and issues. *British Journal of Learning Disabilities*, 27, 43–47.

Michalko, R. (2002). *The difference that disability makes*. Philadelphia, PA: Temple University Press.

Oliver, M. (1996). Defining impairment and disability. In C. Barnes & G. Mercer (Eds), *Exploring the divide: Illness and disability* (pp. 29–54). London: Disability Press.

Patterson, D., & Costa, A. (2005). Down syndrome and genetics – A case of linked histories. *Nat Rev Genet* 6, 137–147.

Shakespeare, T. (2010). The social model of disability. In L.J. Davis (Ed.), *The disability studies reader* (pp. 266–273). NY: Routledge.

Siminski, P. (2003). Patterns of disability and norms of participation through the life course: Empirical support for a social model of disability. *Disability & Society*, 18(6), 707–718.

Tregaskis, C. (2004). *Constructions of disability: Researching the interface between disabled and non-disabled people*. London: Routledge.

University of Guelph. (2016). *Universal instructional design*. University of Guelph, viewed 7 July 2020. <https://opened.uoguelph.ca/student-resources/Universal-Instructional-Design>.