From social connectedness to equitable access: An action research project illuminating the opportunities and the barriers to accessing music for young people with disability transitioning from school to adult life

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ABSTRACT

The action research project described in this thesis emerged from a partnership between the Community Inclusion Team of a large, not-for-profit disability service organisation in Australia, Scope (the Organisation) and the National Music Therapy Research Unit at the University of Melbourne (NaMTRU). The project developed following a question from the Organisation about how music could be an engaging part of young people’s lives as they transitioned from school to adult life. Community inclusion team members of the Organisation had identified that young people who accessed their services, many of who live with more complex disabilities, often experienced challenges in establishing a sense of social connectedness during the transition. The Organisation were interested in how involvement in music may play a role in addressing this challenge. As such, the project began with a focus on the role of music in social connectedness for young people. However, as the project unfolded, the focus began to broaden into the more pressing issue of equitable access to music. The project developed amid the backdrop of the introduction of a new disability funding model in Australia, the National Disability Insurance Scheme (NDIS). This change within the disability sector has had a significant influence on many aspects of this inquiry.

An action research approach (Reason and Bradbury, 2008) was used for the project within a transformative paradigm (Mertens, 2009) as it relates to issues of social justice and human rights. This framework encompasses the aim of personal and
social transformation within communities that experience oppression and discrimination. Grounded in community music therapy theory and disability studies, the project took the form of four cycles of planning, action and reflection. Cycle 1 involved a critical interpretive synthesis of the literature. Cycle 2 involved semi-structured interviews with young people accessing the Organisation to learn about their experiences of social connectedness. Cycle 3 involved focus group discussions with facilitators of music programs accessible to young people to begin building a picture of opportunities to access music and finally, cycle 4 involved the establishment of an ongoing, collaborative community music program with a group of young people.

Findings indicate that young people with disability lack sufficient opportunities to access music as a resource in their lives. A variety of opportunities exist that offer different ways of participating in music, but barriers to this participation are continually faced. These include limitations on independent access to information about the existence of programs and opportunities, inadequate funding for independent action and a lack of community infrastructure to accommodate people with differing needs. Once an opportunity was made available in this project, young people embraced the chance to work collaboratively to create the music program into what they needed. This included growing the group membership to satisfy social needs, taking on leadership and marketing roles, making group decisions about the music, the venue and performances.

The research project outcomes have implications for roles and actions for music therapists and other facilitators of music programs aimed at a structural level to increase opportunities for young people to access music as a resource in their lives.
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CHAPTER 1

Background

This research project was collaboration between the Community Inclusion Team of Scope, a large not-for-profit disability service organisation (here on referred to as ‘the Organisation’) and the National Music Therapy Research Unit (NaMTRU) at the University of Melbourne. The project emerged from a conference hosted by the Social Equity Institute of Melbourne University in August 2013, the Disability Research @ Melbourne Conference. At the directive of the Organisation’s CEO, a Community Inclusion Team member and NaMTRU director Professor Katrina McFerran began developing a concept for a collaborative, participatory research project that addresses a gap identified by the Organisation’s Community Inclusion Team. This gap entailed the lack of opportunities for connectedness that young people often experienced upon leaving school. The Community Inclusion Team had observed that the transitioning period for many young people who used their service presented a particular challenge for establishing a sense of social connectedness. With Professor McFerran’s input, a proposal was put forth for a participatory action research to explore ways that involvement in music may play a role in addressing this gap.
I was engaged as an experienced registered music therapist and PhD candidate to investigate this question at the end of 2013. I began by spending two days a week at a Melbourne office of the Organisation, which is the centre of the Community Inclusion Team for the north and western regions of Victoria. The Community Inclusion Team of the Organisation have transformed over the ensuing three years to encompass different roles, but at the time, it comprised a group of five people assigned to different geographic areas of Victoria to support service user’s involvement in the community. Community, in this context, refers to activities or groups outside of the day service facilities, for example a local photography club, sporting club or library. Their role involved identifying the interests of service users and then sharing information about opportunities in the community in order for people to pursue these interests. This may be through supporting access by identifying existing barriers to participation and working through these with both service users and the community groups. The team also coordinates and runs a variety of arts and sporting activities including balloon football, modified cricket and a national visual arts and writing competition.

Established in 1948 by a group of parents of children with cerebral palsy, the Organisation is one of the largest service providers in Victoria supporting around 6000 people with disability and their families and employing 1500 people across 100 service centres in the state. It is also one of the largest not-for-profit organisations in Australia. The mission is to “enable each person we support to live as an empowered and equal citizen” (Scope, 2017). They provide allied health services, home and respite, day services and employment services. In addition, it has a research partnership with the University of Melbourne’s ‘Disability Research Initiative’.
Prior to 2013, the Organisation received around 80% of its funding from the state and federal governments and the remainder through fundraising. Since 2013 the Organisation has begun to transition to a new disability funding system based on an insurance model. This funding system, the National Disability Insurance Scheme, has had a significant impact on all service organisations in Australia as government funding is now directed to individuals with disabilities rather than organisations who have traditionally managed them. A more detailed description is outlined below. Within the Organisation, the Community Inclusion Team has similarly begun to adapt to the changes brought about by the new funding arrangements.

The ethos of social inclusion in this skilled and passionate team of people fitted perfectly with the aims of the research project in exploring the role of music in social connectedness for young people. The team introduced a new perspective for me as a music therapist experienced in working within organisations as an allied health professional. My role up until this point had been in running group and individual music therapy sessions for people attending organisations such as special schools and day services for people with disability. Through this role, I facilitated opportunities for people to connect through playing music together within the organisations, but did not have experience in working in the broader community. My work had been disability specific and sessions encompassed an ethos of collaboration and choice making whilst focussing on nurturing strengths and abilities. This ethos stems from my music therapy training in the early 1990s drawing on humanist and psychodynamic theory. Although I had observed numerous instances of increased confidence and self-expression, as well as deepening relationships between group members though this creative and shared means of playing music together, I began to question broader notions of choice and opportunity. How did this therapeutic work
benefit participants more broadly and what levels of choice did they have in attending the sessions. Was it simply that it was the only music on offer? People’s membership of these schools and day services was based solely on the fact that they lived with disability. For the adults, were there other opportunities for music participation available? Given the choice, would group members prefer to be having different kinds of music experiences? Would they prefer to be in a community band or choir, or learn a particular instrument, or perhaps work in the music industry such as sound recording and composing or public performance? Were these opportunities available as they are to many other young people who do not live with disability?

In the first few months I began reading extensively through the literature on social connectedness, the transitioning period for young people from school, as well as delving into the writings in critical disability studies. It was the latter that really began to open my eyes. Was therapy part of the problem in preserving the social exclusion of people with disability? According to some writings it was.

“There is a joke amongst Disabled people that non-Disabled people listen to music, do the gardening, hold down jobs, but Disabled people do music therapy, horticultural therapy, occupational therapy. Where Disabled people are involved, almost every activity of life seems to have to be justified in terms of its medical and therapeutic benefits”(Crow, 1992).

Where did these confronting ideas leave me as a music therapist? An early reading that influenced me was the book “Disability in Australia. Exposing a Social Apartheid” by Gerard Goggin and Christopher Newell (2005). The authors plot the history of disability in Australia and write vividly of ongoing oppressive structures and inequities experienced by people with disability despite significant changes over
the past half century. Through a lens of critical disability studies, human rights and
their own lived experience, they posit that post-deinstitutionalisation has led to
another era of exclusion brought about by internalised social and cultural practices.
They state that “the closing of these institutions does not mark the end of the
oppression of people with disability, but merely the beginning of another phase”

Another moment that remains stark in my memory from those early months
was when one of the Community Inclusion Team, was showing me around one of the
day service centres of the Organisation in Melbourne. It was a beautiful, warm sunny
day and we came in from the sunshine to the main room of the centre that included
tables for meals and a large recreation space with a wall of darkened windows on one
side. There were a dozen or so people in the room, mostly in wheelchairs and several
staff moving around. I noticed a woman sitting alone in a wheelchair facing this large
window looking out. Outside the window below was a typical hot day scene in
Australia of a crowded public swimming pool. It was a mass of muted colour and
muted sounds of people enjoying themselves in the sunshine, jumping, splashing,
swimming, laughing - muted because of the thick, darkened windows creating a wall
between the people inside and the scene outside.

I approached the woman and introduced myself. She said ‘Hi’. After a minute
of shared watching, I asked her if she had swum in the pool before. She said, ‘No, I
don’t like to swim.’ Later I asked the Community Inclusion Team member if the
service users ever swam in the pool and she said that it did not have wheelchair
accessibility. As a lover of the sunshine and swimming, this struck me as particularly
unfair. Although I acknowledge that not everyone would relish the opportunity to be a
part of the scene we looked on that day, the *choice* to be a part of it for the people in
the room with me did not exist. Instead, it was merely a daily view of an unattainable
experience and a reminder of the ‘otherness’ of the occupants of the room. As we
drove away, I wondered if I too might say I did not like to swim in order to manage
my feelings of this situation.

**The National Disability Insurance Scheme (NDIS)**

Significant to this project is the backdrop of disability support in Australia. The very beginnings of this project in 2013 coincided with the beginnings of a new model of funding for disability support in Australia. The new model is an insurance model and it has been described as the most significant social reform since the introduction of our public health system, Medicare, in the 1970’s.

The begins of the idea of an insurance model for disability support came during the 1970’s labour government of Australia led by Gough Whitlam who introduced a similar model for health care called Medicare. The academic work for this type of model had already been developed where it was shown the community as a whole, rather than individuals, most efficiently carried the cost of health care. Insurance for disability support is based on the assumption that every person is at risk of having or acquiring a life long disability and the costs of supporting that for individuals and their families is not possible in most cases (Bonyhady & Galbally, 2016). The idea for an insurance scheme was due to be debated in parliament when Gough Whitlam was dismissed as Prime Minister in the mid 1970’s and the incoming liberal government decided not to carry it forward (McDonald, 2013). In 2005 the report was dusted off and the idea began to take shape again. It was examined for
During this time, the disability rights movement was gaining momentum. A report by the National Disability Carers Council called ‘Shut Out’ (2009) was prepared in order to develop a national disability strategy. 750 submissions were gathered from people with disability as well as organisations asking what the main barriers were to full participation in the social and economic life of the community. The voices of two and a half thousand people were also heard in the development of the report in consultation meetings around the country. One of the concluding statements from a carer was that:

People with a disability want to live in a society where they are treated with respect, dignity and importantly with equality, and not as ‘poor things’ nor merely as recipients of services. Additionally they do not want to be segregated as ‘people with disabilities’ (p10).

One problem that needed addressing at the time was the tension between the disability service sector and people with disability and their advocates and carers (Galbally, 2016). According to Galbally the two sectors were effectively ‘at war with each other’ (p.5), as disability support appeared to fall so far short of what people needed. This tension is occasionally felt both as a music therapist part of the service sector, and within the Australian Music Therapy Association as a whole, where the perception that a person needs a therapist to access music is viewed unfavourably within a disability-rights framework. A campaign was launched to address this tension in Australia and create an alliance between the sectors and this was called the ‘Every Australian Counts’ campaign. It was launched in 2012 and ended up with
150,000 members who united to get behind the development of the scheme (Bonyhady & Galbally, 2016).

A productivity commission report was developed in preparation for tabling the idea in parliament (2011). The report overview stated:

Current disability support arrangements are inequitable, underfunded, fragmented, and inefficient and give people with a disability little choice. They provide no certainty that people will be able to access appropriate supports when needed. While some governments have performed much better than others, and there are pockets of success, overall, no disability support arrangements in any jurisdiction are working well in all of the areas where change is required. The current arrangements cannot be called a genuine ‘system’ in which different elements work together to achieve desired outcomes.

The central message of this report is that a coherent and certain system for people with a disability is required — with much more and better-directed resourcing, a national approach, and a shift in decision-making to people with a disability and their carers. This overview explains what is wrong with the current arrangements and how to improve them. It shows how a new system would work for people with a disability and their families, and how it would provide benefits for the community as a whole (p.5).

Trials for the new scheme began in 2013 in the Barwon Region that includes Geelong as well as the Hunter region of NSW. In South Australia, it began with children six and under and Tasmania for young people 15 to 24 years of age. From the
middle of 2016 the scheme began a full rollout across the country. Music therapy is included in the schemes’ list of allied health supports and this government support for our profession is unprecedented since the health system, Medicare, does not financially support music therapy services.

**Overview of Literature and Theoretical Influences**

This literature review is an introduction to the key concepts and the broad overview of the literature that I have drawn on for this project. My reading and understanding of the literature continued throughout the project and its influence has maintained an ongoing evolution in my thinking. As such, this is not a traditional thesis structure where the literature review is written and completed before the practical elements of the study begin. Instead, the literature broadly summarises concepts read over the three years of research and writing. Some of it influenced early stages of the project, for example action research, social connectedness, transitioning and community music therapy. My understanding of disability theory has been cultivated continually through the literature and through the cycles of inquiry and is summarised in this chapter as a whole. The different theories described here are given context within subsequent chapters.

**Action research and influencing theorists**

The institutions of normal science and academia, which have created such a monopoly on the knowledge-making process, place a primary value on pure research, the creation of knowledge unencumbered by practical questions. In contrast, the primary purpose of action research is not to produce academic theories based on action; nor is it to
produce theories about action; nor is it to produce theoretical or empirical knowledge that can be applied to action; it is to liberate the human body, mind and spirit in the search for a better, freer world.

(Reason & Bradbury, 2008, p. 5)

My introduction to an action research framework in music therapy with people with disability came first from visiting Norwegian music therapist, Brynjuf Stige in a public lecture in 2012. He told the story of being a newly graduated music therapist in 1983 working with a group of adults with Downs Syndrome. The group was set up as a conventional music therapy group for that time, focused on work at an individual level or within the group. But the group members, including a man called Knut, had other ideas. In the room where they were preparing to run the session, there were pictures of the local marching band on the wall and Knut asked, “Can we too play in the marching band?” At that moment, Stige was not able to respond to Knut’s question in any practical way given his experience and learning to that point as a music therapist. He subsequently discovered that Knut’s interest in playing with the marching band had come up several times before and was not just a passing whim. Knut’s strong desire coupled with Stige’s knowledge of local and international policy - including that people with disabilities had a right to participate “on an equal basis with others in cultural life” (United Nations, 2006, p. 22) marked a turning point. So began a journey over the next few years of Stige questioning his role in facilitating people’s participation in music and where the boundaries might lie between individuals, groups, the community and social justice. Although not planned as an action research, he co-authored a book in 1987 exploring some of these questions drawing on ideas from Kurt Lewin’s theoretical context for action research (1946)
called ‘With Longing, Life, and Song’ published in Norwegian. For an English summary, see (Stige, 2014).

This project uses an action research framework (Reason & Bradbury, 2008) within a transformative paradigm (Mertens, Sullivan, & Stace, 2011). It includes four cycles of planning, action and reflection as informed by Kurt Lewin (1946). A full description of the design and methodology for this project is provided in chapter 2.

**Conceptualising Disability**

The most commonly used definition of disability used in the Australian context is the World Health Organisation’s International Classification of Functioning, Disability and Health or ICF (World Health Organization, 2001). The ICF conceptualizes disability as a health experience that occurs in a context, rather than as a problem that resides solely in the individual.

Within this classification, ‘disability’ is used as an umbrella term for any of these components:

- impairments—problems in body function or structure
- activity limitations—difficulties in executing activities
- participation restrictions—problems an individual may experience in involvement in life situations.

These components are described as being distinct and also interrelated as a person may experience any one or all three components that constitute disability. Importantly, this concept recognises that disability and functioning are viewed as outcomes of the interplay between *health conditions* (diseases, disorders and injuries)
and *contextual factors*: contextual factors being external such the built environment, social attitudes and social structures, or internal factors such as character, gender, age, coping style, experiences past and present (World Health Organization, 2001).

Ratified in Australia in 2008, the United Nations Convention of the Rights of Persons with Disability (2006) provides descriptions of the disability construct that are more closely aligned with the ideas that I had begun to form over the course of this study.

Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (United Nations, 2006, p. 1).

In particular, the idea that disability is described as an *evolving* concept is more closely aligned with feminist and critical theory.

I found that in order to deepen my understanding of conceptualisation of disability, it was helpful to look through the past century to map the evolution of understandings of disability, particularly as I came to realise how context-dependent these were. At the turn of the 20th Century, people with intellectual, multiple and psychosocial disability were commonly housed in large institutions or asylums (Goggin & Newell, 2005). Foucault named this the “Great Confinement” (1961). The rise of capitalism and liberalism after the industrial revolutions, gave rise to ideologies such as eugenics, a philosophy and practice concerned with improving the genetics of the human race through selective reproduction (Black, 2003). Residents of these institutions were commonly considered undesirable with little to contribute to
society and this de-humanising view led to situations such as involuntary sterilization and in some cases euthanasia (Baroff, 2000), evidenced by the subsequent actions of doctors during the Nazi regime. Shakespeare (1999) explores these ideas through examining narratives of genetic interventions as both contributing to human health and ridding society of undesirable people identified as impaired. Today, beliefs that stemmed from the eugenics ideology are drawn into the complex ethical questions surrounding prenatal genetic testing for impairments and chromosome abnormalities.

A considerable shift in thinking occurred at the end of the Second World War when thousands of soldiers returned from the war with disabilities. At this time with advances in medical treatments, disability was conceived in what is now referred to as the medical model (Spencer-Barnhart, 2016). This model takes an objectivist stance by pathologising disability as a health condition residing with the individual and was primarily concerned with cures, medical treatment and management by experts such as doctors and psychiatrists (Brisenden, 1986; Fisher, 2007).

By the late 1960’s challenges to this view began to take hold with the rise of disability activism and disabled person’s groups, who began to politicise disability and in doing so considered it beyond an individual concern to a societal concern. This evolved into what became known as the social model of disability (Shakespeare, 2006). This model shifted focus away from individuals to external factors such as discriminatory attitudes and barriers caused by the built environment (Barnes, 2000). For example, a vision-impaired person would be disabled by information conveyed in written form and a seeing person would be disabled by the same information in braille. Changes in language also illustrated this shift when person-first language became widely accepted where the person was emphasised over their disability. For
example, ‘person with disability’ rather than ‘disabled person’ (Goggin & Newell, 2005, p. 26). Michael Oliver described the distinction by saying that the impairment was nothing but a description of the body and disablement as the failure of society to accommodate the needs of the person (Oliver, 1996).

The social model of disability is still evident today and informs policy development and legislation, but a critique of the limitations of this model challenged theorists to go a step further (Gabel & Peters, 2004). The ICF refer to this more global view as the biopsychosocial model, first developed by Engel (1977), whereby a synthesis of the medical and social models of disability are designed to reflect the complex intersections of individuals’ experience of disability. This grew from a critique of the social model in that it neglects the impact of individual impairments, which for some people may constitute the greater part of their experience of disability (Crow, 1992). By integrating the two models, the complexities that encompass the experience of disability are acknowledged through considering social, biological and individual elements together. In moving forward, a new paradigm or conceptualisation has become known as critical disability studies.

**Critical Disability Studies**

Dan Goodley (2013) suggests critical disability studies is the process of unpacking and illuminating the complexity of disability and that ‘critical’ implies a re-assessment of where we have come from and where we need to go. It does away with thinking in terms of binaries such as social model/medical model, impairments/disability and even disability and non-disabled (Meekosha & Shuttleworth, 2009) in order to consider disability in more global, socio-political and cultural terms. Shildrick (2007) describes the concept as “slippery, fluid,
heterogeneous and deeply intersectional” (p.223). Critical disability studies have been described as a transdisciplinary community with contributions from post-conventionist (Shildrick, 2007), postmodernist (Corker & Shakespeare, 2002) and post-structuralist (Tremain, 2001) thinking.

Central to critical disability studies is an examination of the notion of power. Tremain (2001) explores disability through a Foucauldian analysis and posits how governing bodies exercise power through the use of classifications and descriptions of people. This power is not overt, but because over time these classifications become normalised, people may then be corralled into certain groups and are then offered limited choices of action as subjects of this group. She gives the example of descriptions of impairments, pointing out that this is not value neutral and not merely a description without being a prescription for the identity of the person. In other words, these “truth-discourses that purport to describe phenomena contribute to the construction of their objects” (Tremain, 2001, p. 621).

Contained within critical disability studies, the concepts of disablism and ableism are examined for their influence in constructing systemic oppression. Campbell (2008) describes disablism as “a set of assumptions and practices promoting the differential or unequal treatment of people because of actual or presumed disabilities” and ableism as:

- a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is cast as a diminished state of being human (p.5).
Campbell goes on to say that impairment, irrespective of type, is viewed as inherently negative and is treated as such, to be changed, fixed or otherwise removed. Related to this, Mintz (2002) points out that narratives around disability are often more to do with maintaining the privileged status of non-disabled. English sociologist, Carol Thomas (2007) describes disablism as a form of social oppression resulting in limitations on activity and the denigration on individual’s psychological and emotional health.

With my background in psychodynamic theory, my curiosity was drawn to consider psychological elements at play within disability discourse and why after more than 40 years of disability activism in Australia and elsewhere including significant changes in national and international policy, that a continued social apartheid (Goggin & Newell, 2005) exists. In reflecting on this, I was reminded of a conversation I had with a friend soon after I graduated as a music therapist when I was telling her about my work with secondary students in a specialist school. She surprised me by saying that people with disability scared her. This conversation has stayed with me and I was able to consider it again in the light of a re-introduction of psychoanalytic ideas that are being drawn into current disability discourses.

Previously, psychoanalytic theories were rejected in disability studies for their alliance with medical model paradigms, however more recent theorists have begun to reintroduce elements of psychoanalytic discourse to assist with describing different phenomena in disability studies. Three elements are of relevance to this study. One of these is in examining attitudes towards the concept of disability and how this relates to sources of oppression and marginalisation. Another is in examining the lived experience for those with disability in terms of internalised oppression. The third is
the relationship between those in the caring industries such as health professionals, carers and volunteers and those with whom they work, as well as broader attitudes to the value of these roles.

Margrit Shildrick (2007) describes the notion of a psychic fear of self-identity loss in the face of non-normative bodies and Tepper (2000) examines sexuality and disability through psychoanalytic theory. Robert Wilton (Wilton, 1998) explores the origins of people’s fear of difference through Freud’s concept of ‘unheimlich’. He postulates that ideas about disability may cause a “fundamental anxiety about the loss of control within the self (177)”. Goodley (Goodley, 2011) critically examines disablism through Freud’s notion of ‘splitting’. Splitting occurs between the masterful ‘ego’ of independence and mastery with the id of dependence and vulnerability. He suggests that this may materialise in negative attitudes towards the concept of disability in a number of ways including a conscious or unconscious fear of vulnerability, manifesting in feelings of anger, violence or avoidance. On a societal level, this attitude results in marginalisation.

Once a person or group of people are marginalised on the basis of this fear, then a whole new industry of caring and correcting may blossom. This includes the allied health fields. Psychodynamic theory has also been drawn upon to examine the emotional investments and pay offs of carers, professionals and volunteers who work in the disability sector (Goodley, 2011; Marks, 2002). Further discussions of these ideas are drawn into cycles 2 and 4 of this project.
Transitioning from School

The period of time when a young person is nearing the end of their school life and begins planning for their future as an adult is one of the major life transitions for every person. What will I do with my life? What are my options? What are my interests and aspirations? Where will I live? Will I have a family of my own? What will my friends be doing? Will I study and gain further education or training or do I want to work straight away? What does being an adult mean to me? How does society view me as a young person and what are the expectations?

The smoothness or otherwise of this transition is affected by multiple factors that shift from generation to generation. These factors impact on the intersection between a young person’s own wishes and needs, aptitude, abilities and resources, with structural elements (Bynner, 2005). These may be the availability of vocational and further education options, the economic and political status of the country and the cultural factors that impact on attitudes to youth and in the case of this project, to difference and disability (King, Baldwin, Currie, & Evans, 2005a; MacIntyre, 2014).

Viewed from a Human Rights perspective, Australia, as a signatory to the United Nations Convention on Rights of Persons with Disabilities (UNCRPD) has an obligation to ensure that young people with disability have the same rights as anyone else. This includes full inclusion and participation free from discrimination and on an equal basis with everyone else;

- to general tertiary education, vocational training, adult education and lifelong learning
• to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities
• to develop and utilize their creative, artistic and intellectual potential, not only for their own benefit, but also for the enrichment of society.
• to live in the community, with choices equal to others

(United Nations, 2006).

Rights alone will not result in desired changes for full citizenship and inclusion for people with disability. As Reinders points out, ‘rights create space for action’ (Reinders, 2002, p. 2) and it is within that space that opportunities may be appropriated such as living in the community, getting a job and participating in community activity. Inclusion requires action, not only on the part of people with disability and their advocates, but also on the part of those communities, employers and training institutions in welcoming and fully including people who wish to participate.

The length of time for this transition is widely variable. Rather than a fixed ‘before and after’ adolescent to adult transition, the period has been more accurately described as an ‘emerging adulthood’ (Bynner, 2005). Longitudinal studies examining aspects of this period have included people aged 14 where transitional planning may begin (Lehman, Clark, Bullis, Rinkin, & Castellanos, 2002), up to 30 years (Edgar, 1995; Levine & Nourse, 1998; Wagner, Newman, Cameto, Garza, & Levine, 2005). The additional challenges experienced by young people with disability often lengthen what is described as the ‘transitioning period’. A literature review on independence and opportunity by Stokes and colleagues in 2013 found that young people with disability are less likely to be involved in education, work and the community and are
“more likely than their peers without a disability to be socially isolated and that they take longer to forge strong relationships of trust” (Stokes, Turnbull, & Wyn, 2013, p. 5).

Within the disability literature, the transitioning period can be categorised broadly into two frameworks; an ecological framework and a self-determination framework. From an ecological perspective (Bronfenbrenner, 1979), the transitioning experience is seen as being impacted by the systems surrounding an individual from families (Clegg, Sheard, Cahill, & Osbeck, 2001), school (Hamm & Mirenda, 2006; King, Baldwin, Curry, & Evans, 2005b), work and neighbourhood communities (Farmakopoulou & Watson, 2003), the wider community cultures and norms (Hall, Williamson, & Coffey, 1998) to government policies. According to Lehman et al. (2002) it is the role of a dedicated transitioning case management team or person to assist a young person to identify and draw effectively on the resources and opportunities afforded by these systems to navigate the transition from school. Within an ecological framework, support afforded by a person’s social networks is considered a major determinant to successful transitioning (Foley, Dyke, Girdler, Bourke, & Leonard, 2012; Hodgins & Cronin, 2004; Stokes et al., 2013).

Related to the ecological perspective is the self-determination construct (Wehmeyer & Bolding, 2001) pertaining either to the rights of a group of citizens to self determination or as a personal construct, referring to having control over one’s life and future (p 372). Within this framework, identity development, autonomy and individuation (Foley et al., 2012; Hodgins & Cronin, 2004; King et al., 2005b; Stokes et al., 2013) are explored as factors influencing the experience of transitioning from school to adult life. The self-determinant construct is evident in the adoption of
person centered planning and individualised funding over the past decade in the U.S.A., U.K., Europe, Australia and New Zealand (Kirkman, 2010). The most recent national policy shift has been the implementation of the National Disability Insurance Scheme or NDIS in Australia beginning in 2013. In the past, disability service organisations received government funding to provide services based on the needs of the service users. The NDIS means that funding now goes directly to the person with disability and they are free to choose the services that best suit their needs and wishes. In effect this means that many young people who have joined the scheme are now choosing services and post-school options provided by different organisations. As mentioned in the background section, this increase in individual choice is predicted to improve quality of life through increasing self-determination along with increased economic and civic participation of people with disability (Council of Australian Governments, 2011).

In Victoria young people with complex disability often move from a specialist school to an adult disability service, such as the Organisation. These organisations provide supported employment opportunities, therapy services and various vocational, educational and recreational programs. A critique of this service model is that there is limited choice for participants which may result in a ‘one-size-fits-all’ arrangement (Deane, 2009). With the person-centred funding model of the NDIS being recently introduced, it’s predicted that young people will have the choice to move between services organisation programs to suit their needs.

Stokes and colleagues (2013), in their review of the transitioning literature focussing on independence and opportunities for young people, highlighted both self-determinant factors and ecological factors in the experience of the transition. They
concluded that a supportive social network was key to successful transitioning and that choice and control was strongly associated with a sense of social connectedness. In addition, their review concluded that community attitudes were seen as the most disabling barrier to social inclusion and that it was this ecological factor that most needed addressing if young people are to improve their transitioning experience.

Further to this, a societal focus on further education or paid employment as a measure of independence for transitioning young people may be considered a disabling construct in itself for people for whom these opportunities are unavailable. More helpful would be to focus on the ability of young people to take control of their own lives (Tisdall, 2001). If choice and control are associated with a sense of social connectedness (Stokes et al., 2013), then placing a focus on growing a satisfactory social network for a young person transitioning from school could then situate them in a stronger position to take advantages of opportunities afforded by individualised funding models (MacIntyre, 2014).

Inclusion is at least philosophically supported in this state but once the young adults leave school there is simply no expectation that they will follow a path that might assist development or lead to a meaningful job or way of life (Deane, 2009, p. 50).

Tisdall (2005) has argued that the continued focus on contribution and status via paid employment continues to exclude young people with disabilities and perpetuates a misunderstanding about disabled young people’s work ethic and potential to contribute. She argues that a flawed understanding of the concept of independence perpetuates the disadvantage faced by young disabled people and
highlights the need for us to understand independence not in terms of physical independence but in terms of a person’s ability to take control over their own life.

The literature presented in this thesis suggests that policies that continue to focus on the contributions of young people with disabilities in very narrow terms are misguided. Instead further thought must be given to the ways in which the contributions that young people with disability do make can be recognized. This is likely to involve supporting young people to develop their relationships and social networks, key things that young people have said very clearly that they value (MacIntyre, 2014). The impact of a sense of connectedness on well-being and development has been a key theme in looking at the success or otherwise of navigating major life changes such as the transition from school (Viner et al., 2012). For young people who experience the additional challenges of living with disability, a sense of social connectedness is a particularly salient aspect of the journey towards adulthood (Stokes et al., 2013). Social support is important in the transitioning period for it’s pivotal role in identity formation and an increase in independence and by prioritising this, it is likely that young people with disabilities will find themselves in a much stronger position to embrace the opportunities that social inclusion policies can bring.

**Social Connectedness**

The human need to feel a sense of belonging and our innate standing as social beings has been an accepted belief, studied throughout written human history. The origins of this is said to stem from evolutionary theories demonstrating how group cooperation increased chances of survival by provided more effective hunting strategies, shared resources and protection against external threats (Baumeister &
Leary, 1995). The main schools of thought in the 20th Century emerged from the disciplines of sociology and social psychology. Kurt Lewin (1939), began to marry theories of sociology with psychology, drawing together ideas around the impact of the social environment into the subjective, physiological processes of individual functioning. Around the same time, the American psychologist, Abraham Maslow’s theory of human motivation placed love and belonging in the centre of his famous pyramid after the basic needs of food and safety are met (Maslow, 1943). Also influential was psychologist John Bowlby’s attachment theory postulating that infants are innately drawn towards bonding as a survival mechanism and this experience in early attachment continues to influence later social functioning (Bowlby, 1969).

The term social connectedness, or lack of, was used by the Organisation in describing the gap experienced by young people transitioning from school. This became a useful umbrella term as it refers to a subjective phenomenon rather than a measurable, objective one such as the size of a social network. In other words it is described as an individual sense of feeling socially connected or otherwise, rather than an objective count of how many people may constitute a person’s social network, or even a concept that others could make an assessment about. Within an action research framework, important features of the project would focus on the perceptions and opinions of the participants involved. Seen from social psychology theory, connectedness may also refer to more than friendships or close relationships; it may also include broader personal encounters and the community (Lee & Robbins, 2000). A lack of social support for example refers to lack of support from a specific source whereas a lack of connectedness refers to a broader feeling of disconnection to the social world (Williams & Galliher, 2006).
There is little consensus on the definition of social connectedness (Phillips-Salami, 2009). Scales used to measure a sense of social connectedness also vary widely depending on the paradigm through which it is considered. During early readings of the literature, an understanding of the phenomena most relevant to people transitioning from school favoured theories that focused on adolescent and young adult populations. These were derived from American counselling psychologists, Richard Lee and Steven Robbins (Lee & Robbins, 1995) as well as American educational psychologist, Michael Karcher (Karcher, 2001) who developed measurement scales for young adults and secondary school students respectively. Celeste Phillips-Salimi (2009) in her doctoral studies provided a useful concept overview of social connectedness through a concept clarification analysis of the literature. Through the analysis, she identified seven attributes of connectedness; intimacy, empathy, reciprocity, belonging or feeling part of a significant relationship, caring, respect, and trust. She found that no single definition used by authors included all these criteria to comprise the attributes of connectedness and therefore derived her own definition:

Connectedness is the degree to which an individual perceives that he/she has a close, meaningful, and significant relationship with another person or group of others. This perception is characterised by positive expressions (i.e., empathy, belonging, caring, respect, and trust) that are both received and reciprocated through social interactions (Phillips-Salami, 2009, p. 55).

The social experiences of people with disability have been explored thoroughly in research, most notably since the shift from institutional living into the community or family homes. The influence of a person’s social network is well
known to impact strongly on quality of life (Yeung & Towers, 2014), with isolation and loneliness leading to mental health concerns including depression, anxiety and behavioural challenges (Cacioppo & Patrick, 2008; Lunsky & Benson, 2001; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Research that includes the voices of people with disability has indicated that social relationships and friendship are placed as a high priority for research agendas (Nierse & Abma, 2011) and more generally as a significant determinant for well-being (McVilly et al., 2006; Sullivan, Bowden, McKenzie, & Quayle, 2015).

As discussed earlier, the historic marginalisation of people with disability is now being addressed through rights-based policy and individualised support, however many challenges remain. The social situation for people with disability continues to be well below that of the average young person with many young people experiencing limited social networks, often made up solely of family and paid support workers (McVilly et al., 2006; Stokes et al., 2013). Research has explored various ways in which young people with disability might build their social networks once they leave school. These might be through supported employment (Forrester-Jones, Jones, Heason, & DiTerlizzi, 2004), further education (Grigal, Hart, & Migliore, 2011), community living (Johnson, Douglas, Bigby, & Iacono, 2012) and the arts, (Hall, 2010; Parr, 2006) but for many young people these options are not always available or even desired. Further discussion of these studies is provided in chapter 3 and 4.

**Music Therapy**

The literature on music therapy has traditionally been focused on how music therapists ‘help’ people with disabilities to get better. This is summarised in a systematic review of the literature, which reveals some consistent trends (McFerran,
Lee, Steele, & Bialocerkowski, 2009). These authors analysed 65 articles examining music therapy with people who have disabilities. They looked at the ages and range of disabilities researched, treatment goals, music therapy methods and research methodology. Their findings reveal standardised treatment methods where goals are varied according to the type and severity of the disability. People with mild or moderate disabilities are engaged in programs that target behavioural, social and learning outcomes whereas more basic communication and physical outcomes are targeted with people whose disabilities are identified as severe and profound.

This traditional approach is now evolving and expanding into more contemporary approaches within music therapy, drawn together under the label of community music therapy (CoMT). CoMT is a practice which incorporates elements of traditional music therapy and expands to include projects that are characterised by collaboration and context-sensitive music making (Murphy & McFerran, 2014). Shared music making in CoMT emphasises the inherent attraction of the participants to music, whilst music therapists also focusing on enabling and empowering the participants as a core value (Aigen, 2004, p. 100). Community music therapists balance their roles as musicians and therapists (Ansdell, 2002), where the musician’s role is to facilitate the musicking (Murphy & McFerran, 2014) of participants and the therapist’s role is to work with the challenges that participants may face in engaging with the community through music because of disability or other disadvantage (Ansdell, 2002).

Music therapists have always challenged notions of what music is and who could and should participate with music (Curtis, 2012). They have developed ways to communicate musically with people with the most profound disabilities and explored
ways in which music may provide a link to human values such as dignity, respect and quality of life (Stige & Aarø, 2011). Furthermore, music therapists to some degree have challenged traditional notions of therapy by developing practices that are strengths-based and may draw out communication with people who have not found other forms therapy practices helpful (Lee, 2014). CoMT goes further than emphasising participant strengths, and challenges the assumption that expert treatment models that privilege the therapist can actually be (unintentionally) disempowering (Rolvsjord, 2010). This leads to models of practice that are collaborative and where both people design the agenda for therapy, which each contributing their own knowledge and experiences from life and training, as well as their musical ability and interests.

Another dimension of the critique of traditional practice relates to where music therapists work. According to Pavlicevic and Ansdell, (2004,) one defining difference between CoMT and more traditional practice is that “traditional practice takes music into the community and CoMT explores ways of working with communities” (p.26). Elefant (2010) has suggest that CoMT is not a unified theory but “a broad perspective exploring relationships between the individual, community and society in relation to music and health” (pp. 15-16). CoMT represents another way of thinking about music therapy which may be seen as a “continuation of and a contrast to pre-existing music therapy discourse and practice” (Stige et al, 2010. p13).

In addition to thinking about ways of working with communities, more sustainable practices have been advocated that do not create a dependence on the presence of a music therapist. Bolger and McFerran (2012) propose that “a sustainable orientation to music therapy involves prioritising and planning for the
ongoing impact of a program beyond the life of the music therapist’s direct involvement.” They broadly describe sustainable practice within music therapy as falling into two general categories: self-supporting music programs in which the music therapist acts as a consultant; and programs that aim to build capacity where the music therapy approach aims to give the participants capacity to utilise music for their own health and well-being in an ongoing manner at the conclusion of the therapy program. Although the term ‘sustainable practice’ is not cited as such in much of the literature on music therapy, the intent of enabling sustainability is nevertheless evident in many programs. The Sing and Grow Early Intervention program is a group music therapy program aimed at strengthening bonds between parents and their pre-school children. The program has shown results in increased confidence in parenting and the provision of resources to use at home (Abad and Edwards 2004). McFerran (2008) undertook a participatory action research with a group of adults attending either CoMT or community music programs at a Salvation Army centre. This program highlighted that despite significant differences between the two programs, many participants and carers described the benefits as being very similar. In addition, further community engagement resulted from the project which culminated in the participants’ involvement in the traditional community Salvation Army Carol Singing events (Baker, Wigram, Stott, & McFerran, 2008).

**Community Music**

Alongside music therapy is the discipline of community music. Community music is defined in many different ways depending on the particular social setting. Veblen (2008) gives five different elements commonly found in community music. This includes 1) that it is generally active music making; 2) the intentions are life-
long learning and access for all; 3) it accommodates all people including all ages, cultures and abilities; 4) it values the sharing of music knowledge, or ‘applied musical knowing’ and finally; 5) that it values the concept of community as both an ‘ideal’ and a ‘reality’ and that the term generally relates to the idea of a sense of ‘belonging’ (p.5). Interestingly, Veblen, in her article examining the concept of community music quotes Norwegian music therapist, Stige (2002) introducing him as ‘Swedish therapist’ (p.4), thereby grouping his ideas on community music therapy among those defined as ‘community music’.

Community music as an institution is well established in the United Kingdom. Sound Sense (2003) a United Kingdom based agency who support community music provide this definition:

Community music involves musicians working with people to enable them to actively enjoy and participate in music. This can happen anywhere and with anyone, because a ‘community’ doesn’t have to be a geographical one. It can be a group of people who share common interests, experiences or backgrounds.

In the local context of this project, the equivalent agency is Community Music Victoria (Community Music Victoria, 2016) and they state:

Our vision is for high quality participatory music-making experiences to be available to all Victorians, and our mission is to facilitate the development of the skills, opportunities and networks necessary to bring this about. Making music together is a great entry point into creativity and results in profound benefits to individual and community health and well being.
The use of the term ‘high quality’ is in addition to the participatory elements highlighted in the UK community music agency statement, Sound Sense. The term ‘quality’ is also unique in relation to common elements identified by Vebe (2008).

There is a growing affiliation between community music and music therapy as music therapy grows toward more community-based, culture-centred work (Stige, 2016). Various authors have looked at similarities and differences between the two professions. O’Grady (2007) noted that music therapy and community music could have similarities in relation to the aims, methods and outcomes of projects, but that music therapists relied on the ethical boundaries of their profession whilst community musicians relied more on their personal values. Ansdell (2002) considered differences along a continuum of individual to communal suggesting that community musicians and music therapists “colonised distinct territories along a naturally expansive continuum” (p.13). People other than music therapists predominantly facilitate the music programs at the Organisation. Some of these facilitators could be called community musicians and others are employed as support workers and are also musicians who use music in their work. Chapters 2 and 4 further elucidate conceptualisations of community music and its relationship to music therapy and this project.
CHAPTER 2

Methodology and Design

We suggest that a theory is a way of ordering beliefs in a descriptive, explanatory or predictive framework; it enables us to adopt beliefs and concepts in order to engage with the world, to make predictions about it, and to explain it. (Freshwater & Avis, 2004, p. 6)

This chapter will be in two parts. The first part will expand on the overview of action research within a transformative paradigm and locate my project among music therapy participatory action research projects. The second half will summarise the design of the project including the rationale for research methods used, data collection and analysis for each cycle of the project.

Action Research

As this inquiry began, early methodological ideas began to formulate after reading two music therapy action research doctoral projects involving people with disability. The first was Cathy Warner’s (2007) research project involving a group of men described as having severe learning disabilities and challenging behaviour in a residential unit in the U.K. The extraordinary journey taken by Warner with the men and their support workers resulted in challenging assumptions about the levels of influence and participation that the men could exert as non-verbal participants over the course and design of the research. The ‘voices’ of the men were valued by reframing their challenging behaviour as communication. The second thesis was
Daphne Rickson’s (2010) action research project looking at service provision for children with special needs in schools in New Zealand. She identified the needs of music therapists to provide services to children with disability and then designed a new protocol of service provision to rural and remote areas of the country.

Both projects took on challenging questions and demonstrated flexibility in methodology in responding to the local context. What struck me particularly was the scale and vision for action that challenged an existing situation and the strong themes of empowerment and social justice. Although very different in their approaches, they demonstrated that through collaborative cycles of action and reflection, as featured in participatory action research, questions and methodology could emerge in an iterative process that resulted in revealing the essence of the respective situations and create the conditions for change.

This project began with a goal of participatory action research (PAR), but because of various circumstances, which will be described in later chapters, participatory elements did not eventuate to the extent that I was aiming. I include the PAR literature here as the principals of participatory inquiry informed my thinking in the project design and methodology.

Participatory action research is one approach of action research; an umbrella term that encompasses collaborative action research, emancipatory research, participatory research, collaborative research and cooperative inquiry (Stige & McFerran, 2016). It has been described as an orientation to inquiry rather than a methodology and is characterised by collaborations with participants in cycles of action and reflection (Reason & Bradbury, 2008).
Kurt Lewin is credited with being the first architect of action research. Although he wasn’t the first to coin the term, he was the first to introduce a theoretical context for action research based on field theory (1939). This theory proposes that the environment influences individual behaviour. This idea was a departure from dominant ideas of the time influenced by Freudian psychoanalytic theory, which postulated that behaviour stems from personality and individual drives. Lewin (1946) demonstrated that people possessed the ability to change their behaviour given different environmental inducements (as cited in Reason and Bradbury 2008. p.78).

Lewin described action research as progressing through a series of spirals beginning with an idea and plan, then moving through phases of action and reflection before building on this process to begin another spiral of inquiry. Also central to Lewin’s formulation was the involvement of participants and the contribution of their lived experience in a given situation to create actions for change.

Subsequent developments in action research and particularly emancipatory and participatory action research influencing this project, are guided by the ideas of Brazilian educator and philosopher, Paulo Freire (1972). Freire’s concept of conscientization refers to “learning to perceive social, political and economic contradictions, and to take action against the oppressive elements of reality” (p.17). His philosophies were shaped from a childhood beginning in a middle class family to one of living in poverty following political unrest in his country. This resulted in a realisation that the situation of helplessness and lethargy brought about by poverty was perpetuated by a system of keeping people ignorant of liberation from their circumstance. Freire’s vision was that in order to be liberated from oppression, people needed to be educated (conscious) about the systems that cause this oppression. It
was only by being armed with that knowledge, that it was then possible to disrupt and challenge inequitable power structures.

Alongside Freire and equally influential in participatory research is French philosopher, Michel Foucault who used an analysis of history through archaeology and genealogy to understand modern constructions of power in psychiatry, medicine and sexuality (Foucault, 1961; Tremain, 2001). His work prompted a re-evaluation of assumptions that modern systems as they relate to human rights and autonomy are an improvement on the past. Foucault suggests that modern exertions of power are present in a less transparent and more insidious ways. Labelling people through various categorisations and then defining and tying them to this label. This label may then be used to govern possible ‘fields of actions’ and conduct and the person internalizes this identity, along with its restrictions in action with society as a whole (Foucault, 1982).

“This form of power applies itself to immediate everyday life which categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him. It is a form of power which makes individuals subjects” (p.781).

This project is largely situated within a transformative paradigm (Mertens, 2007) as far as it relates to issues of social justice and human rights. From my earliest readings and experiences of meeting people within the Organisation, notions of power and social justice through a critical lens emerged as central themes. According to Mertens (2010), a transformative paradigm is “a framework of belief systems that directly engages members of culturally diverse groups with a focus on increased
social justice” (p. 470). Additionally, it serves as an over arching framework in which to consider theories and approaches. Mertens (2007) outlines the researchers tasks within the ontological, epistemological, methodological and axiological association of a transformative paradigm.

**Ontology:** Transformative researchers need to be aware of societal values and privileges in determining the reality that holds potential for social transformation and increased social justice.

**Epistemology:** Knowledge is socially and historically located within a complex cultural context. Respect for culture and awareness of power relations is critical.

**Methodology:** A researcher can choose quantitative or qualitative or mixed methods, but there should be an interactive link between the researcher and the participants in the definition of the problem, methods should be adjusted to accommodate cultural complexity, power issues should be explicitly addressed, and issues of discrimination and oppression should be recognized.

**Axiology:** Three basic principles underlie regulatory ethics in research: respect, beneficence, and justice. The transformative axiological assumption pushes these principles on several fronts. Respect is critically examined in terms of the cultural norms of interaction within a community and across communities. Beneficence is defined in terms of the promotion of human rights and an increase in social justice. An explicit connection is made between the process and outcomes of research and furtherance of a social justice agenda. (p.216).
Transformative research incorporates a wide range of approaches (Rolvsjord, 2016) and in this project, understandings from feminism, critical theory, disability studies and ecological systems theory are drawn on. The theories helped to illuminate different aspects of the project and overlap one another through the discussions of disability, power, oppression and social justice.

Feminist theory, and its praxis is concerned with disrupting inequitable power structures and countering dominant theories through an examination of gender (Frisby, Maguire, & Reid, 2009). Growing from feminist activism in the 60’s and 70’s, feminist theory has expanded to include the concept of intersectionality (Davis, 2008; Mehrotra, 2010). Tying feminist theory to constructs of disability, intersectionality attempts to avoid binary understandings of populations. Kathy Davis (2008) describes intersectionality as “the interaction between gender, race, and other categories of difference in individual lives, social practices, institutional arrangements, and cultural ideologies and the outcomes of these interactions in terms of power” (p.68). Anastasia Liasidou (2013) explores the concept of intersectionality and its influence on identity within populations of students with disability with other sources of marginalisation such as race and class. Shildrick and Price (1999) draw Foucauldian theory into feminist understandings of disability where both identities of ‘female’ and ‘disabled’ are measured as the universal ‘other’ (p.99). Critiques of feminist thinking within disability studies have pointed out that patriarchal myths of women as either maternal or sexual beings ignores the fact that disability has been constructed as both non-maternal and non-sexual (Mintz, 2002). These ideas are elucidated within subsequent chapters.
Drawn also into my understanding of notions of power within action research is ecological systems theory. Being a part of the Organisation in a role as researcher, one of my first days at work consisted of an orientation and explanation of the multilevelled hierarchical system that was the Organisation itself. As a music therapist, I had some experience with working in organisations with a clear hierarchical framework and generally understood my position within it, but not how the various levels impacted my position and that of the people I worked with. Once I had begun to explore this framework, I was drawn to thinking about other systemic structures that impacted on young people in the Organisation, from their own families and communities to local and national government policy and cultural societal values. Ecological systems theory developed first by (Bronfenbrenner, 1979) provides a framework for thinking about these multiple layers and how they impact on people’s functioning within them.

In the literature, there have been five examples of participatory action research (PAR) in music therapy. Warner (2005) as referred to above, explored a collaborative music therapy process with a group of men in a residential facility. Guylaine Vaillancourt (2009) an American music therapist used a PAR framework to look at the experiences and relationships of new graduate music therapists to CoMT and social justice. Cochavit Elefant’s (2010) Israeli PAR project examined how members of a choir could have their voices heard. Melody Schwantes (2011) used a participatory framework to look at music therapy and the mental health of Mexican farmworkers and finally Lars Tuastad (2014) in a Norwegian project looked at the affordances of being in a rock band for a group of ex prison inmates. Of these, Cathy Warner’s was the only one to work with people with intellectual disability in a collaborative process.
A participatory framework within action research was appropriate to strive for with this project as it aims to include participants in as much of the research process as possible. The emphasis in participatory action research is on working *with* rather than *on* or *for* participants of research (Reason & Bradbury, 2008). Given the historic marginalisation of young people with disability, and historic oppressive practices in research, participatory research is arguably the most appropriate form of research inquiry (Walmsley, 2001). Participants are considered as equal partners in the process as experts in their own experience. The level of research participant’s desires for challenging and transforming oppressive practices and structures are also central (Nind, 2008). Foucault (1984) emphasised that through conscientization (Freire, 1972), people could come to understand themselves within their cultural and societal context. This recognition may then lead to actions towards liberation. He writes:

To surmount the situation of oppression, people must first critically recognize its causes, so that through transforming action they can create a new situation, one that makes possible the pursuit of a fuller humanity. But the struggle to be more fully human has already begun in the authentic struggle to transform the situation (p. 29).

In considering the methodology within each cycle, issues of power structures and the potentials for maximising participatory aims and opportunities for transformation were foremost in the decision making process as guided by a transformative paradigm (Mertens, 2007). From this epistemological standpoint, I used various methods of gathering, analysing and interpreting data generated from the project. In each cycle, a critical lens is brought to bear in considering the data.
**Overview of project design**

This action research project involves cycles of planning, action and reflection (Lewin, 1946). There have been two overall stages of the project and two corresponding ethics applications. Within each of these two stages, there have been two cycles (1 and 2) and (3 and 4). Cycle 1 did not involve recruiting participants. Figure 1 illustrates the two stages containing two cycles of inquiry.

![Figure 1. Two stages of the project.](image)

Stage 1, involved a critical interpretive synthesis of the literature (chapter 3) and interviews with young people investigating their feelings of social connectedness (chapters 4 and 5). Stage 2 involved focus group discussions with facilitators of all abilities music programs in Victoria (chapters 6 and 7) and the establishment of a weekly music program in the rural city of Geelong (Chapters 8 and 9). Figure 2 depicts these cycles of planning, action and reflection.
Figure 2. Cycles of planning, acting and reflecting.

Figure 3, however illustrates how the cycles would look in terms of their timeline. The overlapping nature of the cycles reflects the somewhat messy nature of action research where things rarely go to plan (Kemmis & McTaggart, 2005). Delays and hold ups with ethics applications, recruiting participants to the research, various holidays and other factors meant that some sections moved forward quickly whilst others lagged behind intended time lines. The advantages of the delays were that there was an increased opportunity for reading and reflecting and this process continued to cultivate deeper understandings in the project.

Figure 3. Cycles in a real time frame.
Presenting the cycles within their timelines also allows an understanding of the periods that knowledge was generated. I found that movement through the cycles of research was not a neat, linear process. For example, as literature was being analysed for the critical interpretive synthesis, interviews with young people were being conducted and so knowledge from each of these processes was being integrated, to some extent within each cycle. Similarly, recruitment for both the music facilitator workshops and community music workshops was being conducted simultaneously and so each was informing the other. My challenges with recruiting young people was a point of discussion for the facilitator workshops and conversely, findings from music facilitator focus groups influenced the need for a community situated music program and helped me to resist persuasive arguments I had for holding music workshops in a organisational service centre. An expanded discussion of this circumstance is presented in chapter 9.

Procedure

This action research project follows a line of inquiry about the role of music in the lives of young people with disability. As an action research project the inquiry is emergent and reflexive in nature. Each cycle begins with a question and plan, is followed by action and then ends with a critical reflection, stimulating a plan formulation and rolling forward to the next cycle. As knowledge was expanded, it was shared with participants who were then invited to build on this learning and to contribute further as they wished. The various cycles were designed to build an overall picture of the situation from different perspectives and viewpoints. These four viewpoints were from 1) the literature, 2) from young people to gather a sense of their feelings about their social connectedness and to gauge if this was a relevant focus for
the investigation, 3) from music facilitators to investigate current opportunities available for young people to access music and finally 4) a collaboratively designed community music program with young people.

Within these cycles, I was the primary researcher and decision maker. Research questions and lines of inquiry were pursued through different means. The collaborative ethos brought to cycles 2, 3 and 4 involving participants ensured that the design of the investigation and knowledge generated was strongly influenced by the participants. As the primary researcher, I sought to embody an open and enquiring attitude to each cycle to allow knowledge to emerge iteratively. As the cycles involved different participants, I shared findings from each cycle to the participants of the subsequent cycles and then invited them to contribute further if they wished. After individuals completed their participation in cycles, I followed up with a sharing of the findings and invited any comments or feedback.

**Thesis structure**

In writing up the cycles in this thesis, I began in chapter 3 with the critical interpretive synthesis of the literature. Subsequent chapters follow an action and reflection format as inspired by the format of the book, ‘Where Music Helps. Community Music Therapy in Action and Reflection’ (Stige, Ansdell, Elefant, & Pavlicevic, 2010). Cycle 1 is presented in one chapter and a critical discussion is woven through the analysis. Cycles 2, 3 and 4 are represented each by two chapters. This enabled a way to synthesise the writing and presentation of each cycle into similar formats.
The reason I have chosen to include the critical interpretive synthesis of the literature as an action cycle is that it plays an integral role in the aims of action research in “investigating reality in order to transform it” (Fals Borda, 1979). As a cycle, it contained a plan to investigate the literature through a critical lens in order to place it within the current context of disability studies discourse within Australia. The investigation into ‘reality’ as conceptualised by Fals Borda is to transform an objective reality: “things in themselves” into “things for us” (p.38). ‘Things for us’ in this context is what the literature reveals in terms of where to focus action in proceeding cycles. In this case it indicated that young people’s voices should be privileged in investigating the notion of social connectedness and in planning music access. Within action research, collaboration is not always emphasised and inquiry could also consist of “a solitary process of systematic self-reflection” (Kemmis & McTaggart, 2005, p. 563). Figure 4 shows each cycle around the initial subject of the investigation.

Figure 4. Cycles of action research.
Each of the action cycles were conducted as separate projects. Subsequent chapters describing each cycle contain greater details of the methods and procedures used. As the overall project is complex, I will include a summary of the procedures used in each cycle here to introduce the overall structure of the project. These will be under the four headings of ‘rationale’, ‘data gathering’, ‘analysis and reflection’ and ‘ending cycles and feedback’. Cycle 1 does not include participants and therefore there is no section for ‘ending cycles and feedback’.

**Cycle 1**

**Rationale.** Reviewing of the literature has continued persistently throughout the project as each new line of inquiry presented itself and reflections prompted searches into different subjects. The decision to begin a critical interpretive synthesis early in the project was to begin refining my knowledge of the specific question and to reflect critically on this. A traditional literature review would give me an overview of the research and practical landscape, but turning a critical lens to the reading enabled me to hone in on particular aspects that I felt warranted further investigation.

**Data gathering.** The first cycle comprised purposive sampling of the literature detailing music programs with young people with intellectual disability with a social aspect mentioned the data. The age range included those attending secondary school and people up to the age of 30. Articles were drawn from a range of disciplines and countries including academic journals, books and newspaper articles.

**Analysis and reflection.** Inductive analysis was used initially to investigate the social connectedness aspects of music participation. Categories revealed themselves organically through being immersed in the data and comprised gathering different
sections from each article that described what I considered to be connectedness. Subsequent waves of analysis were used to follow other lines of inquiry in the data including the use of participant’s voice in the articles. Discussion and reflections are woven through the body of the chapter.

**Cycle 2**

*Rationale.* The process of conducting the critical interpretive synthesis in cycle 1 revealed that there are few examples of participants’ input in setting research agendas (Nierse & Abma, 2011). In this instance, the agenda of social connectedness was raised by the Organisation. In order to understand this fully, I followed both the research and clinical music therapy technique of establishing the agenda. This could be seen as an assessment period, albeit on a much larger scale and at a far greater depth. In music therapy, we are often working with extra-musical goals such as social and relational goals, physical or sensory goals. Once needs are established, a plan is formulated based on knowledge and research evidence of the role that music might play in these needs and then a music program implemented before an evaluation and decision on ‘where to from here’.

This stage of the research project was different to a traditional music therapy assessment in that the participants who I spoke to in this cycle were from different areas of the state and their experiences and ideas were gathered to represent young people more broadly across the Organisation’s services. At this point in the project, I was not sure how I would proceed. I had some ideas about either examining music programs across different areas of the state, or working with existing facilitators, or establishing smaller music programs in a specific area with interested young people.
The opportunity for me to talk to young people, therefore, would help me to understand their social situation and help to inform subsequent stages of the project.

**Data gathering.** This cycle comprised a series of semi-structured interviews with 11 young people who were service users of the Organisation using collaboratively created maps as a way for participants to think about their social situation. The maps were constructed using computer generated mapping software and provided a visual representation of each young person’s social network. Once the maps were constructed in the beginning of the interview, questions were then asked about the network in order for the participants to reflect upon and describe their social situation.

**Analysis and reflection.** Inductive analysis (Thomas, 2006) was used where transcripts were generated verbatim from the recordings and then themes were uncovered gradually after immersing myself in the data and listening and reading over them several times to generate themes. Categories were allowed to emerge from the data rather than being imposed on the data before hand. This could also be described within a constructivist-interpretive paradigm (Denzin & Lincoln, 1994) where my own interpretation of the data is apparent in the analysis. A critical reflection followed on two key themes of oppression and power using theories from feminism (Tremain, 2001; Young, 2011) and Foucault (1982).

**Ending cycle and feedback.** After I finished analysis of the interview data, a video was constructed with the findings and a copy given to the young people who participated in this cycle of the research. (See appendix A). There were five reasons for this step in the inquiry.
1. To acknowledge the time and generosity of participants in contributing to the research and sharing their own knowledge, experience and ideas.

2. To share the experiences and knowledge of other young people and their feelings about their social connectedness.

3. To share my own observations and interpretation of the data.

4. To deepen understanding of research processes.

5. Invite further feedback and responses if participants wished.

Young people who participated in the interviews had different levels of understanding about what research was. Only one man said that he had been part of a research project before. Consistent with a participatory ethos, I was aiming for participants to be as well informed as possible in the short space of time allowed. It was possible that the young people had differing levels of understanding of why they were participating despite the fact that each young person gave consent to participate. One young man said he was doing it to ‘please the boss,’ meaning the manager in the day service with whom he said he had a good relationship and described as ‘a very nice person’. Young people’s experience for this cycle in concrete terms was that they were asked questions and they answered as best, and as willingly as they were able at the time. The aims and purpose of the interviews was difficult for me to explain during the short periods of our meeting given that it was part of a broader investigation into the role of music and I was also asking about people about their social networks.

By receiving the results of my analysis through a video, I hoped to acknowledge the contributions of each of the young people to the project and to describe how it will be used to generate knowledge for interested parties at conferences, in publications.
and for participants in subsequent cycles of the project. The purpose of the video was also to demonstrate what had happened to the information that they had shared with me. How had their contributions been put together with other people’s contributions? How it had been summarised into themes and categories with an interpretation offered? In addition, I included an invitation for a further opinion from the viewer. In this way, I was attempting to encourage some reflection on the subject and experience of the interview process. As an aim of transformation in action research, Freire (1972) suggests that human agency for creating change begins with an emergence from unconscious engagement with the world and then reflection before possible actions for change. Further discussion on this subject is contained in chapter 5.

**Cycle 3**

**Rationale.** Within the Organisation, there are two well-established programs for the creative arts, one for creative writing and one for visual arts. Each program concludes every year with a competitive event – a writing competition and an acquisitive art exhibition. There was no equivalent for music. Once I was more involved in the Organisation, I found that numerous music programs were being run either in the centre or accessed by service users outside the centre.

The decision to hold the facilitator workshops was to learn more about what these various programs entailed from the perspective of the facilitators. What did they consider to be the focus of their programs? What was working and where did the challenges lie and how might this might relate to what young people had told me in the interviews about their feelings of social connectedness? I wanted to ask these questions in light of my research to date. Additionally, the idea to gather together
music facilitators into focus group discussions was to begin forming a more cohesive music culture within the Organisation and beyond.

**Data Gathering.** The third cycle comprised recorded focus group discussions with facilitators of music programs accessible to young people with disability. Two one-day workshops were conducted with facilitators of music groups that included people with disability. The workshops consisted of sharing findings from cycles 1 and 2 of the project and inviting facilitators to reflect on this in reference to their own experience and knowledge of running music programs. In addition, an online questionnaire was sent to participants after 6 months inquiring into the usefulness or otherwise of the workshops and whether participants had ideas for further capacity building in their work.

**Analysis and reflection.** Recorded discussions were transcribed verbatim. An inductive method of analysis was used to begin identifying themes from the focus group data. After an initial wave of extracting broad themes; a hermeneutic framework (Gadamer, 2008) was drawn on to begin thinking about the data. Gadamer’s concept of a ‘fusion of horizons’ as described by Loewy and Palander (2016) presented a way to consider how music facilitator’s differing worldviews and understanding of their music work could be integrated. A critical reflection followed drawing on both creative arts in disability studies (Gladwin, 2014b; Kuppers, 2013) and CoMT work and specifically, work that focuses on pathways between music therapy and community music (McFerran, 2008; O’Grady & McFerran, 2007; Wood, 2016) within the local context of the National Disability Insurance scheme.

**Ending cycle and feedback.** Directly following the one-day workshops, a Facebook page called ‘music action’ was set up as a platform for continued sharing,
support and information for music facilitators and participants of music groups. I invited people to contribute to it to share any developments in their programs and to connect with others doing similar work. At the time of writing of this thesis, a copy of chapters 6 and 7 pertaining to the music facilitators workshops have not been sent to music facilitator participants. This step will be taken along with a summary of findings from the questionnaire received from participants.

**Cycle 4**

*Rationale.* This cycle involved a plan to establish a community music group with young people with disability as co-researchers and co-designers of the music group. Armed with learning from the critical interpretive synthesis and the voices of young people from the interviews, it was time to start making some music. The establishment of a community music group whilst communicating with facilitators of other music programs would allow interactions between the two with the vital input of young people, as co-researchers who would also be informing the work. It was planned that interested participants would gather as an organising committee to make decisions about where the community group would be, what kind of music group it would be, whether we perform or not, when we would meet, who could join and how to evaluate it. Participants recruited for the organising committee would be aged from secondary school to 30 years old with disability. The resultant group may include people without disability, but the plan included provision for the organising committee to make this decision. “Power imbalances are handled by a methodology in which those who are least heard are given the most attention” (Nierse & Abma, 2011, p. 413).
Data gathering. Data for the forth cycle comprised ethnographic field notes (Emerson, Fretz, & Shaw, 2001; Geertz, 1994) and video footage of the collaboratively designed community music program with a group of young people. This cycle of the project was designed with participatory aims of engaging the young people as co-researchers. The participatory elements of the program however are preserved in aspects other than co-researching, such as program designs and ongoing consultation within the workshops.

Analysis and reflection. Data from this cycle is considered using ecological systems theory (Bronfenbrenner & Morris, 2006) and is then summarised in the form of a semi-fictional case story. A critical reflection of the data follows through a lens of critical disability studies (Campbell, 2008; Goodley, 2013) and community music therapy (Stige et al., 2010).

Ending cycle and feedback. At the end of cycle 4, another video was made for participants of the music program in Geelong, which included an invitation to continue contributing ideas into the ongoing program. A copy of this video is not included in the appendices as it contains video footage of sessions and other identifying information of the participants. Participant consent forms for this cycle included permission to use video footage as a memory aid for discussions about the music program to be shared among research participants only. The format of the video is similar to the one included in the appendices from cycle 2 with the inclusion of video footage from workshops and performances. The purposes of this step were also similar to cycle 2:

1. To acknowledge the time and generosity of participants in contributing to the research and sharing their own knowledge, experience and ideas.
2. To share the experiences of other young people and their contributions to the research in a collated form.

3. To share my own observations and interpretation of the data.

4. To deepen understanding of research processes.

5. Invite further feedback and responses if participants wished.

**Reflexive journaling**

Throughout the project, I continued to record my thinking and reflections in a journal. The purpose of journaling within an action research inquiry is for researchers to “begin to identify gaps between what they know, what they think they know and what they find that they don’t know” (Coghlan & Shani, 2008, p. 648). These authors argue that the process of journaling brings reflections into the open so that privately held ideas, thoughts, assumptions and knowledge may be recognised as constructed. Within feminist and critical theory, reflexivity is viewed as a necessary part of the process (Jaggar, 1989). Extracts from this journal are transparently included in the chapters.
CHAPTER 3

Critical Interpretive Synthesis

This chapter presents a critical interpretive synthesis of literature that investigates the relationship between social connectedness and music with young people with disability. It examines how the research to date has informed the pathways of this relationship. As the beginnings of this project began with a focus on social connectedness; identified by the Organisation as a particular challenge for their young people, I wanted to investigate the literature to date with a critical eye to identify possible gaps in research and also to discover the level of congruence between published literature in music programs and current rights-based disability studies discourse. The relationship between music and social connectedness for young people with an intellectual disability has been addressed in the music therapy literature, but many articles and chapters are based on theoretical frameworks that pre-date more critical discourse about Disability Studies and CoMT. The recent publication of a special edition on Music Therapy and Disability Studies in the Voices journal signalled that it was timely for the literature to be reconsidered with a more critical eye to identify what assumptions have driven research in music therapy and related fields.

A shorter version of this critical interpretive synthesis of the literature was published in a peer-reviewed journal (Murphy & McFerran, 2016). The limited word count of the publication meant that large sections of the discussion were omitted. For
ease of reading for this chapter, I will include the published article as a PDF in appendix B and have written the review here in full.

The literature covered in this synthesis is limited to papers found through data base searches. It is probable that hundreds, if not more, music groups, encounters and meetings occur everyday that have not been published. If we were to have access to information about those, then the picture we could describe may be a very different one. Furthermore, the data is confined to English language literature. Understanding of different concepts, such as ‘inclusion’ and ‘community’ may differ depending on different cultural understandings. Lastly, as the name suggests, this synthesis is interpreted through my own lens, which is coloured by my life experience and beliefs.

My theoretical and practical knowledge of the concepts investigated in this review has been developed from early readings and experience as a practitioner. These concepts include music therapy, CoMT and community music, social connectedness and related terms as well as the transitioning period for young people with disability and disability studies. I will begin with a summary of my understanding of these concepts from the literature as well as a description of the current Australian context.

The evolving rights-based principles in disability studies along with policy changes in Australia following the ratification of the Convention on the Rights of Persons with Disability in 2008 (United Nations, 2006), culminated in the beginning of the rollout of the National Disability Insurance Scheme (NDIS) in 2013. The NDIS shifts the funding model from a welfare model to an insurance model. This significant reform in disability support in Australia has been broadly welcomed and supported both by government and the general population. One informative report for the
change, Shut Out (Deane, 2009), sought to highlight issues present in the disability sector in Australia by consulting people with disability, their carers, families and service organisations. What emerged from this report was a profound dissatisfaction from people with disability with the lack of choice and control in the provision of services and that it was characterised by a “one-size-fits-all approach” (p.4). One outcome for this situation is a lack of social inclusion in Australian society where people are no longer ‘shut in’ institutions but now find themselves ‘shut out’.

Emerging data generated by the scheme has shown that ‘social participation’ is the most frequently documented category of goal in person-centred plans overall. (National Disability Insurance Agency, 2015).

A review of the literature on independence and opportunity for young people with intellectual disability in Australia found that ‘having the capacity for choice and control is strongly associated with having strong social connections’ (Stokes et al., 2013, p. 5). For example, when people have the choice and control to pursue personal interests and aspirations, they have the opportunity to connect with others through a common interest, such as in the arts, sport or further education. Evidence from the Shut Out report (Deane, 2009) and the review of independence and opportunity (Stokes et al., 2013) reveals that young people with disability in particular have very little choice and control in their lives and low levels of social connectedness.

Social Connectedness is a term used to describe the phenomena of relatedness and a sense of belonging to others. Lee and Robbins (2000), describe social connectedness as “an enduring and ubiquitous experience of the self in relation with the world, as compared with social support, adult attachment, and peer affiliations, which represent more discrete, current relationships” (p. 484). Hagerty, Lynch-Sauer,
Patusky, and Bouwsema (1993), add that the experience of social connectedness “promotes a sense of comfort, well-being and anxiety reduction” (p.293). Karcher Holcomb and Zambrano, (2006) define social connectedness as “positive relationships and experiences with others, and more specifically, relationships and experiences from which youth garner esteem and competence” (p9).

For the purposes of this chapter, the term ‘social connectedness’ will be used to describe the sense of connectedness experienced by people and the term ‘social networks’ will be used to describe the actual networks surrounding people. A sense of social connectedness is built on experiences of accumulated relationships from early attachments through to relationships in childhood and adolescence. It is experienced in a fairly stable way, although not rigid, as it may still be influenced by significant experiences of changed relationships through life (Williams & Galliher, 2006). Problems are thought to arise in social connectedness when there is a difference between the level of social connection desired and the level of connection experienced (Cacioppo, J., Patrick, W. 2008).

It has been argued that nurturing and reliable interpersonal relationships are one of the most important factors in supporting quality of life for people (McVilly et al., 2006). Young people with an intellectual disability may experience challenges in building their social networks upon leaving school, when the routine and structure of school and contact with peers may come to an end. Barriers to developing and growing a social network beyond school may be physical, such as the ability for independent travel and provision of appropriate access, a lack of autonomy as well as societal attitudes caused by a lack of understanding for different methods of
communication and an understanding of the abilities of the young person (Deane, 2009; Foley et al., 2012; Stokes et al., 2013; Winn, Hay, Parmenter, & Riches, 2013).

A University of Melbourne report reviewed the literature on independence and opportunity for young people with a disability (Stokes et al., 2013) and found little overall difference in the hopes and desires of young people with or without a disability to exercise choice and control in the management of their lives. This is particularly important since having choice and control over one’s own life is strongly associated with having strong social connections. Their review revealed that young people with disability are more likely to experience limitations of choice and control in their lives compared to those without disability and as a result, limitations in opportunities for building their social networks.

De’Ath and Wall’s (2004) study of young people with disability in Ireland found that during the transition to adulthood, friendships and peer relationships provide significant support in the task of adjusting to new environments. They theorize that relationships function as a mirror, helping adolescents to gauge how others see them and assist in developing self-identity. This process also helps to establish norms of behaviour and provide a sounding board for exploring values and aspirations. This was nicely illustrated in a recent documentary, The Dreamhouse, airing on the Australian Broadcasting Commission (Cullen, James, & Carter, 2014). The filmmakers documented the first ten weeks of the experience of three young people with an intellectual disability moving out of home and living together a share house in the suburbs of Perth, Australia. In one episode, a young man was shown acting as a mediator in an argument between the other two housemates. This young man’s mother expressed surprise and delight at this newly revealed skill. The
opportunity for independent living and the ensuing friendships provided a motivating context for this young man to exercise skills in negotiating a complex social interaction. He displayed empathy through careful listening to the perspectives of each of his housemates in turn and was then able to assist in resolving the disagreement and in the process, to “flourish in the most unexpected way” (Episode 3).

A study in Scotland (MacIntyre, 2014), also examined the transitioning period following 20 young people with disability over six and nine months post school. Interviews were conducted with the young people as well as significant others including carers, employers, lecturers and other professionals involved with the young people. One of the most powerful themes, MacIntyre interpreted from the study was the desire of the young people to be socially included, “to fit in and be like everyone else and perhaps more importantly to develop friendships and social networks” (p. 867). She concluded that the existing opportunities made available to young people through work and further education in Scotland have not necessarily strengthened their social networks and there was little evidence of their potential to promote social inclusion. She concluded that supporting young people to develop their relationships and social networks could be more powerfully utilised to position young people to embrace the opportunities that social inclusion can bring (MacIntyre, 2014).

Strong links connect participation in music and social interaction and it is theorised that the evolutionary function of music may have been for the purpose of creating bonds between groups of people (Cross & Morley, 2012; Freeman, 2000; Huron, 2001). Hargreaves and North (1999) posit that many of the psychological functions of music are social and these manifest in three ways: interpersonal
relationships, including the use of aligning to particular genres of music in adolescence to define social groups; mood regulation, including the use of music to optimize positive feelings; and self-identity, including the use of music preference for defining identity in young adulthood (Hargreaves & North, 1999).

Music therapists traditionally utilise the inherent communicative qualities of music to reach people who have not responded to other therapeutic interventions. In Trevarthen and Malloch’s (2009) theory of communicative musicality shows that musicality develops in the earliest mother/child interactions, is innate and fundamental to connectedness and is unrelated to cognitive ability. The early 2000’s saw a shift in the music therapy profession to a critique of the focus on the therapeutic relationship in exclusion to other aspects of the person’s life in a treatment/medical framework. Value is still placed on the therapy relationship but it became broadened to consider the cultural, socio, and ecological aspects of the person in what was to become known as Community Music Therapy (CoMT) (Stige, 2002, Pavlicevic and Ansdell, 2004). Music therapists, Pavlicevic and Ansdell (2009) then developed a theory towards an explanation of music’s function in a broader group and communal context called ‘collaborative musicing.’ The model they propose has three layers beginning with musicality as the core human capacity, developing to musicianship as a cultivated facility within the sociocultural context, to potentially expanding to collaborative musicing and performance.

Nestled alongside CoMT is the field of community music (Ansdell, 2002). Community music covers a diverse range of music making endeavours from around the world. Definitions are varied but authors tend to agree that it is a group activity where people join together to make music which “reflects and enriches the cultural
life of its participants and their broader community” (Bartleet, Dunbar-Hall, Letts, & Schippers, 2009). Community music may be characterised by “decentralization, accessibility, equal opportunity, and active participation in music-making. These principles are social and political and with numerous examples showing that community music activity is more than a purely musical” (Olseng, 1990, p. 59).

**Design**

A critical interpretive synthesis was selected as the method to examine the literature in this paper. This method varies from a traditional literature review or synthesis in that it does not begin with a fixed method, procedure or hypothesis, rather the process is ‘iterative, interactive, dynamic and recursive’ (Annandale, Harvey, Cavers, & Dixon-Woods, 2007). Such a process allows the early analysis to inform the focus of the synthesis. Rather than synthesising the literature to find common effects or outcomes, it involves a secondary analysis which examines the interpreted and constructed nature of the research by authors (McFerran, Hense, Medcalf, Murphy, & Fairchild, 2016). This in turn leads the reviewers to reflexively examine their own construction of the analysis (Dixon-Woods et al., 2006). The process includes a thorough search of the literature and may include both qualitative and quantitative studies. Importantly, it involves a critique, which may question any taken-for-granted assumptions or biases within the literature (Dixon-Woods et al., 2006).

As well as the study by Dixon Wood and colleagues, a number of other music therapy researchers including myself have used this method of investigating the literature. Together we published an article focusing on how our emotional responses have been integrated into the construction of the critical interpretive synthesis, further
emphasising the subjective and interpretive nature of this method of literature inquiry (McFerran et al., 2016).

**Method**

Search terms employed included music, social connectedness, as well as related terms: interpersonal connection, psychosocial, health, belonging and friendship and well-being; young people including teenager, young person, youth, adolescent, student and intellectual disability, including disabled, mental retardation, developmental delay, learning disability, developmental disability (McFerran, Garrido, & Saarikallio, 2013).

**Table 1.** Search terms.

<table>
<thead>
<tr>
<th>Primary Terms</th>
<th>Related Terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Music</td>
<td>Interpersonal connection, psychosocial, health, belonging, friendship, well-being.</td>
</tr>
<tr>
<td>Social Connectedness</td>
<td>Teenager, young person, youth, adolescent, student</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>Disabled, mental retardation, learning disability, developmental disability.</td>
</tr>
</tbody>
</table>

Searches were conducted through the data bases RILM, ERIC, PsycInfo, CINAHL, SocIndex, Proquest Central and Medline (Web of Knowledge) which yielded an initial 1,077 articles. The titles of these articles were then scanned for
relevancy and a secondary search was conducted using the reference lists in the most relevant articles.

**Inclusion selection**

A purposive sampling technique (Charmaz, 2006) was used with the remaining data which involved selecting articles designed to yield the most comprehensive understanding of the subject. This included articles from a range of disciplines and countries as well as newspaper articles, academic journals and books. Articles were targeted that included a social aspect to the music participation and young people who had cognitive impairment. The quality of the research in studies was assessed as part of the critical analysis. Articles were not excluded based on the quality of the research but rather included for their relevance to the subject. There was no limit on the years searched. The oldest study discovered was published in 1991. Four philosophic articles were included in the first review (Gooding, 2009; Gregory, 2010; Lubet, 2009; Stige, 2010a) and then excluded during the analysis in order to focus on research studies, including case studies. The age criteria for participants were secondary school students up to 30 years old with an intellectual disability, autism spectrum disorder or learning disability. The music element included all forms of music participation from listening through to playing and performing with instruments and/or singing.

The final selection of articles numbered 27. These articles were entered into an Excel spread sheet. Data extraction began under the following headings: title, author, year of publication, discipline, type of disability, music elements utilised, type of connections, age of participants, voice in the article, primary focus, social aims, social outcomes, study method and length of music intervention.
The age criteria used for studies were that participants were in secondary school or older and the studies included people aged 30 or under. Young people were targeted for this paper as part of the broader investigation into the use of music for social connectedness during the transition period between school and adult life for young people with disability. For the purposes of this article, the term young people or young person will be used to describe people in adolescence through to 30 years old.

Although my descriptions of disability in this thesis resist categorisation in acknowledging the fluid and contextual nature of the term, I will include here brief definitions used in Australia and elsewhere that may have informed authors’ understandings of disability in the reviewed papers and help to conceptualise my meaning making at the time of writing. In Australia, intellectual disability is defined as being a disability character by significant limitations in intellectual ability with an IQ of 70 or below, and difficulty with daily living skills such as self-care, communicating and taking part in everyday activities. The disability must originate from before the age of 18 years. A severe or profound intellectual disability is defined as an IQ below 35, a moderate disability is an IQ between 35 and 50, and a mild intellectual disability is an IQ between 50 and 70 (Tracy, n.d.). Learning disability is a term used in the U.K. to describe intellectual disability and developmental disability is often used in the U.S.A. (McFerran et al., 2013). Three articles were included with adolescents assessed as having poor interpersonal skills along with attention deficit hyperactivity disorder and post-traumatic stress disorder, resulting in a learning disability. In Australia, learning disability refers to a life-long difficulty with learning caused by external factors such as childhood trauma or internal factors such as illness (Learning Difficulties Australia, 2015).
The music element included in the selection criteria for articles included all forms of music participation from receptive to active. Receptive participation could be listening to music for the purpose of mood regulation or to reflect the emotions of participants or else listening to recorded music for sharing music preferences. Active participation may include playing instruments together, either improvised with percussion instruments or structured band or other ensemble playing, singing, song writing and music composition as well as performance.

**Findings and discussion**


![Figure 5. Year of publication for articles.](image)

Looking historically at the emergence of this data, it is notable that no studies were found before 1991. Music therapists were publishing on work with people with disabilities in institutions and elsewhere, but were not reporting on the social aspects of their work. It may have been the disbanding of the social structures of institutional
living that saw a need for exploring what was happening for people living in different situations. In Australia, a shift to deinstitutionalization for people with disability began in the 1980’s and continues today with debates surrounding the closure of several small institutions (National Disability Services, 2014). By the early 1990’s changes were being implemented following the Commonwealth Disability Services Act in 1986 to ensure better practice and accountability in the new housing arrangements. In 1991, further reform saw the National Disability Agreement, which shifted responsibility for services to the states and territories. This marked the beginning of a nationally integrated approach to service provision for people with disability. Similar shifts were occurring at this time in the U.S.A. and the U.K. (Braddock, Emerson, Felce, & Stancliffe, 2001). It is at this point that studies focussing on the social aspect of people’s lives began to emerge in this data.

The data demonstrates the majority of reporting on this subject has emerged in the past 10 years and this period coincides with reconsideration about the level of inclusion in society for people who had moved from institutions. Deinstitutionalization heralded a physical move into the community on a wave of calls for justice and the return to basic freedoms and choice, but often resulted in a secondary segregation within the community (Goggin & Newell, 2005). The last decade has seen a shift toward enabling more meaningful inclusion, which could be measured by the strength of people’s social networks and sense of belonging as much as their individual rights (Reinders, 2002).

Music therapy practice has similarly seen a shift in the 21st century. Before this the practice was predominantly aligned with what Ansdell (2002), described as the ‘consensus model’ where the therapist worked in a controlled environment to
change behaviours, address pathologies or gain insight through psychodynamic work. The shift since the early 2000’s has been to adopt a more culture-centred, (Stige, 2002), resource orientated (Rolvsjord, 2010) and social justice (Curtis, 2012) position, working ‘with’ people rather than ‘for’ them and valuing and supporting what is important to the person rather than taking an expert stance. This shift is apparent in the data with the emergence of community-based work, as well as a limited discussion on the generalizing of benefits gained in group or individual sessions being utilised in the wider community.

The majority of articles were found in music therapy publications: six in music therapy journals, four in music therapy book chapters, two online music therapy articles, three music therapy theses and one publication from the Salvation Army in Melbourne, (McFerran, 2008).

![Figure 6. Source of publications.](image)

Music therapists dominate the research identified on this topic. Most of the
work reported is music therapy based followed by music education, then community music. 74% of authors are female, 11% male and 15% mixed, where there are several authors. Seven studies originated in the United States of America and seven in the United Kingdom, six in Australia, two each in New Zealand and Greece and one each in Norway, Israel and Canada. Figure 7 shows the proportions of articles by their discipline type.

![Figure 7. Type of music program.](image)

Articles were classified as music education if the program was designed and facilitated by music teachers or music educators. The one study classified as music technology, (Adkins et al., 2012), was authored by two sociologists, a disability researcher, computational artist and musicologist and examined the relationship between inclusion and technology for people with an intellectual disability.

*Types of connection addressed by the music program*

Initial inductive analysis of the data revealed that the types of connections
being investigated could be divided into four categories. These categories revealed themselves organically through being immersed in the data and comprised gathering sections from each article that described what I considered to be connectedness. In this way, I was able to examine the frequency and type of connections being fostered by facilitators through music programs, and to uncover elements of the connections that were explored through the research.

Also illustrated in figure 8, these categories are:

1. People within an existing group where connections are built between group members in a service or school.
2. Individual therapy where the connection is built between the person and the music facilitator (One-on-one).
3. People within the disability community through community-based workshops.
4. People within the wider community through workshops or through performance/s.

Figure 8. Types of connections.
Having categorised the data in this way, I made separate Excel spreadsheets for each category in order to extract more detail. I used the following three questions to begin analysis within each category:

1. What research methods are used?
2. What are the reported outcomes of the research?
3. What music methods are employed?

**Connections within an existing group**

Twelve articles, or 44%, examine relationships within a group and these were spaced evenly across the years 1998 and 2014. Six groups were made up of people described as having severe intellectual disability, two groups with people with mild to moderate intellectual disabilities, three groups with learning disabilities with additional post traumatic stress disorder, aggressive behaviours, or Autism Spectrum Disorder and one group was with young people with autism spectrum disorder.

Of the 12 studies, four were qualitative and six were quantitative and two were case studies. Of the quantitative studies three reported positive social outcomes and three had mixed results. All 12 of these studies used active music making as the music methods. Of the quantitative studies, the music methods used were gamelon playing over 10 weeks, (MacDonald, O'Donnell, & Davies, 1999) and the remaining five studies used structured music activities such as instrument playing, singing and performance with some improvisation activities, (Gooding, 2011; Hillier, Greher, Poto, & Dougherty, 2011; Hooper, 2001; Rickson, 2003). Only one of the studies cited using music listening as an element of the program. This study was a music education intervention. (Hillier et al., 2011). Quantitative studies had an average
program period of 6.8 sessions as shown in table 2.

**Table 2. Qualitative studies.**

<table>
<thead>
<tr>
<th>Date/Duration of program</th>
<th>Country</th>
<th>Music method</th>
<th>Aim or purpose</th>
<th>Reported Outcome</th>
<th>Measured by:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>U.K.</td>
<td>Gamelan playing</td>
<td>Music ability and communication</td>
<td>Significant improvements in music ability and communication</td>
<td>Pre and post-tests of music attainment and communication assessments.</td>
</tr>
<tr>
<td>10 weeks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2001</td>
<td>U.S.A.</td>
<td>Singing, instrument playing, listening familiar songs</td>
<td>Peer interaction</td>
<td>Increased level of positive interaction and a low level of negative interaction.</td>
<td>Two trained raters using a checklist viewing video footage of sessions.</td>
</tr>
<tr>
<td>5 sessions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2003</td>
<td>New Zealand</td>
<td>Listening, song writing, percussion playing.</td>
<td>Pro-social behaviour</td>
<td>Study suggests the program might help to increase an awareness of the existence and feelings of others and assist with the development of positive relationships with peers.</td>
<td>Parent and teacher checklists for developmental behaviour, checklist of positive and negative ‘events’ on video segments.</td>
</tr>
<tr>
<td>16 sessions, twice a week over one term.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2011</td>
<td>U.S.A.</td>
<td>Singing, playing, composing and improvising</td>
<td>Attitudes towards and relationships with peers</td>
<td>Significant increase in self-esteem, reduced self-reported anxiety, and more positive attitudes toward peers.</td>
<td>Self-report questionnaires.</td>
</tr>
<tr>
<td>8 weeks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Parent questionnaires.</td>
</tr>
<tr>
<td>2011</td>
<td>U.S.A.</td>
<td>Movement, drumming, instrument playing, improvisation, singing, music poetry</td>
<td>Social skills: eye contact, active listening, personal space, appropriate facial expressions, appropriate</td>
<td>Teacher ratings results approached significance. Researcher rating results were significant. Self-report ratings were significant, with self-ratings increasing by</td>
<td>Teacher and researcher ratings and participant self-rating.</td>
</tr>
<tr>
<td>5 weeks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date/Duration of program</td>
<td>Country</td>
<td>Music method</td>
<td>Aim or purpose</td>
<td>Reported Outcome</td>
<td>Evaluation method</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------</td>
<td>--------------</td>
<td>----------------</td>
<td>------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>1998</td>
<td>Greece</td>
<td>Vocal and instrumental improvisation.</td>
<td>The results of long term group music therapy</td>
<td>Evolution of life attachment bonds between participants and carers</td>
<td>Case notes of the music therapist author.</td>
</tr>
<tr>
<td>2006</td>
<td>U.S.A.</td>
<td>Participation in a high school band</td>
<td>Case study examining integration of students with disabilities</td>
<td>Students could learn about music while having social interactions with the general population.</td>
<td>Observations of an independent music educator.</td>
</tr>
<tr>
<td>2007</td>
<td>U.K.</td>
<td>Percussion improvisation</td>
<td>Changing patterns of relating</td>
<td>Increase in connectedness within the group.</td>
<td>Interviews with participants and key workers</td>
</tr>
</tbody>
</table>

Each of the qualitative studies used a less structured approach to the use of music methods. The two case studies were a music education project and a music technology project. Length of time for the programs varied from three weeks to three years. Of the ten studies that specified the length of time of the group music program, the average was 28 weeks as shown in table 3.

Table 3. Qualitative studies.
The next layer of analysis focused on the social and inter-relational references in the data in order to further develop my understanding of the connections being fostered. Questions such as: Was this focus explicit in the aims of the study, or was it cited in the discussion section of the paper? Was it measured or evaluated specifically, or reported anecdotally? Were studies focused on social skill attainment or more generally on relationships within the group? Of the 12 studies looking at connections within a group, six explicitly stated the aim or purpose of the study as focusing on relationships within the group.

- Peer interactions (Hooper, 2001).
- Pro social behaviour (Rickson, 2003).
- Changing pattern of relating (Fillingham, 2007).
- Attitude towards and relationships with peers (Hillier et.al. 2011).
- Peer relations and self-management (Gooding, 2011).

The remaining six studies focused on:
• Effect of long term therapy (Agrotou, 1998).
• Inclusion (Lapka, 2006).
• Musical attainment, communication skills, self-perception of skills (Macdonald, et al., 1999)
• Changing patterns of behaviour (Warner, 2007).
• Choice and agency (Adkins et al., 2013).
• Value of long term group music therapy (Pavlicevic, et al., 2014).

The four pre-2006 studies focused on social skill attainment in the U.S., U.K., and New Zealand, with the exception of the one long-term psychodynamic study from Greece (Agrotou, 1998). In studies post 2006, three focused on social skill attainment within the therapy group from the U.S. and the remaining five focused on relationships within the group from a social inclusion (Adkins et al., 2012; Fillingham, 2007; Lapka, 2006; Pavlicevic, O'Neil, Powell, Jones, & Sampathianaki, 2014) and participatory action research framework (Warner, 2007). It is only in the U.S.A., that social skills have continued to be measured with this population of young people after 2006.

**Social skills**

The validity of social skills acquisition is now questioned from both a practical sense and from a social model framework (Crow, 1992). Robertson, Richardson and Youngson (1984) reviewed the literature on social skills training for people with disabilities and found there was a lack of evidence for programs and their relationship to successful independent living. By focussing on the measurement of
social skills at the level of appropriate personal space, tone of voice, facial expression, researchers are effectively making assumptions around a particular set of ‘ruling norms’ (Hadley, 2014; Young, 1999). These norms may appear acceptable and universal but they are based on assumptions of normative behaviour and imposing them can result in privileging some people over others and those ‘others’ may then become further disadvantaged (Hadley, 2014). Warner (2005) stated in her participatory action research that ‘I am not so interested in determining whether music therapy helps participants move to a different developmental level, but rather what sense they make of it, and how other participants also learn from this’ (p.80).

Each of these studies focused on factors occurring within the group with the exception of the study by Pavlicevic, which explores the value of long-term music therapy group work (Pavlicevic et.al. 2014). This study took a more collaborative approach in line with a social model of disability which draws away from the person’s impairment to the systems and mechanisms surrounding the person that are disabling (Crow, 1992). This study analysed data from two focus group discussions and the results of the study suggested that:

“rather than leading to developmental change, long term, shared musicking provides young adults with ongoing opportunities for experiencing confidence and self-esteem with feelings of shared acceptance and success, and also provides young adults and their families with opportunities for developing and sustaining friendships.” (P.5) and ‘real-life’ experiences of ‘getting to know others’ and to find relief from relentlessly disabling environments (16).

Interestingly, the authors stated that they had originally intended to include the participants in focus group discussions in this study, but were discouraged by some
parents who were concerned that the young people may disrupt the focus groups. The ‘absent voices’ were represented by the parents in one focus group and by professionals associated with the young people in another focus group, exploring the value of long-term music therapy for young adults with described as having severe intellectual disability. This led me to a questioning of ‘voice’ and whose voice is privileged in the studies. My curiosity was piqued when reading this study and it resulted in an additional exploration of the data, focussing specifically on the use of voice. This is in a separate section following.

Beyond the therapy room

Of the 12 studies looking at relationships in a group, three reported outcomes of social interactions outside the music group which were attributed to the influence of the music program. One aspect of CoMT draws on ecological systems theory (Bronfenbrenner, 1969) as cited in (Pavlicevic & Ansdell, 2004) where it posits that “if therapy leads to change, there may be a ripple effect in that the environment reacts, both positively and negatively – to the changes in the individual” (p.280). Each of these outcomes was reported in the discussion section of each article. One study was a case study of a school band that included students with a disability (Lapka, 2006). Discussions with parents revealed additional benefits of relationship building in the band. One parent said:

“I can’t tell you how many times we have been downtown and a band member has come over to talk to my son, or just passes by and says “hey (name of son) how’s it going? These are kids who would never had said that before, if they hadn’t been in the band together.”
A student without a disability said that “when you are forced to spend time with someone, you learn to understand the person” (Lapka, 2006, p. 58).

One study reported increased interaction and cooperation between group members in an occupational therapy session following the music group, (Hooper, 2001) and one reported that young people met up outside the therapy program (Hillier, et.al, 2011). By including these anecdotes, the authors of these papers demonstrated an acknowledgment of social benefits that extended beyond the therapy group, where as in contemporary CoMT practice, this ‘multi-system approach’ is ‘active’ and ‘consciously directed’ (Stige et al., 2010, p. 280). Within this framework, partnerships and networks are actively fostered and the level of this action is dependent on the resources and needs of participants in each context. A fostering of wider networks for young people through music programs will be of benefit for those with a desire for greater social participation, for example the fostering ‘social–musical pathways’ (Pavlicevic et al., 2014) to community groups such as choirs or other music ensembles.

**Connection between young person and therapist**

Six studies describe the connection between the young person and the therapist. A similar process of analysis was undertaken to examine this category. All six studies were music therapy programs. All adopted a primarily psychodynamic or humanistic framework for the therapy and one American study utilised the addition of cognitive behavioural techniques, such as ‘praising the desired behaviour’ and ‘ignoring negative behaviour’ (Clarkson, 1991). The remaining five studies were from Greece, (Agrotou, 1994), Australia (Lee, 2014; McFerran & Shoemark, 2013) and the U.K. (Graham, 2004; P.G. & Coleman, 1994).
Four studies examined therapy programs with people described as having multiple and profound disabilities and no verbal language. One was with a person with moderate disability and limited speech and one with a person who was described as having severe autism and very limited verbal language. Five studies specified the length of time of the therapeutic relationship and of these, the average length of time was two years. The shortest time was 30 sessions and the longest programs occurred in the five therapy relationships examined in Lee’s (2014) study where the average length was four years, as shown in Table 3. This is in contrast to the group sessions, where programs ranged from three sessions to three years of weekly sessions and quantitative group studies averaged 8 sessions.

Table 4. Studies of one-on-one sessions.

<table>
<thead>
<tr>
<th>Date/Duration of program</th>
<th>Research Method</th>
<th>Aim/Question</th>
<th>Reported Social Outcome</th>
<th>Evaluated by</th>
</tr>
</thead>
<tbody>
<tr>
<td>1991</td>
<td>Case study</td>
<td>Increase direct eye contact, increase signing to indicate choice, increase tolerance of physical contact</td>
<td>Eye contact is steady. Physical contact is tolerated through dancing. Signing for communication is increased.</td>
<td>Music Therapy Clinician</td>
</tr>
<tr>
<td>2 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1994</td>
<td>Quantitative</td>
<td>To examine how changes in the levels of engagement and avoidance within music therapy shed light on the therapeutic process.</td>
<td>A deepening rapport over time and a containment of capacity for the therapeutic relationship.</td>
<td>Music Therapist researchers</td>
</tr>
<tr>
<td>30 sessions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1994</td>
<td>Case study</td>
<td>In the beginning: Connect with breathing (the young man’s sole output) The paper describes the process of the therapy as a two-way phenomena</td>
<td>Clear musical communication is continuously increasing, asserting a misdiagnosis of deafness.</td>
<td>Music Therapy Clinician, independent observers of video footage</td>
</tr>
<tr>
<td>Year</td>
<td>Study Type</td>
<td>Research Question</td>
<td>Findings</td>
<td>Author(s)</td>
</tr>
<tr>
<td>---------</td>
<td>------------</td>
<td>----------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>2004</td>
<td>Case study</td>
<td>To describe music therapy with a pre-verbal client where vocalization is used to establish an interactive relationship.</td>
<td>Vocalization can play an important part in establishing and developing a therapeutic relationship in which clients’ communication skills can grow.</td>
<td>Music Therapy clinician</td>
</tr>
<tr>
<td>2013</td>
<td>Qualitative</td>
<td>How does music stimulate the development of the relationship between a child with a profound disability and a music therapist?</td>
<td>Spontaneous initiation is sought from the young person and the relationship is built over time.</td>
<td>Music Therapist researchers, independent observers of video footage.</td>
</tr>
<tr>
<td>2014</td>
<td>Qualitative</td>
<td>What is the experience of the interpersonal relationships between 5 music therapists and their adult clients with profound and multiple disability?</td>
<td>The process requires mutual effort over time and the relationship fosters psychosocial wellbeing for the client.</td>
<td>Music Therapist researcher</td>
</tr>
</tbody>
</table>

Each of these studies explicitly aims to describe or measure the interpersonal relationship between the therapist and person with disability. Two studies were authored by a music therapist outside the therapy program and aimed to describe the process of the therapy and relationship between the person with disability and the therapist (Lee, 2014; McFerran & Shoemark, 2013). Three studies were case studies authored by the practicing music therapist where the aims were to build a therapeutic relationship. Two of these aimed to build an interpersonal relationship (Agrotou, 1994; Graham, 2004) and one study stated the aim as increasing social skills. In the outcome of this study after several years, the author describes an aspect of their interpersonal relationship that had evolved over time,
At the end of his sessions, Jerry now regularly signs ‘Goodbye Ginger’. One day an observer took Polaroid pictures while Jerry and I were dancing together and playing the ‘Goodbye Song’. When he was shown the photos, Jerry pointed to himself and to me and smiled. In response to my signing “We are friends,” he signed “yes” (Clarkson, 1991, p. 383).

The remaining study aimed to measure engagement and conversely, avoidance behaviour through independent observers of video footage of a music therapy session (P.G. & Coleman, 1994).

**The nature of relationships in one-on-one therapy**

Clarkson’s (1991) use of the word ‘friend’ in the conclusion to her case study of individual sessions raises the question of the nature of the relationship between the young person and therapist after a long therapeutic program. In describing the consensus model of music therapy, Ansdell (2002) wrote, “a separation of client/therapist roles is maintained by clear personal boundaries – assuring the engagement remains professional and avoiding social relationships.” In Juyoung Lee’s study of the relationship between the young person and the therapist, Lee reported a significant theme as “music therapists experience emotional bonds and attachments with the clients” (Lee, 2014, p. 79). Each of these studies examined programs that lasted more than two years. In Claire Fillingham’s music therapy study of “Friendship and Group Work (2007), several of the young people interviewed nominated staff members from their residential homes when asked ‘who are your friends?’
Relationships between client and therapist are a complex subject that provoked lively debate at a recent disability conference in Melbourne. Among the presenters was speech pathologist, Sheridan Forster describing her Hanging Out Program (HOPS) (Forster, 2014). HOPS aims to embed the practise of regular, interactions between support workers and people with profound and multiple disabilities by giving 100% of attention for at least 10 minutes each day. She states that it is very important not to de-value the relationships people have with their support workers and added that complexity arises when policy and training of staff for work in group homes in Australia may limit the building of emotional relationships with their clients Sometimes these may be the only close relationships that residents have. Another conference delegate stated emphatically that if you are being paid, then you are not a friend.

Music therapists place an emphasis on the relationships as the basis for therapeutic growth (McFerran & Elefant, 2012) in contrast to the often more consultative roles in other allied health professions such as speech pathology and occupational therapy. In contrast, Ansdell (2002) proposed that in CoMT the relationship with clients is “individually and pragmatically negotiated, are in the first place ‘moral’ rather than professional, and are as equal as possible under the circumstances” (p.131).

The quality of relationships in one-on-one music therapy work is explored by Rolvsjord (2014) who offers a critique of what she refers to as the ‘client-therapist binary’ in mental health. Here, the concepts of client and therapist are connected to binaries that “locate pathology and problems with the client and solutions to solve problems or cure pathology in the therapist” (p.10). Rolvsjord concludes that this
inherent power imbalance may be destabilised if the client’s competence is explored and valued. These include “(1)’musical competence’, (2)’theories of change’, (3)’reflexivity and agency’ and (4)’clients’ ways of making use of therapy in everyday life’” (p.21). Three elements of this competence could be found in the data describing one-on-one sessions and these are ‘musical competence’, ‘reflexivity and agency’ and ‘client’s way of making use of therapy in everyday life’.

Musical competency is described by Rolvsjord in three ways; communicative musicality, musicianship and musical experience skills. As described in the introduction, communicative musicality is “the innate capacity for musical relating” (Rolvsjord, 2014, p. 12). With the exception of the early (Clarkson, 1991) study, each of the remaining five studies describes ways in which the young person’s own musicality is explored. The therapist in McFerran and Shoemark’s 2013 study neatly summarises this: “I am listening, encouraging, providing a framework for the child to express themselves. I am not challenging, demanding, holding back, repeating – more learning strategies” (p.4).

It should be noted that following several years of individual therapy, Ginger Clarkson’s reporting of the therapeutic relationship turns from a focus on social skills acquisition for the young man toward the interpersonal relationship between client and therapist. This model of working is reflective of the time and it is interesting to follow its evolution. McFerran and Shoemark (2013) note that music therapists often write treatment plans that outline aims to develop communication and social skills, as schools often require observable outcomes, however music therapists may implicitly focus on fostering the interpersonal relationship as a strategy for enhancing well-being for the young person.
Reflexivity and agency is demonstrated in each of the studies where the young person makes choices and clearly influences the course and direction in the therapy sessions. Provision for reflexivity and agency in music therapy is fundamental in humanistic, psychodynamic and collaborative work and aligns well with the philosophy of choice and control in current disability studies discourse.

‘Theories of change’ includes the therapist and individual’s knowledge and experience of how change happens in their own lives both within themselves and between themselves and the healthcare system. An acknowledgment of the young person’s experience and knowledge of change is not found in the data and could be a subject for future investigation.

Mention of ‘the client’s way of making music in everyday life’ was found in the data in four of the six individual studies. However, this was not an explicit focus for the studies for example, “On one weekend outing, when he was given the opportunity to buy himself a present, he chose a reggae tape, which he uses as background music for dancing” (Clarkson, 1991, p. 383). Further emphasis and intentional action is needed on how music may be incorporated into young people’s lives outside the therapy room.

Four of the six studies discussed some generalising of the experience of the therapeutic relationship outside the session in building on social relationships. The authors from two studies included anecdotal reports of “improvements in temperament and social behaviour” (P.G. & Coleman, 1994, p. 443) and “improvements generally in their communicative and social skills” (Graham, 2004, p. 27) following music therapy. One author discussed having the intention of
introducing opportunities for social contacts outside the session (Clarkson, 1991) and one discussed the significance of this step saying;

“By actively striving to generalize positive experiences of relationships beyond the therapy room, music therapists will be able to make a more significant contribution to the young person’s well-being while simultaneously acknowledging the strong emphasis they place on the development of relationships with (a person) who has profound intellectual disability.”

(McFerran & Shoemark, 2013, p. 12)

**Length of program. How long is long enough?**

These studies were of significantly longer duration than studies examining group therapy and in the studies the majority of young people participating were described as having severe and profound disability. One field that has had little research in music therapy is the questioning of length of therapy programs. This is becoming an increasingly significant subject in the current context of individualised funding in Australia as music therapists are increasingly being funded to conduct short term consultative work in line with other allied health professionals. This phenomenon is discussed further in chapter 6.

In the field of psychotherapy, a concept called titration has been used to measure and chart change and development throughout a therapeutic program. This was in response to a questioning in the profession about the effectiveness of long-term therapy and whether such therapy could become addictive by fostering dependence (Hubble, Duncan, & Miller, 1999). These authors found that an initial period of growth occurs during the first 12 sessions, before a plateauing period. At this point,
the frequency of therapy sessions may be adjusted to occur less often in response to lessoning change observed in the therapy process. Similar studies with people with profound and multiple disability have been conducted in intensive interaction programs.

Intensive interaction has been shown to have similar features to one-on-one music therapy processes (Nind, 1996). In a study of people with multiple and profound disability engaged in intensive interaction, the initial period of change in social and communicative behaviours was found to be closer to 12 months taking into account the person’s different rates of processing information, before a plateauing to a lesser rate of change (Firth, 2009). It is at this point that an intensive period of therapy may be adjusted to become less frequent. It is possible that a task at this stage for the music therapist could be directed towards capacity building and sharing information with a community based group or others associated with the person that could begin to meet broader socio-musical needs of the individual (Pavlicevic & Ansdell, 2009).

In examining the data in these long-term therapy studies, benefits for the young person such as developments in initiating communication, (Clarkson, 1991) are reported throughout the therapy process, even when it stretches towards four years. In another study, the author states, “Discovering at last the piano as it really is, a music-making object separate from the human creator, stirred up pleasure and a kiss of affection to the keys and then to me sitting next to him” (Agrotou, 1994, p. 364).

No reference was found in the data on the consequences for the young person when the therapy program comes to an end or what an optimal timeframe may be for a particular therapeutic program. Elefant and McFerran (2012) suggest that continuing years of therapy may be valuable for the young person, but it is not the only context
for music participation. If a shift towards greater independence is the goal for the young person, then the focus needs to be on sharing and generalising these skills. The National Disability Insurance Scheme in Australia as an insurance model is viewing funding for therapy intervention as a short-term investment with explicit goals for enabling the person to participate in the broader community. For example, the planning officers from the NDIS are commonly suggesting ten sessions as adequate for this purpose in most cases. As individual music therapy has traditionally constituted much longer timeframes, this has caused concern and insecurity among music therapists and NDIS participants alike.

**Connection to the disability community**

Studies that look at connections to the community were divided into the disability community and wider community to explore the purposes of each project and how decisions were made to facilitate these particular connections.

An Australian study of friendships with adults with intellectual disability (McVilly et al., 2006) found that some participants believed that having a disability was an important factor for friendship. They described this as being ‘at my level.’ and qualified it by saying; “It’s hard to be friends if they ain’t got a disability. They just don’t understand” (p.699). In contrast, Lippold and Burns (2009) described how some authors measured successful integration as friendships between people with and people without disability. The nature of these friendships has been explored in several other studies (Amado, 1993; McVilly et al., 2006; Rickson, 2014) and it was a subject raised in a recent conference held in Victoria by people with disability. One young woman gave a talk on her experience of a friendship with someone who did not have a disability. She ended the talk saying, “don’t give up hope. It is possible” (Stevens,
Six studies were categorised as focussing on connecting groups of people with disability with other people in the disability community. Five of these were music therapy projects and one was a community arts project. These studies were published in the past six years with the exception of one study (Ely & Scott, 1994). This study was ahead of its time in exploring a connection to the community in what might now be described as ecological or CoMT (Ansdell, 2002; Stige, 2002). Table 5 describes some of the aims of these studies.

**Table 5. Stated aims of studies within disability community.**

<table>
<thead>
<tr>
<th>Year</th>
<th>Method</th>
<th>Setting</th>
<th>Intervention</th>
<th>Aim/Purpose</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>1994</td>
<td>Qual</td>
<td>Adult Training Support Service</td>
<td>Music Therapy</td>
<td>Extend communication, develop social skills and group interaction, develop self-confidence, and develop independence. (Ely &amp; Scott, 1994)</td>
<td>Australia</td>
</tr>
<tr>
<td>2009</td>
<td>Mixed</td>
<td>Salvation Army centre</td>
<td>Music Therapy</td>
<td>Convey the needs and wants of participants through musical access. (McFerran, 2008)</td>
<td>Australia</td>
</tr>
<tr>
<td>2010</td>
<td>Qual</td>
<td>Festival</td>
<td>Music Therapy</td>
<td>The festival is an arena for the cultivation of respect. (Stige, 2010b)</td>
<td>Norway</td>
</tr>
<tr>
<td>2010</td>
<td>Qual</td>
<td>Choir</td>
<td>Music Therapy</td>
<td>Mix groups to ‘give voice’ to the Remanin choir. (Elefant, 2010)</td>
<td>Israel</td>
</tr>
<tr>
<td>2012</td>
<td>Qual</td>
<td>Disused Cinema</td>
<td>Community</td>
<td>Build community arts capacity. (Stickley, Crosbie, 2012)</td>
<td>U.K.</td>
</tr>
</tbody>
</table>
Note. Qualitative (Qual)

Of six studies, each describes some purpose or outcome in extending the social networks of participants and creating connections.

• “The festival brings people together for company and cultural purposes” (Stige, 2010b, p. 116). Summary of speech by the Director of Culture in the opening ceremony. Participants come together from local communities once a year.

• “To increase social networks and opportunities for social interaction for clients”. (Ely & Scott, 1994, p. 10). A stated future program aim for this project was for the sessions to be held in a community setting to further extend participant’s social network to general members of the community.

• “Social interaction was considered to be a significant outcome of this community service where different adults from different services came together” (McFerran, 2008, p. 29). Summary of group leaders’ comments. The Salvation Army participatory action research project compared community music and music therapy.

• “The groups have developed and cemented friendships” (Stickley et al., 2012, p. 255). A summary of comments by organisers.

• “Create an opportunity to be in contact with a broader community” (Elefant, 2010, p. 190). Written by the author describing the purpose of bringing together two choirs of people with disabilities to perform.

• “The choir gives its members an opportunity to meet new people and make friends” (Rongzhi, 2010, p. 54). Summary of comments made by participants
of a community choir for people with disabilities.

**Connection to the wider community**

Four articles explore a connection through music between people with a disability and the wider community. One study describes a music therapy program and three describe various community music projects. A music therapist authored one of the studies of a community music project (Rickson, 2014), another included an author who is a music therapist (Dingle, Brander, Ballantyne, & Baker, 2012) as shown in table 6.

**Table 6.** Studies of music programs exploring connections with the wider community.

<table>
<thead>
<tr>
<th>Year</th>
<th>Article type</th>
<th>Method</th>
<th>Setting</th>
<th>Discipline</th>
<th>Aim/Purpose</th>
<th>Country</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2004</td>
<td>Study</td>
<td>Qual</td>
<td>University</td>
<td>Music Therapy</td>
<td>Canada</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Provide performing arts experiences with intentional communities within the broader community.</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>2012</td>
<td>Case study</td>
<td>Descri</td>
<td>Community Music theatre</td>
<td>Community Music</td>
<td>U.S.A.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Provide opportunities for all young people regardless of income or ability including developing skills and building confidence.</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>2013</td>
<td>Study</td>
<td>Qual</td>
<td>Community Choir</td>
<td>Community Music</td>
<td>Australia</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(Authors include a music therapist)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
A further analysis on the nature of the connection was explored in the data to reveal people who made up the ‘wider community’ in each of the music projects, as well as the reported outcomes of the intervention. The numbers 1 to 4 in table 6 correlate with the numbers in table 7.

Table 7. People who make up the wider community and outcomes of the studies.

<table>
<thead>
<tr>
<th>Connection for young people with a disability through music participation are with:</th>
<th>Reported Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Undergraduate students, music therapy faculty members and members of the community with a shared understanding of the challenges faced by people with a disability and a shared desire to create diversity.</td>
</tr>
<tr>
<td>2</td>
<td>People who would encounter obstacles at most youth music theatres such as lack of finance, lack of training, mental health, transportation, stressful home lives.</td>
</tr>
<tr>
<td>3</td>
<td>‘Disadvantaged adults’ through mental illness, drug and alcohol dependency, domestic violence, immigration or homelessness and the audience.</td>
</tr>
<tr>
<td>4</td>
<td>A professional orchestra, a school, a charity, tertiary groups and audience members.</td>
</tr>
</tbody>
</table>
Three studies describe a connection between the audience and performers. Two studies describe this connection from the perspective of the audience, and one describes the connection from the participants’ perspective. A brief description and relevant quotations are provided to illustrate the nature of this connection.

1. Audience response to performance:

- Ricksons (2014) study of the orchestral performance measured audience responses through interviews. Three audience members were interviewed who did not have an association with the performers and were described as ‘outsiders.’ Their responses were summarized as being “genuinely moved by the creativity, expression and artistry demonstrated by the learners.”

- Curtis & Mercado (2004) reported 100% positive responses to audience enjoying the performance and 100% said they would attend another event by performers with disabilities. Comments were “It was far better than I expected”, “It is wonderful what you have done, they can do so much more than expected” and “this is testimony that people will achieve when given the opportunity” (P.9).

2. Participant response to audience.

- Dingle, et al. (2012) reported that a sense of connection to the audience was a common theme of the social impact of choir singing. “A lot of people were standing around and listening. It was a good feeling.” “It make you feel better – A good reaction from the audience”. (P.415)
Within each category of connections to the disability community and to the wider community, there was no mention in the data of who made the decision to foster these particular connections, for example whether participants had input into the decisions. It did reveal that connections made with the disability community tended to report more on the formation of friendship and social interaction. Rhonzi (2010) reported, ‘The choir gave members opportunities to meet other members in their ages and their levels’ (p.58).

Connections made with the wider community, particularly through public performance, had reported more of a political focus as well as broadening the experiences of participants and extending social opportunities (Curtis & Mercado, 2004; Rickson, 2014). Curtis (2004) described the participants in her choirs from the university as ‘intentional’ and that they created ‘communities of resistance’ in order to ‘enact social change’ (p. 2). She said that while some argue that disability arts groups may ‘ghettoize’ disability artists, they also create opportunities to challenge society’s views by performing or exhibiting to the public. Disability advocate, Stella Young (2012) summarised this in her views on the proposal to integrate the Paralympics with the Olympics,

We get so few opportunities to publicly and raucously celebrate our community and the amazing contributions people with disabilities make. The Paralympics are ours. Hands off (p.4).

**Voice**

“Problems arise in social connectedness when there is a difference between the level of social connection desired and the level of connection experienced”
(Cacioppo, J., Patrick, W. 2008). For each individual, their perception of their sense of social connectedness is unique. Therefore, to inquire into the satisfaction or otherwise of people’s social networks, relationships and sense of connectedness requires the voices of the participants themselves. A separate analysis was undertaken to explore articles that utilise the young people’s voice.

Eleven of the 27 articles used the voice of participants to explore the experience of their music participation. Each of these studies was published in the last ten years with the majority in the past 4 years as shown in Figure 9.

![Figure 9. Year of publication for articles including participant voice.](image)

The analysis began by exploring the questions being asked of participants and how this related to their sense of social connectedness. Italics are used in table 8 to indicate foci specifically related to social aspects of participation.

Table 8. Studies that include participant's voice.

<table>
<thead>
<tr>
<th>Year</th>
<th>Intervention type</th>
<th>Method</th>
<th>Country</th>
<th>Study focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year</td>
<td>Discipline</td>
<td>Method</td>
<td>Country</td>
<td>Summary</td>
</tr>
<tr>
<td>------</td>
<td>------------------------------------</td>
<td>--------------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>2004</td>
<td>Music Therapy</td>
<td>Mixed</td>
<td>Canada</td>
<td>What participants’ liked about the music program. Suggestions for improvement</td>
</tr>
<tr>
<td>2007</td>
<td>Music Therapy</td>
<td>Qual</td>
<td>England</td>
<td>Thoughts and feelings on relationships and quality of life.</td>
</tr>
<tr>
<td>2009</td>
<td>Music Therapy and Community Music</td>
<td>Mixed</td>
<td>Australia</td>
<td>Quality of Life and Session Satisfaction</td>
</tr>
<tr>
<td>2010</td>
<td>Music Therapy</td>
<td>Qual</td>
<td>Israel</td>
<td>Satisfaction with performance</td>
</tr>
<tr>
<td>2010</td>
<td>Music Therapy</td>
<td>Qual</td>
<td>U.S.A.</td>
<td>Emotional well-being, social inclusion, interpersonal relationships, self-determination, personal development.</td>
</tr>
<tr>
<td>2011</td>
<td>Community Music</td>
<td>Qual</td>
<td>England</td>
<td>Enjoyment, skill development, relationship building, social inclusion</td>
</tr>
<tr>
<td>2011</td>
<td>Music Education</td>
<td>Quant</td>
<td>U.S.A.</td>
<td>Attitude towards peers</td>
</tr>
<tr>
<td>2011</td>
<td>Music Therapy</td>
<td>Quant</td>
<td>U.S.A.</td>
<td>Social Skills functioning</td>
</tr>
<tr>
<td>2011</td>
<td>Music Therapy</td>
<td>Quant</td>
<td>U.S.A.</td>
<td>Social skills functioning</td>
</tr>
<tr>
<td>2013</td>
<td>Digital Music</td>
<td>Qual</td>
<td>Australia</td>
<td>Descriptions of use of digital tool</td>
</tr>
<tr>
<td>2013</td>
<td>Community Music</td>
<td>Qual</td>
<td>Australia</td>
<td>Connectedness, personal meaning, health benefits.</td>
</tr>
</tbody>
</table>

*Note: Qualitative (Qual). Quantitative (Quant). Mixed methods (Mixed)*

Six articles were qualitative, one was quantitative and two employed mixed methods. Of the mixed method studies, one elicited the participant voice through a quantitative method and qualitative interviews were conducted with others involved in the project, mainly comprising carers (McFerran, 2008). In the other mixed method study, the participant’s voice was elicited through a Likart scale by means of an oral interview. Direct quotes from participants with disability were also used in this article.
in a response to the implied question, “what was your favourite activity?” This suggests there was a qualitative element to the interview (Curtis & Mercado, 2004).

Of the quantitative studies capturing the participant voice, one was conducted with adolescents and young adults described as being high functioning with Autism, Asperger’s syndrome or Pervasive developmental disorder. Pre and post self-reported questionnaires were used with participants (Hillier et al., 2011). The other two studies were contained in the one article exploring the effect of music therapy on social skills functioning. One was with adolescents in a school setting with learning disabilities and social skills deficits and the other was with adolescents in a residential treatment program with a learning disability and social skills deficits. Each group of participants completed likert-type social skills self-rating scale developed by the researcher after the first and fifth session. (Gooding, 2011)

![Pie Chart]

*Figure 10.* Research methods of articles using the participant’s voice.

In the remaining six articles, participant’s voices were elicited using different qualitative methods. In each of these, participants were quoted directly, although in one study with people in the wider community, the direct quotes that were reported in the article came from participants who did not have an intellectual disability. The various methods were;
• Brief informal interviews before and after sessions (Stickley et al., 2012).
• Individual interviews before the program regarding current music use and then group interviews after the intervention (Adkins et al., 2012).
• Individual interviews with participants (Dingle et al., 2012).
• 7 Individual and 2 group interviews with participants. Of the individual interviews, the participants had a parent or carer present to assist with the interview such as repeating questions if needed (Rongzhi, 2010).
• Semi-structured interviews before and after the intervention. Interviews were also conducted with key workers and residential staff (Fillingham, 2007).
• Participant voices were gathered via interview in a participatory action study (Elefant, 2010).

Of the eleven studies, five specifically measured an aspect of social benefit. Fillingham’s (2007) study with six people in the U.K. included the question, ‘name your friends’. Participants reported an increase in the number of friends at the end of the music therapy program, with three of the six participants reporting one other group member as a friend not mentioned before the intervention, although only two of these statements were supported by key workers. One participant named five service users as friends, two of whom were in the music program with her. Before the intervention, the participant had mentioned two staff members as her only friends.

In Rhonzi’s (2010) U.S.A. study, the question was asked, ‘what do you like about being in the choir’, All members indicated they liked being with people, being part of groups and developing friendships.

• I like we talk to each other
• I like talking to people I know
• I like the people in the choir
• I just enjoy being around people
• I just like we all get together
• I like to make friends there
• I like we pass the ball to each other

For the question ‘Do you like the people in the choir’, every participant said ‘yes’.

There was no reporting of any negative aspects of choir participation. There was only one question that included a negative option as a response – How do you feel when you come to the choir ‘happy’, ‘bored’, (circle yes or no). No participants circled ‘bored.’ It was unclear in the article whether these questions were asked in the group or individual interviews.

**Reporting negative experiences**

One omission from the data is a balance of negative reporting from participation with the groups. Although it is heartening to discover so many positive outcomes to music participation for young people, it is difficult to imagine that all participants had positive experiences all the time. The tendency to say ‘yes’ regardless of the question, or acquiescence, has been a commonly cited problem for research with people with intellectual disability (Finlay & Lyons, 2001).

In conducting research into acquiescence, authors found that having a cognitive impairment may predispose people to response biases. This may occur when questions contain concepts that may be difficult to comprehend or when questions are too long or complex. A study from the Netherlands into research agendas described a process of interviewing people with an intellectual disability that
began in formal settings. The researchers decided that this resulted in “superficial socially acceptable answers that only conveyed the idea that everything was perfect” (Nierse & Abma, 2011, p. 415). The process was abandoned in order to conduct interviews in more familiar surroundings in which respondents became more relaxed and open in their responses.

There were two exceptions in this data, both with community choirs. Dingle et.al. (2013) conducted a study with an Australian choir where choir members were asked if there were any negative emotional aspects to the experience. All nine could not think of anything. The authors did however document participants’ reporting some negative aspects that were not revealed in response to the direct question of satisfaction or otherwise with the choir experience. Participant’s comments were reported such as “tired, sore throat, anxious, feeling that I can’t do as well as other people.” Another person said they got “very stressed, very scared. Certain about singing wrong notes at the wrong time. Agitated. Had to not think about it at all or it was too much” (p.413). It was unclear whether these were comments made in response to another direct question. It would be interesting to know this, because asking a direct question such as; ‘were there any negative aspects to your participation’ did not reveal the comments made above.

In the Israeli choir study, members from one choir reported dissatisfaction with their performance saying “The performance was too scary for me”, “We were swallowed by the other group”, “We were hardly heard”, “I hate to perform”, “The performance took away the fun” (Elefant, 2010, p. 193). Interestingly, each of these negative responses were from participants who did not have an intellectual disability. There were no other negative experiences or aspects reported in the data on
connections to the community. One reason was that many questions asked of participants appeared to be leading to positive responses such as ‘what did you like about…?’ rather than open questions such as ‘what do you think about…’.

**Discrepancies in reporting experience**

In Hillier et al (2011) U.S.A. study measuring peer relations, the results indicated improved attitude towards peers from self-report questionnaires. (p. 0.016) Parents of the participants completed the same questionnaire and although there was an improvement measured with these results, it was less significant (p.0.049). The authors reported anecdotally that a number of participants met each other outside the therapy sessions as well as communicated via social media. Participants were recruited via advertisement to various organizations and it was not documented whether participants were known to each other before the program intervention.

In each study where a comparison is made with others, the young person’s evaluation of their social participation is consistently more positive than others questioned. Whether this demonstrates the phenomena of ‘acquiescence’ (Lewis & Porter, 2004), or that young people were simply more satisfied than others’ were able to perceive, is difficult to determine from the data. For instance:

Jean names two service users and five staff as friends and her key worker says, ‘Jean talks a lot but they’re not friends.’ Maggie names two staff members as friends and Maggie’s home leader said she has ‘no friends, as such.’

(Fillingham, 2007, p. 81)

report less improvement in peer relations and social skills than the young people themselves.

In Stickley et al, (2012) U.K. community arts project, participants were asked ‘what do you enjoy about the group?’ A participant said, ‘I love these people here.’ This was the only quotation related to a social aspect of participation from a young person with disability. The authors documented quotes by workers and organizers of the program on the social benefits of participation and summarize their comments by saying that “the groups have undoubtedly created and cemented friendships.” (P 254)

In the Dingle et al (2012) Australian community choir study, when asked if they felt connected to the choir, all but two of the 21 participants answered ‘yes’ and the remaining two gave ‘mixed’ answers although these answers were not quoted. Results of the other questions were summarize as reporting benefits in reconnecting to the local community and connecting with the audience during performances as well as improved social functioning with increased confidence and tolerance of others, and general well-being. No direct quotes were reported from the two participants interviewed with an intellectual disability (Dingle et al., 2012).

The inclusion of participants’ voice in the reporting data is provided only in the past ten years. For some participants, having a cognitive impairment may hinder understanding of concepts in questions and some people may have other ways of communicating than verbally (Finlay & Lyons, 2001; Rabiee, Sloper, & Beresford, 2005). This means that effective ways of reporting and including the voices of participants needs to be explored further and given equal or higher priority in the literature. It is through hearing directly from participants that facilitators of music programs can learn how best to design and evaluate programs and through this
collaboration give greater choice and control to participants. In a broader literature review of young people with disability, Stokes and colleagues (2013) found that “the extent to which decision-making processes acknowledge and include young people playing a role in studies highlight the ‘lack of voice’. Young people with a disability are not properly involved in decision-making at crucial points in their journeys to adulthood” (p. 16). As research ultimately aims to affect the lives of people with disability, having their active participation in program and research agendas is an important consideration (Nierse & Abma, 2011). The catch-cry of the disability rights movement in the U.S. in the 1990’s summarises this with, ‘nothing about us without us’ (Charlton, 1998).

In the ‘Making Music, Making Friends’ study (Pavlicevic et al., 2014), the purpose was to explore the value of long term music therapy for young people with severe and profound disability. As stated earlier, the authors discuss the unfortunate lack of participant voice in this study and explain that difficulties were encountered when attempting to involve the young people. Their lack of inclusion in the research indicates the assumption that participant’s voices are not required to give an evaluation of their involvement. Their exclusion sends the message to other young people with disability that they are not the experts in their own experiences.

When Participants are non-verbal.

Within the data another category of ‘voice’ was created where participants do not use speech to communicate. Their experiences are very often absent in research because of challenges in reporting communication (Morris, 2003; Pavlicevic et al.,
2014; Rabiee et al., 2005). In several of the studies, the therapist interprets participants’ voices through rich descriptions of behaviours and responses during the music sessions. Using this method, researchers attempt to make the opinions and choices of the young people explicit in the data gathered and therefore represented in the results of the studies. Three of the five identified studies examine the relationship between the therapist and young person and two examined the relationships between group members of people with disability, as well as with the support people closely involved with the participants. Each of these articles describes a music therapy program.

From the five studies, I extracted a communicative behaviour from the participant(s) to illustrate ‘voice’ in order to make a comparison of the types of communication being reported with the young people. I searched for an extract that demonstrated intentionality by the participant in the communication.

**Individual Therapy**

1. Emilio brought along a quietness that hardly needs the reassurance of his self-stimulations nor the punishment of his self-inflicted injuries. It is the quietness that find its roots in the security of a human relationship that leaves him free from now on to take pleasure in his hearing (Agrotou, 1994, p. 364). (Written by the music therapy practitioner and author after three years of psychodynamic weekly therapy).

2. So as for moment, those are the moments where she will vocalise. Just the
other week, she was doing two syllables, ‘I-yee-yha’, “I-yee-yha’. It’s something that’s usually different. Usually it’s high-pitched vocalisation like ‘Ah- Ah- Ah’. And I always say, ‘Ah, you’re gonna sing for me today. Ah, it’s good to hear you singing Eva. Playing shaker and singing! Oh! Good to hear you.’ So they are the moments that I guess really define the relationship. It’s the interaction and then vocalising, making eye contact, and trembling. Then interaction increases during the hello and good-bye songs and there are more reactions as well (Lee, 2014, p. 73). (Words by the music therapy practitioner following two years of weekly therapy. The theoretical orientation of the therapist is not specified).

3. Once Melissa resumes her position in front of Allan, she returns to strumming the opening upbeat sequence of punchy chords. Allan’s head stabilizes and he smiles with intention and vocalizes his signature open vowel ‘ah’ sound. Melissa takes turns vocalizing with him. Allan’s constant dyskenetic movement stops and he smiles frequently. At times he turns his head and appears to listen intently to Melissa’s music, while at other times he turns to vocalize into the microphone. He smiles as he turns his head away, apparently enjoying himself (McFerran & Shoemark, 2013, p. 7). (Written by the music therapy author describing video footage taken 2 years into a weekly music therapy program).

**Group Therapy**

4. Sessions 17-19 were dominated by Bill’s distress and deteriorating condition, and it was then that Nick and Bill had the most musical connection, with Bill
standing on the threshold of the room, but leaving if Nick moved towards him. 
Jack’s attendance noticeably decreased, as if saying something for the group 
about how unbearable the feelings were in the house at the time. In the week 
of session23, Bill was too sick to get up. All the other men were standing at 
the front door waiting for the music therapist to arrive. Such anticipation was 
unusual (Warner, 2007, p. 54). (Written by the music therapy researcher and 
author describing a music therapy intervention in a participatory action 
research.)

5. Again Pamina chooses to combine her two repertoires and starts another two 
"phrases" of foot-beatings: a four-note phrase, followed by a nine-note phrase. 
This time it becomes clear that she makes some delay over some of her foot-
beatings, causing the group music to slow down, but also making it more 
difficult for us to keep our turns in a clear dialogue form. It may be that she 
was checking, in this way, the predictability of our responses to her (Agrotou, 
1998, p. 160). (Written by the music therapy practitioner and author after one 
and half years of weekly psychodynamic group therapy).

All five of these studies were unique to music therapy. In the study by McFerran 
and Shoemark (2013), four key principles of musical engagement are identified in 
long-term music therapy practice:

• The music therapist listens

• The music therapist takes responsibility for structure
• Spontaneous initiation is sought from the young person

• The relationship is built over time (p.11).

As these authors discuss, benefits will be achieved if these communications are shared with people outside the group so that social opportunities for the participants may be broadened. Agrotou (1997) and Warner (2007) include carers in the therapy program in order to build their knowledge of communicative techniques and to draw significant others involved with the participants into the musical relationship. Music therapists are in a unique position to take this knowledge and disseminate it in new ways to benefit young people, so that future ‘principles of musical engagement’ may commonly include another bullet point,

• Music making occurs beyond the session.

In summary, through exploring the published literature in this way, specific questions were asked of the data relating to the types of social connections being fostered, the level of collaboration with participants and ‘voice’. Current disability studies discourse as well as CoMT theory (Pavlicevic & Ansdell, 2004) over the past decade have influenced this particular interest.

Through this lens, the synthesis revealed persistence in working from a medical model framework with some studies including developmental goals such as social skills acquisition, with its implied aim of normalizing behaviour. The synthesis has revealed a lack of any critique of programs from young people participating who have cognitive impairment and a marked discrepancy between the perspectives of those young people and others regarding their social interactions. The synthesis has revealed a shift in thinking during the past ten years to include a more collaborative
approach to facilitating music programs, particularly in community programs as well as an acknowledgment of the need to foster music opportunities in broader areas of the person’s life. However, it needs to go further. Collaborative decision making in the design of programs, setting research agendas and evaluation will all provide opportunities for young people to exercise greater independence and control in their lives and to influence the evolution of future opportunities for music involvement. There is a need for music programs facilitators to “embrace diversity rather than normalcy” (Rolvsjord 2014 p.16) to contribute to the creation of a welcoming music culture in which people of all abilities and can take part and flourish.
CHAPTER 4

Interviews with young people

“I’ve got 40 friends. I wouldn’t want to have hundreds.”

Spoken by an interviewee from a disability organisation.

This chapter begins to turn the focus to the local context of this project. It contains the process, analysis and findings of a series of interviews with young people who are service users of The Organisation. The purpose of the interviews was to begin investigating whether social connectedness was a relevant agenda topic for the research and if so, what young people themselves had to say about it in relation to their own experiences. An inductive analysis was used to examine the data. The following chapter 5 contains a critical reflection of the findings.

The first few months at the Organisation was spent considering the question of social connectedness for young people. As well as extensive reading on the concept of social connectedness and related terms, I gathered perspectives from the Organisation staff including therapy staff and the Community Inclusion Team in informal conversations. A picture that formed on the basis on these perspectives was that challenges with feeling socially connected for young people transitioning from school were a familiar phenomenon. The Organisation staff said they felt that it was problem for their service users and the literature supported this view. However, in order to
move forward with this agenda, I needed to hear the perspectives of young people themselves. There were two reasons for this. One was to establish whether social connectedness was a relevant focus to pursue through music therapy inquiry and two, if it was then young people’s voices would be privileged in forming a picture of social connectedness in this context. This is congruent with a transformative paradigm where an important way of addressing power issues in research is by involving participants in establishing research foci (Mertens, 2007). In participatory action research, there are few examples of participants input in setting research agendas (Nierse & Abma, 2011). In this instance, the agenda of social connectedness was initially raised by the Organisation.

Many authors have described the construct of social connectedness in the past three decades from individuation theory (Grotevant & Cooper, 1986), social psychology (Beyers, Goossens, Vansant, & Moors, 2003) as well as from an ecological perspective (Karcher et al., 2006). Descriptions vary widely depending on differing theoretical underpinnings. In this study, the definition developed by psychologists Richard Lee and Steven Robbins (1995) has been used as a guide to understanding the concept. These authors developed their understanding and measures from psychoanalytic self-psychology theory (Kohut & Stepansky, 1984) and describe social connectedness as “an enduring and ubiquitous sense of the self in relation to the world,” that it is built on experiences of accumulated relationships from early attachments and extending throughout the life span. The “aggregate of all these social experiences is gradually internal by the individual and serves as the foundation for a sense of connectedness” (Lee & Robbins, 1998, p. 338) As such, the person views the social world through their individual lens and experiences it in a fairly stable way. However, a sense of connectedness is not rigid and may still be influenced
by significant or long lasting changes to relationships in life (Williams & Galliher, 2006). As stated in the previous chapter, problems are thought to arise in social connectedness when there is a “mismatch between the level of social connection desired and the level the environment provides” (Cacioppo & Patrick, 2008, p. 23). Seen from this perspective, if there is a significant or long-lasting disruption to a person’s social network, such as during the transition from school, then the effects of social disconnection or chronic loneliness, may impact on the person (Cacioppo & Patrick, 2008). Following from Chapter 1, Celeste Phillips-Salami’s (2009) concept clarification analysis of social connectedness and resulted in this definition based on key elements of the conceptualisation in the literature.

Connectedness is the degree to which an individual perceives that he/she has a close, meaningful, and significant relationship with another person or group of others. This perception is characterized by positive expressions (i.e., empathy, belonging, caring, respect, and trust) that are both received and reciprocated through social interactions (p. 55).

An Australian review of the literature on independence and opportunity for young people with disability by Stokes and colleagues (2013), found that having choice and control over one’s own life is associated with having strong social connections. The function of these connections has been found to provide support during the adjustment to adult life by assisting in the development of identity and a sense of independence (Hodgins & Cronin, 2004). A review of the literature for young adults transitioning from school found that friendships appear to decline once the young person leaves the formal supports of school life and that their social
networks are then often limited to family and places of employment or day services (Foley et al., 2012).

The experience of being socially connected is particularly relevant to young people who are transitioning between the structured and relatively predictable environment of school to the more independent life as an adult (Hodgins & Cronin, 2004). This transitioning period is one of the most significant changes in life for all young people and for people with disability, it can prove to be a particularly challenging time (Stokes et al., 2013). As one parent said,

“Inclusion is at least philosophically supported in the education system in this state but when the young adult leaves the school, there is simply no expectation that they will follow a path that might assist development or lead to a meaningful job or way of life” (Deane, 2009, p. 50).

**Methodological Considerations**

The use of qualitative interviews as a method to elicit the views of young people with intellectual disability has been used in a wide variety of studies. These range from establishing relevant research agendas (Nierse & Abma, 2011), to exploring quality of life (Rhongzhi, 2010) and the value of community experiences (Ouellette-Kuntz, 2012). As the interviews were planned as a verbal exchange, it meant recruiting people who had verbal language as their mode of communication and would be able to articulate aspects of their social situation and how they felt about it. This meant excluding people who do not use verbal language and yet I was interested in including people with all types of communication techniques who accessed the Organisation as well as other service organisations in the project as a
whole. In methodological terms, ‘sampling’ from a transformative paradigm, Mertens (2007) warns against the “dangers of the myth of homogeneity, to understand which dimensions of diversity are important in a specific context, to avoid additional damage to populations by using labels” (p.220).

In this light, I decided to use a qualitative interview method in order to gather the perspectives of a sample of young people in this cycle of the research. I would then open an invitation to a broader range of young people to participate in subsequent cycles. These subsequent cycles would include music making as a mode of communication in order to gather the voices of people who may not use verbal language to communicate. Congruent with an action research paradigm, I sought to embody a spirit of participation between myself as the interviewer and the young people as interviewees. I had the aim of creating a dialogue in which each of us had a “shared objective” (Fals Borda, 1979, p. 37) of adding their voices to a broader understanding of young people’s social situation and taking that knowledge to begin addressing any challenges identified.

**Ethics**

Ethical approval was gained to interview 10 young people who could participate in a verbal interview. In order for the young people to give consent to participate, they were given a plain language statement describing what would be involved in the interviews and a consent form to sign. (See appendices C and D for approval letter and plain language statements). In order to assess the ability of the potential participants to understand the notion of giving their consent, a proforma called ‘Deciding on the Capacity for Consent’ was used as a guide by a support worker in deciding whether the person could understand what the study was about,
what they would be doing, the benefits and risks, voluntariness and the complaint process. (See appendix E). Additionally, when the interviews began, I started by explaining the process again and asking the participant if they were happy to participate. I also said that that they could finish at any time and were free to say if they did not want to answer any questions. An extended discussion of ethical considerations including power relations is discussed in the following chapter 5.

**Privacy**

The first time that I presented the findings from this cycle described below was to the Community Inclusion Team at the Organisation. I was cognisant of the fact that participants being identifiable would be most high with this group because the Community Inclusion Team involves members that worked over each of the geographical areas where interviewees resided. All names were changed to pseudonyms and I mentioned at the beginning of the presentation that people had signed consent forms with the understanding that their contributions would remain anonymous and so I asked people not to speculate on who they may think someone was. Even so, I observed the natural curiosity of team member’s piecing together information that could compromise anonymity of participants and so for this chapter, I decided to further obscure people’s identity by changing the names within the tables and quotations so that different names are paired with one person’s contribution to the data.

In addition, I had initially planned that visual maps created in the interviews of people’s social networks would be available to participants after the interview. I changed my mind about this because of potential problems I saw in people displayed on the maps being able to view them. For example, I asked the question, ‘would you
describe someone on this map as a best friend’? Anyone who has participated in the complexity of schoolyard politics with friendships may see a problem with this being publicised for a person. Similarly, there were frank discussions about how people felt about family members and their levels of intimacy and closeness, including within separated families. There were also conversations about members of staff in the Organisation centre. I realised upon listening during the first couple of interviews that these were very private conversations and having people categorised on a map, as being ‘close’ or ‘not so close’ could potentially be problematic for the young people. I explained this to participants once I began interviewing in explanation for why I would keep the maps, but went on to say that I would send findings from the interviews collectively back to participants once I had finished with name changes.

I applied to ethics to interview 10 young people attending the Organisation services across Victoria. An additional person was interviewed in the last round of interviews that had expressed interest in participating. This brought the number to 11 young people.

The research question investigated in the study is:

- How do young people accessing the Organisation services describe their own sense of social connectedness?

To investigate this question, data was consistently collected in response to a number of specific questions, including:

- How many people do young people have contact with?
- What is the nature of those relationships?
• How do young people feel about their social situation including whether they would like to know more people and do they experience loneliness?

Method

Semi-structured interviews were conducted in the various day centres that participant’s attend. They were recruited by advertising through the centre and through direct contact with the service centre managers who identified potential participants. Interviews took place at different times of the day, arranged to suit the young person. Each person was previously unknown to me as the interviewer.

Participants

The young people recruited had left school, were 17 years to 28 years and accessed the Organisation. The eight men and three women were from Melbourne and three different regional cities or towns in Victoria. The following descriptions of the participants are the only place where I have used their pseudonym as I have described above. I asked the first couple of people what they would like their pseudonym to be if I were to write up these findings, but I found it a difficult concept to convey in the short time that we had together. For example, one man said that he was only ever known by his own name and did not know what another name could be. In providing these descriptions of the people I interviewed, I hope to represent them in ways that show a little of their personalities and the individual characteristics that struck me in the short time that we had to talk. See table 9. Following anti-oppressive practise framework (Baines, 2013), I consciously document participant’s strengths and abilities.
Table 9. Descriptions of young people

<table>
<thead>
<tr>
<th>Name</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrew</td>
<td>Careful, considered answers. Warm and engaging personality.</td>
</tr>
<tr>
<td>Billy</td>
<td>Talkative, likeable young man. A bit of a larrikin.</td>
</tr>
<tr>
<td>Liam</td>
<td>Earnest, kind young man giving detailed and thoughtful answers.</td>
</tr>
<tr>
<td>Stella</td>
<td>Chatty, outgoing and funny. Sociable and curious. Cup half full! Doesn’t dwell on the negatives.</td>
</tr>
<tr>
<td>Robin</td>
<td>Comedic and extroverted. Intelligent and a dreamer.</td>
</tr>
<tr>
<td>Lizzy</td>
<td>Softly spoken, shy and reserved. Keeps her cards close to her chest.</td>
</tr>
<tr>
<td>Ben</td>
<td>Gentle and thoughtful. Empathic, observant and warm.</td>
</tr>
<tr>
<td>Sean</td>
<td>Sociable, outgoing and cheeky. Also angry and expressive of frustrations.</td>
</tr>
<tr>
<td>Amanda</td>
<td>Considered, intelligent, ambitious and strong. Yearning to make the most of life.</td>
</tr>
<tr>
<td>Tom</td>
<td>Quiet, quirky, intelligent and humorous. Self contained and content.</td>
</tr>
<tr>
<td>Oli –</td>
<td>Shy, sweet, gentle and wanting to please.</td>
</tr>
</tbody>
</table>

Data Collection

The semi-structured interview questions were drawn from social connectedness scales developed by Lee and Robbins, (2008) for college students and Karcher, Holcolmb and Zambrano, 2008, for secondary school students and adapted by me for people with intellectual disability. The questions focused on three areas: the number of connections, descriptions of the connections and then the young person’s reflections on their individual social situation. In the established social connectedness
scales, questions are concerned with reflections on individual social situations, such as the agreement or otherwise with statements such as, “I feel disconnected from the world around me” (Lee & Robbins, 1995). In order for the young people who had cognitive impairments to more easily reflect on their social situation, a multi-pronged approach was taken to support understanding and communicative opportunities (Ouellette-Kuntz, 2012). In this instance, a map was first constructed of each person’s social network during the interview upon which they had the opportunity to think about their individual network and overall social situation.

The map was constructed after the first question, which was to ask each person what he or she did on each day of the week. This straightforward question was designed to put the young person at ease and allowed me to get a sense of the young person’s ways of communicating. Their responses illustrated the extent of each young person’s activity during the week, as well as where they lived. It was at this point that I introduced the idea of the map.

The map was constructed using computer based mapping software as shown in figure 11. I told the young person that we would make a map together to make a picture of all the people in their lives. I first asked if they would choose a central pattern from a menu of different colored and shaped patterns. The pattern was then inserted into the middle of a fresh screen and their name was placed inside. Branches were then added to come out of the central pattern and were named with each place the young person mentioned in their description of their week. I then asked the young people who they knew at each place and as they mentioned a person, I inserted their name on a branch coming from the main branch of the place where they were known. In some cases, the young person answered the question with, “everybody”. In this
case, I asked who was important to them in that place. In this way, young people began to see how a map could be constructed to name all the people in their social networks.

Each of the 11 participants lived at home with their family. This is not the case for all young people at the Organisation who also live independently and in group homes in the community. Figure 11 shows an example of a map constructed with a participant.

Figure 11. Example of a map as seen and created with participant.

I then asked questions about those people such as, “Tell me about so and so”, or “Why are they important to you?” Each name was colour coded by giving them a category mentioned by the young person such as ‘friend’ or ‘someone I help’ or ‘best mate.’ More general questions about the people were then used to solicit additional information, such as:

• “Who do you feel most close to?”
• “You mentioned friend and best friend, what is the difference between these two for you?”

• “If you had a birthday party, who would you invite?”

• “If you had a big decision to make, whom would you go to?”

In discussing the person’s social network as a whole, I asked questions such as:

• “Would you like to have more friends than that?”

• “Do you ever feel lonely?”

• “When you look at your map, what do you think?”

• “Do you feel a part of (community/neighbourhood)?”

• “Do you feel like you belong (community/neighbourhood)?”

The questions above varied for different participants depending on their level of understanding of concepts and questions as well as their communication skills. For some people, I asked the first three questions only, i.e. “What do you do each day of the week, who do you know there and tell me about (that person)”, and for others, I was able to ask most of the questions listed.

**Results**

Each participant had one branch as the Organisation and one branch as family. For eight of the participants, these were the only main branches on their map. The three people who had connections outside of this were the three women. Table 10 summarises the places named by the young people and how many people they mentioned in each place.
Table 10. Places mentioned by people interviewed and the number of people mentioned in that place.

<table>
<thead>
<tr>
<th></th>
<th>Home</th>
<th>The Organisation</th>
<th>1. Additional Places</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrew</td>
<td>7</td>
<td>7</td>
<td></td>
<td>14</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Billy</td>
<td>7</td>
<td>19</td>
<td></td>
<td>26</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liam</td>
<td>6</td>
<td>16</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>22</td>
</tr>
<tr>
<td>Stella</td>
<td>11</td>
<td>10</td>
<td>Music Group 5</td>
<td></td>
<td></td>
<td></td>
<td>31</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Community Social Group 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Robin</td>
<td>6</td>
<td>16</td>
<td></td>
<td>22</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lizzy</td>
<td>4</td>
<td>3</td>
<td>Tafe 5</td>
<td>12</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ben</td>
<td>7</td>
<td>22</td>
<td></td>
<td>29</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sean</td>
<td>2</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>Amanda</td>
<td>11</td>
<td>4</td>
<td>Course 5</td>
<td></td>
<td></td>
<td></td>
<td>49</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Committee 13</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Community Centre 12</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Music Group 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tom</td>
<td>12</td>
<td>3</td>
<td></td>
<td>15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oli</td>
<td>3</td>
<td>5</td>
<td></td>
<td>8</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Inductive Analysis

Each of the interviews was recorded and transcribed verbatim. An inductive method of analysis was used (Thomas, 2006) which allows for research findings to emerge from the data without the “restraints imposed by structured methodologies” (p. 238). This involved reading several times through the transcripts and looking at
the maps, followed by highlighting anything that related to what I interpreted as social connectedness.

I then inserted text boxes next to all the people mentioned in the interviews and inserted this text, as well as any other comments relating to social connectedness as floating text on the maps. This created a visual representation of each young person’s social network and their commentary on that network in the form of a map. Figure 12 is an example of one of these maps. It is intentionally blurred to obscure the words.

![Figure 12. Example of a map after transcription.](image)

The analysis was conducted under the four categories of relationships that were described in the interviews; those from the Organisation, family members, those outside either the family and Organisation, that I have named ‘Community’ and an additional group labelled as Informal Relationships. This group included all those relationships that were not with either paid staff or family members. In addition, the answers to questions about loneliness and a desire for more friends, as well as the
overall satisfaction or otherwise with each person’s social connectedness was analysed inductively.

**Social connections at the Organisation**

Since recruitment for the study was conducted through the Organisation, it is no surprise that all of the young people described relationships within the Organisation. Table 11 summarises the types of relationships mentioned by the young people, using headings that were inductively derived from the analysis of the data.

*Table 11. Relationships with people at the Organisation.*

<table>
<thead>
<tr>
<th>Name</th>
<th>Friend</th>
<th>Best friend or close friend</th>
<th>I do things for them</th>
<th>No description</th>
<th>Relationship with conflict</th>
<th>Good to me</th>
<th>They do things for me</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrew</td>
<td>2 - SU</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5 – St</td>
<td></td>
<td>7-SU</td>
</tr>
<tr>
<td>Billy</td>
<td>2 SU</td>
<td>12 - St</td>
<td>5 - SU</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>7SU/12St</td>
</tr>
<tr>
<td>Liam</td>
<td>1 - SU</td>
<td>6 - SU</td>
<td>2 - SU</td>
<td>4 – SU</td>
<td></td>
<td>2 - St</td>
<td></td>
<td>13SU/3St</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1 - St</td>
</tr>
<tr>
<td>Stella</td>
<td>8 - SU</td>
<td>2 - SU</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>10- SU</td>
</tr>
<tr>
<td>Robin</td>
<td>5 - SU</td>
<td>2 - SU</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3- St</td>
<td>7-SU/3St</td>
</tr>
<tr>
<td>Lizzy</td>
<td>2 - SU</td>
<td>1 - SU</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3-SU</td>
</tr>
<tr>
<td>Ben</td>
<td>4 - St</td>
<td>2 - St</td>
<td>2 - St</td>
<td>1 - St</td>
<td>9 - St</td>
<td></td>
<td>4 St</td>
<td>22-St</td>
</tr>
<tr>
<td>Sean</td>
<td>1 - SU</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1-SU, 4-St</td>
</tr>
</tbody>
</table>
Of the eleven young people, nine described other service users at their Organisation centre as friends and four of these people mentioned staff as friends. Previous studies into social circles for people with an intellectual disability have looked at the nature of the relationship between carers or support staff and service users (Bigby, 2008; Forster & Iacono, 2008; Lee, 2014). As previously mentioned, this raised lively debate at a disability symposium in Melbourne with workers and carers where one woman in the audience said, “if you are being paid, you are not a friend” (the Organisation Symposium, 2015). However others suggest that it is important not to devalue these relationships, as they are sometimes the only friendships that the person has (Forster, 2014). This was the case with three of the young people in this study.

Both Tom and Oli described staff as friends. They had limited expressive communication and each described the staff in similar ways, as ‘she’s nice’, or ‘he’s nice’ or, ‘she’s my nice friend.’ Ben also described staff as friends and when asked who he was most close to in his life, he mentioned a member of staff. For young people who spoke of staff in terms other than friendship, three categories were created to encompass descriptions present in the data based on my interpretation of their meaning:

<table>
<thead>
<tr>
<th></th>
<th>SU</th>
<th>St</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amanda</td>
<td>4 - St</td>
<td>4St</td>
</tr>
<tr>
<td>Tom</td>
<td>5 -St</td>
<td>3 - St</td>
</tr>
<tr>
<td>Oli</td>
<td>1 - St</td>
<td>1 St</td>
</tr>
</tbody>
</table>

Note. SU = Service User St = Staff member
In the presentation of these categories, I have chosen to use a narrative style that emphasises the voice of the contributors, and highlights the subjective nature of the data. Specifically, this means using quotes embedded within sentences and offering minimal objectification of the data through the inclusion of numbers or my own ‘expert voice’ as the narrator of their stories.

**People I help.** Andrew said, “When (staff) says, ‘Oh I want (something or), can you do something?’ I just do it. And I don’t want to make her upset and that.” “The staff call me ‘helpful’ cause I help round the centre and that.” Oli says, “A is nice. I help her in the office sometimes.”

**People who help me.** Billy, “If I am having a down day, I usually go to one of my staff” and another man says, “If someone is being nasty, I’ll go and tell (staff) and she helps me with what’s going on.” Amanda said of carers, “They let me pick where I like to go.” I asked her if she would call them friends and she answered, “No. They’re just carers.” Andrew, “If there is anything I want, I just ask her.” (A staff member)

**Humour.** Liam described his taxi drivers with, “He’s cheeky. He’s always cheeky to me. He says, ‘What’s up’ and all that. I really like them two.” Andrew said of staff, “All my friends treat me badly, but in a good way, if that makes sense.” ” All the people who work here that I can give shit to and they can give it back to me.”
Informal relationships

Johnson and colleagues (2012) categorised relationships experienced by people with complex disability in their study as formal and informal relationships. Formal relationships are those with people who are paid and informal are those where the only reason for the relationship is a desire for both parties to spend time with each other. Both these types of relationships were shown to have value for the young person. Five people of the 11 described informal relationships, all three women, as well as two men. The informal relationships described by these young people were all peer friendships either at the Organisation or outside. From the descriptions of these peer friendships, I created two categories to represent the two main attributes of informal relationships that I interpreted from descriptions provided by young people:

• Time
• Being there

Time. Having known someone for a long time appeared to be significant in the recognition of informal relationships for young people in this study. Building into another Australian study examining the concept of friendship with people with intellectual disability, the need for knowing people for a long time to be a close friend is considered. Focus group discussions included some people who said this was essential and others who stated that sometimes you know straight away when you meet someone if they will be a friend, particularly if you have something in common. (McVilly et al., 2006).
To the question, ‘why is that person a friend?’ one man said, “I've known A for a very long time and V. I’ve known them since I was little. They have always been very nice to me.” One woman said,

“The reason why they are my bestest friends is because A1 used to go to playgroup with me when I was about 2 or 3. And I just know A2 through respite and I used to go to holiday program on the school holidays with her since 2006 and that's when I first met A2. M's another best friend of mine...cause M used to go to the same crèche as me. Yes. They are my three best friends.”

In contrast, another woman described three people as close friends that she had met at a course three weeks prior to the interview and she said that they had already been out to dinner together. “Yeah, I met some friends.” I asked her if they were close friends or just friends, and she said, “Close friends. We went out to dinner. The four of us out to dinner. Well I only just met them.”

**Being there.** Being there was a concept used to describe a close friend or best mate. When I asked one person to explain why someone was a best mate, he said, “Oh, he’s always been my best mate. Yeah, he's always been there.” Another man said, “Closest friend you are just feeling, just help each other out, help each other through the tough stuff.”

**At my level.** In addition, the notion of being ‘at my level’ was suggested by one participant and I intentionally explored this further because I was interested in who young people may want to include in a community music group. Having explored the literature on community music groups for young people with intellectual disability, I found that some groups were organised to be inclusive of people with disability, and
some intentionally involved people outside the disability community (Curtis & Mercado, 2004; Elefant, 2010). In these studies, it was unclear who made the choice for group membership and so I was interested in posing the choice to young people who might participate in music activity in subsequent cycles of the project.

The use of the word ‘level’ was also used in an Australian study into friendship with adults with intellectual disability (McVilly et al., 2006). The participants qualified this by saying, ‘It’s hard to be friends if they ain’t got a disability. They just don’t understand’ and ‘at school you get left out’ (reporting on four years of experience of an integrated high-school); “at TAFE you are all on the same level; we have all been through the same things” (p.196). Stella similarly responded to my question about why someone was a best friend, “Best friend is cause they’re sort of like my level.”

Lippold and Burns (2009) describe how some authors have measured successful integration as friendships between people with and people without a disability. The nature of these friendships has been explored in several other studies. (Amado, 1993; McVilly et al., 2006; Rickson, 2014) and as previously mentioned, it was a question that was raised in a recent conference held in Victoria by and for people with disability. One young woman, Simone Stevens, gave a talk on her experience of a friendship with someone without an intellectual disability. She ended the talk by saying, “Don’t give up hope. It is possible” (Stevens, 2015).

In this study, there was the only one person who described friendship with two people who did not have intellectual disability. When I asked her how she met them, she said,
One of the staff took me out there (to a community arts centre) ‘cause she thought I might like it and (her friend), she was all dressed up doing a play out there and kept asking me to come back. And she kept asking me, you know, and I was looking at her as if to say ‘what, I've never been here before.’ And anyway, she kept on saying come back and she really liked me and everything and I been out there.

**Family**

Most notable in conversations about family was the importance of grandparents in the social networks of young people. Eight young people mentioned a grandparent and of these, seven spoke about them as a significant person in their lives. For one man, his grandmother was his primary carer and he describes her as a, “very, very nice person.” One of the women said, “I love hanging around my grandma” and another man said his grandma says, “thank you” to him and “has nice manners” to him as well as “kind and ‘always there.” Another participant described the loss of one of his grandparents as a significant loss in his life and described a close relationship to his other grandparent, saying his grandma is the one who is “always there for them”. He was the only young person I spoke to who described a large extended family to whom he was very close. His extended family were connected to a church and he also described having a religious faith and connection to God.

Parents were most often mentioned briefly in reference to being the people they live with, except for Stella who had a very close relationship with her father. The young people described relationships with their mothers in more complicated ways. They were sometimes described as ‘the bad cop’ (author’s term) in the network and I discovered that their role was often one of protecting the young person, which was not
always welcomed by the young people during this adolescent and young adult life stage. This is supported in another study from Ireland that found tensions between what young people felt they were capable of and parental fears of harm coming to their child (McConkey & Smyth, 2003). I asked one woman if she would say she was close to Mum. She said, “I wouldn’t say that. Sometimes we clash.” Other comments were, “Mum doesn’t let me do a lot of things because I am not lucky” and:

Mum and I are well. We, you know I am at the age where I, I don’t hate her but everyone my age hates their mother, so I do love her, but you know, I going through between this and puberty and an adult. Well I am an adult, but you know what I mean.

In contrast, two men whose social network was limited to parents and some staff, described their mother in more positive terms as, “She’s a nice lady” and “Mum’s really good.”

**Connections to the broader community**

Asking about connectedness to the broader community was a more abstract concept and open to different interpretations. For the young people I interviewed, I found it challenging to choose words to convey what I was trying to investigate and thought it might be somewhat difficult for some participants to grasp. For example one person interpreted the question as meaning ‘the weather’ when I asked about the wider community and he described it as “torture” because it was too cold. The word ‘community’ is very general and may refer to all types of communities including the Organisation community or a person’s extended family. What I meant by the question was how people felt about the community beyond the Organisation and their
immediate family. I was thinking about the local shops or going into town or the city. In order to support understanding, this question occurred towards the end of the interview, when I asked four of the participants:

“When you think about (town or city of residence), would you say you feel like you belong or feel a part of?”

Billy was able to give a detailed answer and said, ‘No.’ He described feeling fear when going on public transport and going into the city by himself, as well as fear of “idiots” at train stations. Only two people spoke of feeling a sense of connection to their community in general and they were both from small towns:

(Robin) I think it has been very close. I say ‘hi’ to people in the street and help the elderly people out. They just say ‘hi’. I feel like I finally belong somewhere.

(Lizzy) Yeah. I have lived here all my life. Mostly we just say ‘hi’.

Cummins and Lau (2003) emphasis that a connection to community cannot be measured by the amount of time spent in community activity but that a sense of community connection is more about having a sense of community such that people feel they are part of a supportive and dependable social structure. It is not surprising then that this feeling of connection is more easily achieved in a small community.

**Loneliness**

When asked whether they felt lonely, five people said ‘no’, three people said ‘sometimes’, one person said they ‘used to but not now’ and one person said ‘yes’. I asked people if they could say more about this if they did not expand and once the
conversations around this question was analysed, it became apparent that interpretations of the concept differed. Some answers suggested the concept was interpreted as *bored*, for instance, when I asked Billy if he gets lonely, he said “no” and then went on to explain that whenever his brother suggests they do something together, he always says yes, so that he doesn’t stay home and get bored. Stella similarly said “no”. She said she avoids being at home with her mother to prevent feeling bored.

In other cases, the concept seemed to be interpreted as *alone* rather than lonely. Billy said, “Lonely as in by yourself? No.” Robin said, “No, because I’ve got everyone around me, so why would I feel lonely?” Ben answered ‘no’ as well, because he said there is always someone with him to talk to. Ben has a support person with him almost constantly to assist with daily tasks. Later in the interview, Ben said he would like to have more friends. This suggests that the relationships with the people who are constantly with him are not fulfilling his need for connectedness.

These interpretations of ‘bored’ and ‘alone’ do however bear a relationship to each other and to loneliness. Kirova (2004) suggests that boredom may be described as “feeling distance between us and the world,” as well as a state of feeling “a mobilization for action against the absence of pleasure” (p 249). Billy going out with his brother illustrates this action along with Stella avoiding staying home with her mother. Seen in this way, boredom may have more in common with Lee and Robbins, (2000) description of social connectedness as “an enduring and ubiquitous experience of the self in relation with the world,” (p. 338) with boredom being a feeling of disconnection. These authors describe loneliness, however as “feeling the pain of being unable to share ourselves – our thoughts, our truths, our feelings – with those
whom we love” (p.263). Other authors describe the concept of aloneness as being related to loneliness depending on the perception of the experience (Cacioppo & Patrick, 2008). For example, being alone is a much-desired state where there is a need for peace and quiet, but if it is perceived as loneliness or boredom, as in the case of the young people interviewed, then aloneness is an undesirable state. In another study, a participant describes this phenomenon:

I am bored out of my own brain. I am ready to go out but [have] no one to go night-clubbing [with]. Nobody’s there to go out with ... nobody’s there ... I don’t want to take my carers. I don’t have enough friends (Yeung, Passmore, & Packer, p. 71).

Two people gave answers to this question that implied a sense of powerlessness and reluctant acceptance. Andrew said he needed to “knuckle down” and remember that he is the “man he is supposed to be. It’s not going to change and so that’s it”, when asked if he ever feels lonely. This suggests that he is not encouraged to voice his feelings about loneliness. Instead he is encouraged to accept his situation, which will not change. Similarly, Sean responded with a level of helplessness at having to accept a challenging situation.

Me- Do you ever feel lonely?

S- Yes, but what can you do?

M- yep

S- You know. Shit happens. I mean that. Shit really does happen

M- Mm, hmm. Can you tell me more about feeling lonely?
S- Yeah I guess, I know it could be a lot worse. I’m glad I’m not in a home. I, I walk in to (local shopping centre). Not walk, but yeah. I get around.

I asked Sean if he goes with anyone to hang out at the shopping centre. He said that sometimes it is with a carer and sometimes by himself. I ask if he would describe any carers as important to him and he said, “Yeah, but they all change, come and go, yeah.” When I ask what he does at the shopping centre he said he goes to look at girls. Later in the interview, I asked him what he sees for his future. After a pause, he answered, “umm, I’m not sure. I don’t know, you know. I hope I have a good life. Yeah. I can only hope.”

The sense of helplessness expressed by these young men contrast to some others I interviewed. O’Brian & O’Brian (1993) cite delegates with disability at a friendship conference who describe a possible barrier to developing friendships as giving in to the perceived safety and familiarity of a situation of care. The delegates describe how a certain degree of autonomy is relinquished in order to fit in with the agendas of the care organisation or family situation. This makes it a difficult situation to break out of and it is easier to just go with the flow. Authors, Wehmeyer and Bolding (2001) framed this phenomena in terms of ‘learned helplessness’ which could grow from being given little opportunity to make choices and experiencing low expectations.

More friends

When I asked 10 of the young people if they would like to have more friends, six people said “no”, one said “in the future”, one person said “sometimes” and three people indicated ‘yes’. One participant responded to this question by saying, “I have
cerebral palsy”. When I asked him what he thought about that, he said, “It’s not nice”. I asked him if he thought it affected how he could make friends and he said, “Yeah”. His verbal language was very difficult to understand in the interview. There were some words that I could not make out at all, despite asking him several times to repeat and guessing as many words as I could. He was patient and persistent with my attempts to work out what he was saying but I wondered what challenges this would present in making new social connections and establishing friendships. His answers to many of my questions were very brief and although it felt like he could have a lot more to say, the process of making himself understood, particularly to someone who did not know him, was so difficult that he seemed to have learned to keep it brief. His answer to the question of whether he would like to have more friends was one of the longest sentences he said in the interview, “I have cerebral palsy”. The young man felt that a description of his condition was sufficient to describe why he couldn’t have more friends.

One participant’s answer to this question served as a reminder about assumptions made for an ideal social network size. He was clear that he was satisfied with the way things are. His social network was made up of his immediate family and several staff at the Organisation who he described variously as ‘good’ or ‘nice.’ When I asked him if he would like more friends, he said “No.” I left a pause and he said, “That’s all.” I then asked him if he would say he had a best friend. He said “Here at (the Organisation)? I like them all.” I asked about home and he said, “I have Mum.” I probed a little more in the interview asking him if he had a birthday party who he would invite and he said “every one here at (the Organisation) because, I like them all.”
In contrast to the eight men, the three women interviewed described relationships with people outside their family and the Organisation. Stella belonged to a music group in another city, which she attended weekly, as well as a social group in her own city which is a disability specific group but separate to the Organisation. One woman attended an adult training centre in her town and described a connection to friends there, as well as the Organisation. She said she would like more friends. Another woman had the largest network of friends outside the Organisation and family, including a music group, a committee, a community course, and a community arts centre. When speaking of the Organisation, she describes her connections as being with a few staff members who organise outings for her. In other words, she views the Organisation as a provider of services for her, not a source of meeting or having contact with friends.

Dissemination of research outcomes

A challenge for researchers in disability studies is how to feedback findings in an accessible way to participants as well as meeting the requirements of academic institutions (Goodley & Moore, 2000). For this cycle of the research, I made a video of the results of the analysis to send to the participants using the iMovie software on my Macintosh computer. This was to share my interpretation of the findings and to invite any comments or feedback from participants. The video contained a combination of talking to camera and also a presentation with presentational software, Prezi. The video was an adapted version of an international conference presentation of these results. Since participants would be unable to attend the event, the video was made up in a similar format, with sections of me talking to camera and sections of the presentation software. The content was modified to be less formal and more
conversational and also to included questions to the listener such as ‘what do you think’? Further decision-making processes related to data inclusion is discussed in the following chapter.

I put copies of the video on to USB sticks and mailed them to each of the participants along with an iTunes voucher as a ‘thank you’. (See appendix A). I received a phone message from one participant thanking me for the opportunity to take part in the study. I met with another participant later during the recruitment process for the next cycle of the research. I asked her whether she had been able to watch the video and she said she had not. I asked if she wanted to watch it with me and she said ‘yes’. We watched the video together and she smiled when she recognised quotes of her own. She also commented from time to time about whether she agreed or not with the findings from other participants.
CHAPTER 5

Reflection. Interviews

As qualitative researchers engaged in contemporary practice, we accept that the researcher is a central figure who influences, if not actively constructs, the collection, selection and interpretation of data (Finlay, 2002, p. 212).

The analysis of recorded interviews in chapter 4 describes the social networks and feelings associated with this through the voices of 11 young people who were accessing the Organisation services. This chapter presents my interpretation of those words and highlights aspects of the conversations that I felt were important to the research. This includes excerpts from my reflexive journaling in what could be described as a reflexive social critique (Finlay, 2002) where I have attempted to reveal my own thoughts and their influence on the discussion of the interview data. In doing so, I attempt to avoid the “mire of the infinite regress of excessive self analysis and deconstructions at the expense of focusing on the research participants and developing understanding” (Finlay, 2002, p. 212). Modern philosopher, Noam Chomsky expresses a critique of academic work in post modernism where it neglects any form of truth generation and serves only the elitism of academia without attempting to provide practical outcomes and ways forward (Chomsky, 1998). I agree with this stance somewhat although acknowledge that it would be a fiction to imagine that my interpretation of the data is either natural or neutral. I have attempted, therefore to balance my position with the contributions of the young people I interviewed to present a picture that would lead towards the next cycle of action.
What to include

The data that is discussed is by no means a summary of all that transpired in the conversations. For instance, Robin, as a budding comedian and had me in stitches in the second part of the interview with his impersonations and quick wit. Stella was equally very funny and delighted in her ability to get me laughing. She was also curious about me and asked many of her own questions, establishing my marital, parental, living status and age. In the music therapy graduate research group, my colleagues and I discussed the quandary of choosing what to include or to leave out when writing up analysis of interview data. We acknowledged the fine balance needed between honouring the voices of those who have given generously by sharing something of their lives and the restrictions placed on word counts in publications and presentations as well as staying on topic for the research.

I intentionally left aside information about people’s impairment labels. The criteria for involvement in the interviews were simply age and having communication through hearing and speech in order to participate in a verbal interview. This came about as my initial reading into the social model of disability informed my ideas about the project. In the social model, emphasis is placed on the societal causes of disabling conditions for people (Priestley, 1998). In critical disability studies, this thinking has evolved further by placing the notion of impairment back into focus as far as it relates to the issues under investigation (Goodley, 2013). For example, how much does the impairment impacts on each person’s life and how is this then situated in the cultural and political landscape? If I followed this thinking, then knowing the young person’s impairment was not important to identify in the beginning, or indeed at any point if it wasn’t raised by the young person themselves, or seen to have a particular impact on
the way that the young person experienced a feeling of social connectedness. This was a shift for me as a researcher from being a practitioner music therapist, where identifying impairment was often a part of initial assessment information. In this case, my interest was in the person and what they made of their situation separate to labels, diagnoses or descriptions made by others.

Representing and providing an interpretation of the young people’s voices necessitated more than thinking about what to include or not. Much has been written on the subject of representing marginalised people’s voices from being conscious of avoiding presenting the interviewee as helpless and tragic, in need of the experts help (Fairchild & Bibb, 2016), to issues of power imbalance between researcher and participant (Cotterill, 1992; Muhammad et al., 2015), and further ethical considerations when interviewing people with learning disabilities (Lewis & Porter, 2004). One way to counter the former was to include descriptions of the young people in the analysis to show a side of each person beyond their age, gender and the fact that they were service users of the Organisation. Each meeting presented an opportunity for us to connect for a short time and to delve into the worlds of each other, our voices and gestures, humour and quirks, frailties and strengths. In describing something of the impression that I was left with after the interview, I attempted to show another side to each person and in doing so, broaden the picture represented of the young people that I interviewed.

**Power balance in interviews**

Action research emphasises the investigation of power imbalances (Reason & Bradbury, 2008), and prompted me to reflect on the set up and location of the interviews. This arrangement presented both challenges and advantages to our self-
assurance as interviewer and interviewee. They were conducted in the familiar
surrounds of the young person’s Organisation’s day centre, which were not familiar to
me. In each case, this was in a room chosen by the manager or other staff person that
would be reasonably quiet and undisturbed. The interview was the first time that I
had met each of the young people and so I felt there was a degree of formality and
nervousness in each of the interviews. I knew very little about each person
beforehand, apart from his or her name, which was written on the consent form
returned to me.

My long experience in working with young people with varying cognitive and
communication abilities meant that I was at least a little confident in being able to
establish initial rapport and found myself looking forward to the conversations. My
unease came from being a novice interviewer and researcher. I felt stressed,
particularly in the first few interviews thinking about how I would remember the
information I had learned about qualitative interviewing and then making sure that the
recording equipment would not fail. In turn, the young people would have at least
some familiarity with middle aged white female Australians given the typical
demographic of therapists and support workers in disability organisations. Beyond
this, the situation was a novel one for the young people and this will have had an
influence on the type of information shared during the interview.

In a participatory study conducted in the Netherlands, researchers felt that the
information gathered from their initial interviews in formal settings lacked credibility
and that participants appeared to be giving answers to questions that they thought the
interviewer wanted to hear. They subsequently began interviewing people informally
in their living and work places as they went about their daily routine (Nierse & Abma,
2011). Conversely, feminist interviewer, Pamela Cotterill found that in some instances, being a ‘friendly stranger’ could help the interviewee reveal more, precisely because the interviewer is outside of the usual social networks of the interviewee (Cotterill, 1992).

The following excerpt is taken from my reflexive journal written after interviewing one of the men.

After the interview, each staff member I spoke to asked whether he had repeated his favourite words containing a (consonant) sound. I said that he hadn’t really. The manager told me that his mother would have worded him up carefully about the interview and how to conduct himself. I wonder if this explains the rather stilted turn of the interview. When he went back to the day room, the staff were very animated and joking with him saying (words containing the consonant). He responded with arm waving and smiles. This was a different persona to the serious young man in the interview. I wonder whether his answers were not as free because he had to censor himself or perhaps even more considered because he wasn’t going off on a tangent?

In considering the methodology, the potentials for maximising participatory aims and as well as opportunities for transformation were foremost in the decision making process as guided by a transformative paradigm (Mertens, 2007). The use of the qualitative interviews enabled the sharing of a certain degree of information to inform the next step of the project. The young people I interviewed appeared to engage willingly in mapping out their social networks including everyone they could remember and spoke as openly and generously as they felt able on the day. There were two people for whom the interviews seemed more challenging. Lizzy, who I
described as quiet and reserved had come to the interview at the end of the day and had been busy with pre-Christmas celebrations. She became quiet after about half an hour and said that she couldn’t think any more. I asked her if she wished to finish to which she readily agreed. My interview with Oli was also shorter because he was concerned about the fact that it was his last day before the Christmas break and he began to answer, “Don’t know” to questions after 20 minutes or so. He then told me that he was tired. I also asked him if he wished to finish to which he replied “yep”.

Addressing my assumptions

In order to address the influence of some of the assumptions I might have before interviewing, I used a technique from phenomenological research where researchers create an epoche. Epoche comes from the Greek word, “‘epochein”, and it means “suspend, refrain, bracket” (Lewis & Staehler, in Lee, 2014). This process helps to identify biases, pre-judgements and pre-conceived ideas about the subject of the research in an attempt to bracket them out to limit the level of influence of those assumptions on the subsequent data collection and analysis. The following were my identified assumptions.

1. Young people with disabilities may speak of many people that they know but may be less able to talk about the nature of those relationships and how they contribute or otherwise to their lives.

2. Based on my experience of gender, the men may talk more about doing things with others and women may talk about the emotional aspects of relationships in more detail.

3. Based on what I have read so far, staff may be counted as friends and this is seen as less than ideal, but I want to know how young people feel about this.
4. Based on what I have read, young people with disabilities have less than desired social connectedness.

Just after the interviews were completed, I had a meeting session with my supervisor and she asked my first impressions of the results of the interviews regarding the young peoples’ sense of social connectedness. I replied that almost all the young people were lonely and said that they would like to have more friends. Later, when I began to analyse the data, I realised that only half of the young people indicated that they experienced loneliness and half said that they would like to have more friends than they do. I had made an assumption based on the size of the social network maps that the young people would like to have more friends, or at least the people who did say they would, were ringing loudly in my memory and those that said they were content with their situation had faded away. This prompted further reflection about the assumptions I had brought into the interviews, particularly as they progressed and I began to look more closely at the conversations and questions I asked in the later interviews. Had I already made up my mind that people would be lonely and in need of broadening their networks and building on a sense of social connectedness? This is an extract from my journal at the time.

On of the things that I need to examine further is the different way I asked questions of the participants. There are so many variables here. What part of the interview I asked the question, what wording, what was going on at that particular time, what preceded it and how was the person feeling. All of this indicates that it is OK to make some comparisons (between the people I interviewed) but only up to a point. Really it is an answer that was given in the moment. I can describe my opinion of why an answer was given in a certain
way, but otherwise, I can’t really know. All I can do is explain the circumstance as well as possible and then let the reader make of it what they will.

As this became apparent in my analysis, I became particularly conscious of the fact that I needed to remain as open as possible to represent what the young people had shared with me. “We need to keep asking ourselves what trust we can place in our methods and check that we have not overly predetermined the views that we have encouraged to be heard” (Lewis & Porter, 2004, p. 196).

**Communication**

One challenge I experienced during the interviews was in understanding the speech of some of the participants. There were two people in particular that I had difficulty in understanding and I found myself trying to decide how much to intercept during the interview to ask for clarification and how much to allow the young person to speak freely and then trust that I could decipher the words once I listened back in the recording. The following is an extract from my reflexive journal.

*I felt it was difficult this time as I had real trouble understanding the young man. I wanted to let him talk and not interrupt all the time to ask him to clarify what he was saying and I was hoping I could understand a bit later, but I often didn’t get it at all. I am hoping when I listen back, I might understand a bit more.*

In one way, it was the participant that helped me to decide what to do in each circumstance. The young man I was referring to above spoke in long dialogues and it was definitely disrupting to stop him constantly for clarification. I did this at first in
the beginning of the interview, but as it went on, I just allowed him to speak and picked up what I could. I was able to decipher most of his words as I listened back to the recording. The other young man gave very brief answers and seemed keen that I understood everything he said by looking at me and gauging my reaction. He repeated words himself if I looked unsure about something. Those more acquainted with the young person would be better able to understand the speech, but it did make me reflect on the impact of this for the young men on meeting and connecting with new people.

**Oppression**

There is no doubt that the networks of the young people I interviewed were almost all very small and included a significant proportion of people in what could be described as formal relationships (Johnson et al., 2012). If we think about young people we know who have left school and are in their late teens or 20’s, it would be unusual to find anyone with no peer friendships at all and yet this was the case for four of the men. New data that is emerging from the NDIS has shown that one third of 15 to 24 year olds report having no friends outside of paid staff and family (National Disability Insurance Scheme, 2015). Similarly, a study conducted in the U.S. A. into the social networks of 540 people with intellectual disability found that if paid staff were excluded, the median size of peoples’ social network would be two (Robertson et al., 2001).

The segregation of many people with disability into day services and other disability specific settings has set up a situation that has become accepted both by the people segregated and restricted in their activity; ‘this is the situation and I need to accept that’ (spoken by interviewee in this project), as well as those around them...
including the service organisations and workers in the disability sector and society at large. French philosopher, Michel Foucault (1982) describes this situation as a form of structural power where a person is labeled and then their identity and ensuing life choices are further governed by that label.

This form of power applies itself to immediate everyday life which categorizes the individual, marks him by his own individuality, attaches him to his own identity, imposes a law of truth on him which he must recognize and which others have to recognize in him” (p. 781).

The resulting oppression is a systemic one and it is difficult to counter because it differs from a single dominant power ruling over an oppressed people, but rather it is embedded in the,

“vast and deep injustices that some groups suffer as a consequence of often unconscious assumptions and reactions of well meaning people in ordinary interactions, media and cultural stereotypes, and structural features of bureaucratic hierarchies and market mechanisms – in short, the normal processes of everyday life” (Young, 2011, p. 41).

The situation has continued for so long that it’s hard to imagine how else it might be. Acceptance comes from our experience of where many people with disability reside and spend their days; out of sight and out of society (Goggin & Newell, 2005) and it is only now beginning to become widely questioned following successful disability rights movements across the world. Recently in the U.S.A., a legal question was raised about whether many people’s segregation during the day in
day services may violate the integration mandate of the ADA or Americans with Disabilities Act (Diament, 2016).

I follow a Facebook page for people who share current issues associated with the new funding model, the National Disability Insurance Scheme (NDIS) as described in chapter 1. One of the administrators of the page who is a parent of a young adult with complex disability writes of her successful advocating to have her child involved in multiple activities throughout her week not organised by a single day service. She encourages others who are making their individual plans with the NDIS to do likewise and to challenge the notion that their child will automatically go to a day service that will organise their whole week. This is a call out to parents in 2017, demonstrating that breaking away from the well-worn pathway of special school to day service is still a novel idea. This is not to say that day services don’t provide valuable and much needed programs and opportunities for people, but that the idea that they are not the only option is still a novel one, particularly for those with more complex disability. One of the challenges is the limitation of accessible options for people outside of these services and subsequent cycles of this project explore some of those limitations as well as opportunities. Of the eight young people interviewed who were exclusively attending the day service, one person indicated strongly that he was happy with this arrangement. Others expressed different degrees of dissatisfaction.

The current solution to this problem is to embrace the ideals of individualism and self-determination as seen by the introduction of the NDIS. Whether this provides the best outcomes for people is still in question. A more detailed discussion and critique of the NDIS is contained in chapter 9. Foucault (1961) examined notions of
power through historic examinations of the lives of marginalised peoples and found that concurrent solutions to address the welfare of marginalised peoples could serve to move problems out of sight and then out of mind through top down management. Dan Goodley (2014) describes the embrace of the newest turn in disability policy as neo-liberal abelism where the notion of autonomy and independence is held up as the gold standard. Autonomy and self-determined pathways may be ideals to strive for, but there is a risk of accentuating inequalities where the onus is on the individual to make their own way in life. Goodley argues that a contribution from disability studies is the reminder to us all that dependency and reliance on each other is a positive and natural state to which we are all attracted and may flourish. Modern society’s preoccupation with individualism has also resulted in increased mental health issues through the isolation and loneliness associated with a decline in social capital (Putman, 1995). The notion that this is a solution to counter historic oppressive practices and status is not necessarily a given.

Seen from a Freireian aspect (1972) however, individualism and self-determination may also serve to create opportunities that would otherwise be unimaginable by enabling models of possibility. For example, for people who successfully navigate the system and set up a good life for themselves, this may then in turn set a precedent for others who can demand a situation that is similar for themselves.

Critical feminist writer, Iris Young in her seminal book, the Politics of Difference provides an analysis of the concept of oppression from the perspective of emancipatory social movements and found five common elements; exploitation, marginalisation, powerlessness, cultural imperialism and violence (Young, 2011). The
remainder of this chapter will explore these elements with reference to the interview
data. The concept of oppression that she refers to is structural oppression. Not
oppression as a single entity, but a type of power with is “embedded in unquestioned
norms, habits, and symbols, in the assumptions underlying institutional rules and the
collective consequences of following those rules” (p.6).

**Exploitation**

Feminist scholars identify exploitative practices involving women in the form
of unequal power, wealth and status as well as identifying how the mostly unpaid
carer work in the home, the majority of which is carried out by women, contributes
favourable conditions for men in allowing them the freedom and opportunity to
pursue work and other activity to enhance their status. In contrast to the role of ‘carer
as unpaid worker in the field of disability’, it is the ‘cared for’ that are the focus of
exploitative practice (Watson, McKie, Hughes, Hopkins, & Gregory, 2004). The role
of carers in the disability sector is one laden with complexity and this is being
countered somewhat by the use of the term support worker by the disabled people
movement (Watson et al., 2004) and sometimes PA (personal assistant). This term
usage attempts to shift meaning from benevolent carer with its emotive overtones and
reference to passivity and charity, to a professional paid assistant whose job it is to
support the person where needed. In the case of two of the women I interviewed,
when I asked about the nature of their relationship with support workers, “would you
consider them friends?” answered, “No, they’re just carers” and “How are they
important to you? “They organise outings for me”.

However, if we were to maintain this purely utilitarian meaning of the role of
a support worker, it would deny the close relationships that form between some
people and their support workers as illustrated in the interviews. Paid staff played an important role in the social networks of eight of the 11 people interviewed where the relationships were described as friendships. Forster (2011) emphasises the importance of fostering relationships between people with profound and multiple disability and their support workers, as often these are the only relationships that the person has outside their family. This interaction has been found to increase the work satisfaction of the care workers as well as increasing social interaction for the person with disability (Johnson et al., 2012). In guidelines for support workers, limitations are often imposed on the depth of these relationships in an attempt to protect service users and to maintain appropriate boundaries. A balance is therefore needed between professional conduct and the value in fostering these types of relationships. In CoMT literature, Ansdell (2002) proposed that the close relationships that develop between the therapist and participants required individual negotiation and are firstly ‘moral’ rather than professional (p. 28).

Exploitation within the disability service sector may be seen in its investment in the maintenance of keeping its service users in a ‘cared for’ state. Recently there has been a class action settlement in Australia demanding minimum wages for people working in sheltered workshops who were being paid as little as 99 cents an hour, based on a system called the Business Services Wage Assessment Tool which calculates wage rates of workers with intellectual disability based on their productivity competency. Oliver (1989) argues that the work of people in sheltered workshops make a considerable economic contribution. Service organisations, by failing to adequately involve their service users in the decision-making and running of their organisations, contribute to the dependency of their service users and power safely remains with the managers, support workers and specialists who benefit from
this arrangement through continued employment. During the interviews, I found myself feeling uncomfortable when one man spoke of staff at his centre. He said they ask him, “‘can you do something’ and I do it. And I don’t want to make her upset and that. I’m there to do it for her”. He said this again in terms of his agreement to do the interview with me, saying that he was doing it not to upset the manager. When I finished the interview and stepped out the door with the young man, a member of staff spotted him and immediately said she had been looking for him to do something for her.

A person’s involvement in a day service is to be served by staff rather than to serve. In this case, the young man appeared to be very capable and described how he was often called upon to help out in his centre such as pushing wheelchairs, gardening and even staying with other service users when staff couldn’t be there. I did not know anything of this person’s role in the centre and it could be that he was most contented being occupied in this way, but it occurred to me that a paid position would be more appropriate.

**Marginalisation**

Young describes marginalised people as those that the state will not or cannot use and she describes this form of oppression as the most dangerous where a whole category of people are excluded from participating in social, economic and cultural life (2011, p. 53). The young people I interviewed were marginalised from the usual life course opportunities that might be expected for a young person in Australia to be involved in. Each of the young people had left school and they were on the pathway of emerging adulthood (Arnett, 2000; Bynner, 2005). It is during this period of time that both independence and identity formation continue developing as opportunities
present themselves beyond school (Schwartz, Côté, & Arnett, 2005). For young people in Australia, these opportunities might include further education, work, travel, new relationships and the pursuit of particular interests. The transitioning journey towards adulthood begins in school and includes the development of propensities and abilities that may be recognised and encouraged during school. For example a child might show particular interest and aptitude in playing music, or be skilled building and constructing, or demonstrate particular academic or sporting abilities. These abilities or interests may then be sought post-school and begin to guide particular pathways into adult life.

In the process of emerging adulthood with a focus on identity formation, the changing landscape of modern life means that the transitioning periods have become longer and more complex in the past few decades (Bynner, 2005). This is seen as the result of increasing individualization and an expansion of life course opportunities for young people. The traditional normative idea of ‘finish school, get a job and settle down’ is just one pathway of potentially limitless ways in which a person might go forth and create a pathway for himself or herself. Within the current era of neo liberalism with consumer and market led economies (Furlong & Cartmel, 1997), the array of possibilities available puts an emphasis on individuals to forge their own life pathways and to then take responsibility for the success of otherwise of their choices (Schwartz et al., 2005). In other words there is an increased emphasis on personal agency and responsibility. The introduction of the National Disability Insurance Scheme is designed to support this expectation for people by providing funding to individuals rather than organisations.
For the young people I spoke to, it seems that they have been largely excluded from the change being experienced in the broader community. Their pathways were not determined by particular interests or aptitude, but by their disability identity. A disability identity that is a culturally constructed (Priestley, 1998) and internalised to differing degrees by the young person themselves, illustrated by the comments:

“Would you like to have more friends?” – “I have cerebral palsy”.

“I need to knuckle down and be the man I’m supposed to be, “

“Shit happens, what can you do?”

The fact that each person attended an organisation for people with disability was the first example of this. This fact then becomes a determinant for the activity that they may involve themselves in each week and the people that they come in contact with. In terms of their individual strengths, abilities or interests, this seemed to make up a secondary determinant for their individual pathways, as shown with eight of the 11 young people who only had contact with people at their Organisation centre and their family. No participant said that they had paid employment. Two of the women attended further education. In terms of independence of movement, three people spoke of ‘going out’; including Billy who said he experienced fear and Sean who said he goes by himself to a shopping centre to ‘look at girls’. Amanda who was in her late 20’s, although requiring a lot of physical support, described having the ability to get around independently. She said she used to experience loneliness and desired more friends, but she was now happy with her situation.
Young argues that the Marxist notions of class remain relevant in contemporary society where the labours of most people augment the power of a few. She defines the powerless as those who lack any meaningful authority, that they take orders and rarely have the right to give them, have social positions that allows for little opportunity for exercising skills and abilities and have little or no say in decisions that affect their lives and actions (2011, p. 22).

The notion of power imbalance is synonymous with the disability experience (Goggin & Newell, 2005). People with disability do not regularly participate in the decision-making that goes into organising and affecting their lives, from government policy, trickling through the disability sector to individual organisations and to the day-to-day decisions that are mediated by others. Power structures are apparent within the disability sector where managers and disability professionals such as therapists have the power to move in their work to better positions, are most often university educated and although may be answerable to people higher up in their organisations, generally have power over day to day decision making and a more powerful position over other workers and their clients. A sense of powerlessness was heard throughout the interviews illustrated with young people saying,

- About getting married, “Mum wouldn’t let me do that because I’m not lucky”
- On feeling lonely, “Just refresh my memory and just have a quiet… and just remember that you are here to have fun and to learn.”
According to Young (2011), cultural imperialism involves the universalisation of a dominant group’s experience and culture and its establishment as the norm. In disability theory, this is sometimes referred to as normalisation or ableness. Fiona As stated in chapter 2, Kumari Campbell (2001) describes ableism as;

a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is cast as a diminished state of being human (p. 44).

The existence of the notion of ‘disabled’ is only possible with its twin, ‘able’ with which to define it. Cultural imperialism in this context is enacted partly through the ability of those who identify as able or non-disabled as the dominant group “to assert their perspectives and experience as universal and neutral” (Young, 2011, p. 60).

The categorisation and awareness of difference is a learned skill. We are not born with identity labels in our consciousness. Christy Brown, famous for the movie that came from his autobiography, My Left Foot, illustrates this by describing a moment of his life at the age of 10. He grew up in Ireland in a large family in the 1930’s. He did not use speech or walk or have use of his hands and he was taken everywhere in a cart fashioned by his numerous brothers, trundling down roads everywhere they went and was a part of their rough and tumble adventures. One day the axel broke on the cart and his siblings began to go off on an adventure without him while they organised another cart. Christy wrote,
Up to then, I had never thought about myself. True, there had come sometimes a vague feeling that I wasn’t like the others, an uneasy sort of stirring in my mind that came and went. But it was just one dark spot in the brightness of things, and I used soon to forget it. I had gone on playing with my brothers, enjoying the little of life which I saw, all the time unconscious of myself.

Now it was different. Now I saw everything, not through the eyes of a little boy eager for fun and brimming with curiosity, but through those of a cripple, a cripple who had only just discovered his own affliction (Brown, 1954, p. 50).

During the process of analysis, there was one moment where consciousness of the affect of impairment was starkly expressed by one of the participants. The poignancy of the moment only struck me upon re-listening to the interview. When I asked Ben if he would like to have more friends, he simply said, ‘I have cerebral palsy’. Ben had paired his impairment with his lack of friends and felt that this was explanation enough for his situation. In this instance, for this young man, he had internalised the belief that the acquisition of friends required ableness or non-disablement.

**Violence**

The threat of violence is experienced by marginalised people including people with disability and the reason violence is considered in the context of oppression is because of the social context surrounding it. This too revealed itself in the interview data when I asked one man if he felt like he was part of the community and he...
answered ‘Nope, no’. He spoke of fear of ‘idiots’ at train stations and when I asked if anything had happened to cause this fear he answered, “the trains. The buses and the trains for me cause’ if I hop on a train and bus and that I can’t even do it cause you never know what they could do to you”. (‘they’ referring to ‘idiots).

Similarly, systemic sexual and physical violence experienced by disabled people in residential homes has recently been brought to light in Australia prompting calls for a royal commission (Irvine, 2017). Violence and unrest is exaggerated in times of perceived economic hardship. Negative attention is turned to people seen as ‘leaners’ rather than ‘lifters’ as stated by Australian ex-treasurer Jo Hockey (Galloway, 2013) in neoliberal ideology. Blame is placed on those seen as not contributing but instead perceived as being a drain on society (Goodley, 2014).

Where to from here?

The disability movement in Australia has been pushing out against this situation for several decades and this has been supported from a policy standpoint since the ratification of the UN Convention on the Rights of Persons with Disabilities (United Nations, 2006) and more recently with the National Disability Insurance Scheme (NDIS). The scheme’s philosophy was borne out of the recognition that a lack of choice and control is at the heart of how this situation has come to exist. As Stokes and colleagues (2013) found, social connectedness is associated with choice and control, but the reality so far is that a lack of trust in the ability of people to make decision about their own lives continues to impact on people’s freedoms. The scheme in its current form gives little credence to people’s ability to make informed decisions about the types of services that they need. In its current form, the implementation of the NDIS appears to be falling into familiar patterns of paternalism and welfare where
government agents are given significant power to assess the reasonableness of requests for support with the aim of reducing spending (Fabig, 2013).

The experiences of the 11 young people in this study are widely varied. I discovered that if the young person had little or no activity outside of their family and the disability service organisation, then their social networks appeared limited from the outside. Some people were fortunate to have close informal friendships at the Organisation like Robin, Billy and Lizzy. In contrast, Sean, Andrew, Liam, Ben, Tom and Oli, did not describe informal friendships within the Organisation, or any outside of it. This would appear to paint a fairly lonely picture, even though Tom said he was not lonely and did not desire more friends.

The social networks for the three women interviewed are larger and they each describe peer friendships fostered outside the Organisation. These women had good verbal skills and in the case of Stella and Amanda, had outgoing and gregarious personalities, which may have some bearing on the size of their social networks. The distinction between the eight young men and three women in the study contrasts with previous studies into the social circles of people with intellectual disability that do not report significant differences in gender (Wagner et al., 2005).

In terms of whether the larger social networks and networks beyond the Organisation and their family reflected greater satisfaction with their level of social connectedness, it did appear to be the case. Stella said she wouldn’t want more friends although she said that she tried to avoid feeling bored. Amanda said she used to feel lonely and wished for more friends but that recently, she was finding increased enjoyment in connecting with more people through her busy social life. Lizzy
similarly reported enjoying her friends as well as an intimate relationship although she said that she would like to meet more people in the future.

In summary, the young people interviewed varied in their descriptions of social connectedness. Some people expressed satisfaction, some people said they experienced loneliness and would like to have more friends, and some expressed a somewhat dispirited acceptance of their situation. This is impacted by the young person’s particular social lens and their need for connectedness, as well as where they live, their communication ability, access to varied community groups and sometimes, just luck in having potential friends at their Organisation centre. The young people I interviewed showed enthusiasm and a willingness to share their experience and opinions. This demonstrated a will on the part of the young people to express opinions about their lives and the ease to which they could become involved in a participatory research project. This participation could potentially lead to the types of meaningful action that could address some of the problems with a lack of social connectedness.

Each young person reported a sense of connectedness with some communities in their social network, whether it was with family, the disability organisation or the wider community. The strength and closeness of this sense of connectedness is said to influence the likelihood of further relationships and friendships (Foley et al., 2012). In order to address social connectedness, current relationships that are regarded as important by the young person in whatever form they take, from paid support workers to peer friendships need to be valued and further opportunities for meeting people need to be made available particularly with peers from all walks of life.

My task from this point was to think about how these systems of oppression that cause isolation for some of the young people I interviewed could be countered or
resisted through involvement with music. In order to do this, I wanted to investigate the opportunities currently available for accessing music, as well as to begin the process of establishing a community music program with interested young people. Given the knowledge shared by young people in this cycle of the project, I would aim to provide opportunities for choice making at each step possible and would prioritise actions in which young people, myself as researcher and any others within their social networks could unmask and counter oppressive conditions wherever they were encountered.
CHAPTER 6

Music Facilitator Workshops

This chapter contains the analysis of focus groups discussions from two one-day workshops with facilitators of all abilities music groups in Victoria. The aim of the workshops was to learn more about accessible music groups currently available to young people from the perspective of the facilitators. In addition, the aim was to bring the facilitators together to share their experiences. Nine people participated in the workshops. Three people were community musicians, five people were disability support workers who are also musicians and one person was a registered music therapist. The term ‘all abilities’ is used to describe music programs that include people with disability. The chapter following this provides an extended critical discussion of these findings.

Rationale

After talking to young people about their feelings of social connectedness, I was keen to find out what opportunities were available if they wished to be involved in music. I discovered that there was music activity in and around the day service centres during the previous year when I was conducting the interviews. This came about during the recruitment period when I introduced myself to managers of the centres and said that I was a music therapist researcher who was investigating the role of music in social connectedness. Managers then initiated an arrangement where I was invited to sit in on music groups that were being provided by the centre, or else were
being accessed by service users. This happened in each of the five locations that I visited to conduct the interviews. Through these encounters, I was able to establish that there were pockets of music activity throughout the Organisation, however there seemed to be little connection between the programs or between program facilitators.

When I began the project, I asked Community Inclusion Team members and other staff members about music programs within the Organisation. The answers were varied and often vague. Most people did not seem to be aware of programs in general. It seemed a logical step to begin thinking about how to bring some communication and unity between the facilitators and to then take steps to make the music programs more widely known within the Organisation. In the process I would be investigating the music facilitators’ experiences of running the programs including any successes and challenges that they may face.

During this time, I was beginning to see changes in the Geelong area during the trial of the National Disability Insurance scheme (NDIS). The changes were bringing into focus the idea that people were going to have greater support to access community based services in addition to those provided by the service organisations to which they belonged. The schemes’ guidelines for specialist allied health services such as music therapy was that as far as possible, the service should be a short term springboard to transition people to what they term ‘mainstream services.’ It would then become important for music therapists to understand more about the non-specialist programs that were available to people who would be participants of the NDIS. Mainstream services are described by the NDIS as those that anyone can access and are not necessarily disability specific. The NDIS will not fund the facilitator’s fee for these services but will fund access for people to attend, such as
paying for transport and a support person if this is needed (National Disability Insurance Agency, 2016c).

Across the whole sector, the NDIS has meant that organisations and sole practitioners have had to re-think how they provide services to people that they support. In the past, funding was directed to service organisations and the organisations directed this funding in ways that they deemed appropriate for their service users. Criticism of this system included the fact that it created a one-size-fits all approach to service provision and placed control of funding and programs with the providers rather than the participants or people with disability and their carers (Productivity Commission, 2011). As described in chapter 1, the new funding model of the NDIS is an individualised system, where people receive a funding package based directly on their individual needs. In theory, this means that people will have greater choice in how they lead their lives.

The significance of the NDIS on music therapy practice is that as an insurance model, it aims is to phase out people’s long-term dependence on specialist services such as the allied health professions. The guidelines state that therapeutic services are funded to “facilitate functional improvement through adjustment, adaptation and building capacity to participate in the broader community” (National Disability Insurance Agency, 2016c). Allied health professionals are typically approved to work with people to formulate an assessment and plan for therapy in order for non-specialised people such as carers, support workers or therapy assistants to continue work with the person. In the field of music participation, this means transitioning between music therapy, which the NDIS funds as a specialised allied health profession, to mainstream music programs such as community bands, music lessons,
singing groups, jamming groups or school based programs for children and adolescents. The current recommendation is that the NDIS will fund six to ten sessions for an allied health professional to do an assessment, devise a plan and then refer the person to a non-specialised support and/or a community group.

The challenge this presents is that unlike other allied health professions, music therapists have not traditionally worked in a supervisory role with allied health assistants. Music therapists place emphasis on the relationship as the basis for therapeutic growth (Lee, 2014; McFerran & Cochavit, 2012) whereas speech pathology, occupational therapy and physiotherapists might do a detailed assessment, make a plan and then supervise an assistant to continue the therapy program. Similarly, there are few documented programs of music therapists making referrals to mainstream services such as community groups, although music therapists are increasingly considering individuals within their broader social contexts in CoMT (Stige et al., 2010) as well as models of working which emphasise socio-musical pathways beyond the therapy room (Rickson, 2014; Stige et al., 2010; Wood, Verney, & Atkinson, 2004).

The critical interpretive synthesis of the literature in chapter 2 found that without exception, all reported studies of one-on-one music work with young people with disability was music therapy based and five of the six studies reported music sessions with people with severe and profound disability. The average length of time for the therapy was two years with the shortest time being 30 sessions and the longest time being five years (Murphy & McFerran, 2016). The critical review of the literature questioned the duration of the therapy programs and found that longer periods of time are typically needed for people with severe and profound disability to
establish a trusting therapeutic relationship within which therapeutic goals may be met (McFerran & Cochavit, 2012, p. 57). Music therapists respond to this need by working with people for longer periods. There was, however little reporting of sharing the work created in music therapy programs with others involved with the young person such as family members who are carers, professional support people and the community. The sharing of a young person’s skills nurtured in music therapy work could potential provide broader musical and social opportunities in that person’s life.

The NDIS guidelines state that if an individual needs longer-term therapy, then this should be funded by the health system. This is problematic for music therapy in Australia as it is not currently included in the allied health schedule of the government health system, Medicare. For music therapy, the recommendation of six to ten sessions will be inadequate in many cases, although the guidelines state that further therapy would be funded if it could be demonstrated that functional goals were being met. Further discussion on the implications of the new insurance scheme is described in chapter 9.

The goal for decreasing dependence on specialised services is a sound one and one that is supported by people with disability and their advocates (Deane, 2009), but only when there is adequate support and opportunities in non-specialised programs that continue to fulfil people’s needs. ‘Non-specialised’ in this context refers to support provided by people without specialised training in an allied health or medical profession. The purpose of the music facilitator workshops was to begin to investigate music opportunities available to young people in more detail. Initially, I was interested in recruiting facilitators of groups accessed by the Organisation service users, but in noting developments in the roll out of the NDIS where people could
potentially be supported to join any music program, I opened recruitment to facilitators of all abilities groups across Victoria.

**Method**

The use of focus group discussions as a research method was appropriate in this circumstance as part of the aim of gathering music facilitators together was to begin to create a community of people with this common role. The aim of focus groups is utilise discussions between participants in order to create data on participants’ knowledge and experience (Kitzinger, 1995). Discussions between participants have the potential to reveal aspects of their experience and knowledge including “how and why people think the way they do” (1995, p. 299). I was interested in gathering information about the philosophical views of facilitators following my increased understanding from a human rights perspective in disability studies. Additionally, the importance of music therapists’ gaining understanding of different facilitator’s skill and knowledge in the current context would be paramount if we were to refer people to mainstream programs and increase people’s rights and opportunities to access music. Therefore, there would be a duel purpose in using this method; generating data for the project and bringing people together who were previously unknown to each other. In creating a community of music facilitators, it was hoped that this action would further the transformative (Mertens, 2007) aims of building opportunities for people to access music.
**Research Questions**

**Primary Question**

What are the current music participation opportunities available to people with disability in Victoria?

**Secondary Questions**

1. How do the facilitators describe the goals or intentions of the music groups?
2. What do music facilitators observe about the social aspects of those who attend their music programs?
3. To what extent does this meet the needs of young people?
4. Does collaboration between music facilitators including attendance at the workshop result in increased capacity?

Ethical approval was granted by the Organisation (91/15) on the 6\textsuperscript{th} of October 2015 (see appendix F) and the recruitment process began in January of 2016. The same ethics application included the establishment of collaboratively run music workshops with young people. This element of the application caused significant delays and resulted in an extended gap between the interviews at the end of 2014 and this next phase of the project. The one-day workshops were held in February 2016.

An email was sent to each of the music facilitators that I had observed during my visits to service centers interviewing people. Contained in the message of the email was an invitation to forward it to other people who they thought might be interested. As a result, nine people signed consent to attend the workshops within two weeks.
**Recruitment**

The one-day workshops were advertised to people who were currently running all abilities music groups as well as people interested in running them. The stated purpose of these workshops was to investigate what opportunities were being offered to people and to share information between facilitators to increase capacity building and support for the programs. The workshops aimed to highlight aspects of music groups that were considered successful by the facilitators as well as to share any challenges that were experienced.

In running the workshop for people interested in facilitating music groups, I hoped to share information gathered from the first workshop about programs already running, as well as the findings from the first cycles of my project. In this way, I would be honouring the terms of the project, which was to create further opportunities for people to become involved in music. In travelling to the various centres interviewing young people, I also met some people who expressed interest in running music groups, but they were not sure how to go about it. Of the people who signed up to the research, only two fitted this category. Both had already been working musically with the people that they supported, although not formally in a program and so there was really no workshop participant who was completely new to the area. Consequently, each one-day workshop was conducted with a similar format.

**Addressing power**

As a tenet of action research, power structures are continually examined within a population and assumptions are challenged about its distribution (Stige & McFerran, 2016). Based on the writings of Paolo Freire (1972), education and
subsequent conscious making or **conscientization** of structural inequalities may be used as a tool for empowerment. Within the project to date, the notions of power had been raised time and again. For example, with the lack of collaboration and voice in the majority of music based projects reported in the literature, to a lack of choice and control in the ability of young people to access an adequate social networks and life opportunities.

It was my intention in each step of the project to disrupt power imbalance wherever possible. I was aware that there might be feelings of disempowerment between community music facilitators and myself as a registered music therapist. Music therapists might be seen to work in relative luxury compared to community musicians in relation to individual work, professional protections in terms of the conditions of work including continuity of income and professional status (Ansdell, 2002). The workshops were being held at the training centre for music therapy in Melbourne. This was a conscious choice given the availability of high quality equipment and instruments to use for jamming and presentation and the centrality of the location for people travelling from around Victoria.

A way of addressing a possible perception of power imbalance during these workshops was for me to run the two days as openly as possible and to embody a curious attitude to the contributions of facilitators. Focus groups have been described as ‘horizontal interaction’ rather than ‘vertical interaction’ (Kamberelis & Dimitriadis, 2005) meaning that conversations can flow across and between participants as much or more than the flow from the researcher to participants. In this way focus groups have the potential for creating a social space in which power may be reshaped in ways that “promote rich and enlightening discussions and research
data” (p.898). From this standpoint, I designed each day to be a series of focused discussions beginning with the sharing of my findings from different cycles of the project as a starting point to discussions and then to invite workshop participants to reflect on this in light of their own experience and practice. In between these sections would be opportunities to jam together if participants wished as a way to connect our musical selves.

As such, the one-day workshops comprised a series of recorded focus group discussions following the sharing of my research findings. In the participant information forms and agreement, it was stated that there would be a one hour recorded group discussion during the workshop. At the beginning of the groups, I discussed the idea that it may be better to have more frequent but shorter recorded discussions. I explained that having reflected on the breadth of experience and knowledge that the facilitators had, it may be better captured in shorter, more focused discussions. The music facilitators agreed to this format. By embodying this idea as I ran the workshops, by listening curiously and asking questions I aimed to adopt the attitude needed to share power.

As a further intention of an action research framework, “dissemination and expansion of research results beyond journal and university publications may be used to enact practical and/or social change” (Stige & McFerran, 2016, p. 2356). Armed with knowledge generated from the project so far, it was hoped that music facilitators could utilise elements of the workshops in their own practices. In order to evaluate this, questionnaires were sent to participants of the workshops six months later with questions related to the influence or otherwise that the workshops had on their music practice.
**Format of the workshops**

The workshops on each day were in four sections. This format was used to focus discussions during the day and to investigate the facilitator’s thoughts, ideas and experiences in relation to these topics.

**Section 1. Literature**

- Share what is currently known about the social aspects of music groups with the disability community of young people through findings from the critical interpretive synthesis, including membership of music programs, types of music methods, levels of decision making afforded to group members and the aims of programs.
- Ask music facilitators how congruent or otherwise this is with their experience.
- What other responses do they have to these findings?

**Section 2. Social connectedness**

- Share the findings of interviews with young people on their sense of social connectedness including opportunities for building social networks and choices afforded for establishing friendships through weekly activity.
- Ask the music facilitators about this in relation to their own programs and experience.
- Ask whether facilitators have observations about the social aspects of their groups?
Section 3. Recruitment and group membership

- Share my experience of recruiting people for a community music group.
- Ask the music facilitators to respond in light of their own experiences with recruitment or group membership more generally.
- Include questions about challenges and successes.

Section 4. National Disability Insurance Scheme (NDIS)

- Share my knowledge so far of working within the funding system of the NDIS and what the implication may be for music therapists, community musicians and participants of the scheme. (This section was information for workshop participants only and therefore their questions and discussion are not included in the data analysis. No music facilitators were working with the NDIS at this point).

Group discussions tended to follow a pattern where each participant was given space to talk about their work with minimal disruption, in effect being like an individual interview. After their narrative was drawing to a close, other group members sometimes asked questions or sought clarification, in effect deepening the understanding of the phenomena being questioned (Bradbury-Jones, Sambrook, & Irvine, 2009). This was not a directed format for discussions, but emerged organically.

In addition to the workshops, I created a closed Facebook page called ‘Music Action’ directly following the workshops and invited participants to join this to continue conversations and to update each other on what was happening with their music work. The Facebook page was also designed to be a support network.
Membership for the Facebook group has subsequently broadened to include anyone running all abilities music groups as well as people who are interested in doing so as well as members of the groups. Consequently, there are a growing number of members who were not participants of these workshops.

**Participants**

Between the two groups, there were nine participants - three men and five women as shown in table 11. Three people were community musicians, five people were working in disability service organisations employed in non-musical roles and were also musicians using music with the people they supported. One person had a background in this role and was in the process of setting up a community music group and one person was a registered music therapist. I have used the term ‘community musician’ here to describe a person who is a musician and shares their music with others in an active way in the community but is not trained specifically in this work. A music therapist might be similarly described with the addition of training in the use of music as a means of therapy. I have used the term ‘support worker’ to include employees of service organisations, even though some participants were working roles other than support within their organisation. Some of these roles were quite distinct and would lead to a loss of confidentiality if specified. All were working directly with users of the service in some capacity.

**Table 12. Background of music facilitators.**

<table>
<thead>
<tr>
<th>Community musicians</th>
<th>Susan, Angela, Katherine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support workers who are musicians and using music with the people for whom they work.</td>
<td>Thom, Amir, Russell, James</td>
</tr>
</tbody>
</table>
Analysis

An inductive, thematic analysis was used with this data in a similar way to analysing the interview data with young people in chapter 4. This involved immersing myself in the transcripts of the recorded focus groups discussions and drawing out themes related to the research questions. These included anything related to the goals, aims, intentions, outcomes and methods discussed by facilitators as well as any social or inter-relational aspects observed by facilitators in their music programs, any challenges and successes discussed as well as anything related to facilitator’s perceptions of their work and the people they work with.

Within the first wave of analysis, I made broad categories and extracted lengthy quotes. I then moved away to a period of reflection of the overall study and research questions before delving back into the data to investigate what was being revealed. The back and forth nature of this analysis into which I was drawn was different from the analysis of the interviews with young people. Two reasons for this became apparent. One reason was that I was further into the project and had knowledge of the first two cycles in my mind whilst doing the analysis. The other reason was my closeness to the role of the facilitators. As an experienced facilitator of music groups, I found myself relating very differently to the experiences of the facilitators. Because of this I found myself drawn to aspects of hermeneutic theory.
Within the framework of action research, the use of specific research methods emerges from the context and aims of the project (Kemmis, 2001). In this case the interpretivist design of hermeneutics emerged as a way to analyse the data. Hermeneutics involves a back and forth process of examination of both the data and one’s own interpretations of the data in order to bring together an understanding of the phenomena being investigated. This is sometimes known as the hermeneutic circle where there is a process of examining details before focussing out to the whole picture then back into detail (Loewy & Paulander, 2016).

Stephen Kemmis (2008) draws on critical theory and the work of Jurgen Habermas to argue that in conceptualising understanding in action research, we must think of interpretation as a process of interpreting ourselves as well as the object that we are attempting to interpret and in doing so become aware of the how our interpretations are shaped by history and the “service of particular kinds of interests””(p. 125). In this case my music therapy training, particularly in psychotherapeutic thinking and humanist theory as well as my experience as a practitioner was shaping my thinking. In addition to this, my interpretation was being influenced by my growing knowledge in the project including recent learning in critical disability studies and CoMT.

In grappling with the data generated from the focus groups discussions, I began to realise that coming to deeper understandings between the views of music facilitators with the aim of collaborative practices would increase possibilities for young people to access music. Gadamer’s (2008) concept of a ‘fusion of horizon’s’ presented a way to think about developing this understanding. The concept of finding
a fusion of horizons was also useful as I became further immersed in the data and began to see differences and similarities in the worldviews of participant as well as myself. According to Gadamer (as cited in Lowey and Paulander, 2016), each person has their own viewpoint on a given situation as well as limitations to that viewpoint and the area in between is called their horizon. Although Gadamer (2008) proposes that we cannot think beyond our horizons, he says we can expand on them (Trede, Higgs, & Rothwell, 2008) and that horizons therefore are changeable spaces. By moving back and forth between the viewpoints of participants and researcher, the aim is to find a ‘fusion of horizons’ (Loewy & Paulander, 2016). The importance of this understanding to the research project was to find points of difference and similarity with people working in the field of musicking (Small, 1999) with young people.

![Fusion of horizons diagram]

*Figure 13. Fusion of horizons.*

However, there appeared to be epistemological tensions between the traditions of Gadamer’s hermeneutics (Packer, 1985) and critical theory as described in chapter 3. Trede and colleagues (2008) examine this tension and describe critical
hermeneutics as privileging critique and resistance whereas philosophical hermeneutics, incorporating ‘fusion of horizons’ is concerned with reflection and understanding without transformation. Finding common ground between music facilitators in the focus groups and sharing a deeper understanding could be viewed as a starting point for a critical interpretation of this understanding.

The use of hermeneutic phenomenology in focus groups has drawn criticism with the argument that phenomenological research seeks to uncover essential characteristics and that this requires an ‘uncontaminated’ environment between researcher and subject. By analysing data from focus groups, the discussions could be “unduly muddied by the differing opinions and worldviews of the participants” (Webb and Kevern 2001) as cited in Bradbury-Jones et.al, (2009 p.666). Conversely, they argue that focus groups can enhance the understanding of the phenomena in question by “helping to expose prejudices by challenging assumptions during the discussions, as well as stimulating and opening up different perspectives and deepening understandings” (P.667). This is illustrated by a particular discussion during the focus groups about the artistic merits of participants’ music making where assumptions were challenged and the ensuing conversations deepened exploration of the phenomena being explored (See chapter 7).

There is no prescriptive method for analysing data within a hermeneutic framework, but the process could be described as “a kind of casuistry where judgment, practical reasons, and argumentation are of importance. It is more about forming a kind of inter-subjectivity than finding the absolute truth” (Loewy & Paulander, 2016, p. 2599). Therefore, two advantages to hermeneutic thinking in focus group analysis may be enrichment of data as a result of participants reflecting
on and sharing their experiences, and secondly, there is the chance for clarification and checking for understanding both among participants and between participants and researcher (Bradbury-Jones et al., 2009). Ultimately, within a transformative paradigm, “the consequences of accepting different versions of reality over another are evaluated in terms of their ability to challenge oppressive systems” (Mertens, 2007, p. 2). In this way, the search for meeting points among and between participants of the focus groups is considered a way to challenge ways of thinking which may subconsciously contribute to oppressive practices.

**Findings**

Categories of music programs were described from the critical interpretative synthesis (cycle 1) along with a description of the findings from this cycle. Facilitators were asked in which category they felt that their program might be placed or whether there was another type of category that had not been mentioned. Each participant said that their programs could be located within one of the categories described and the majority of these were closed groups of people with disability as shown in figure 14. Five of the nine facilitators identified with this category and most often these were held in day service centres, correlating with the results of findings in the literature. Two facilitators were running groups in the community exclusively with people with disability and one facilitator ran a choir that includes people with and without disability as shown in figure 14.
The reason for creating these categories in the critical interpretive synthesis was to considering the social aspects that music programs may afford. If programs are in a disability organisation, then participants will already know each other and the groups may serve to deepen or develop existing relationships. If they are in the community and include those from the disability community, then they provide opportunities to connect with others in the disability community and their disability identity continues to define their membership. If the program includes people from the wider community, then membership criteria are based on an interest in musicking (Small, 1999) first. This is significant to the project both in terms of people’s choices of who makes up their social networks and their way of self-identifying. I discovered that there were different perspectives on the importance of a person having a disability or not to be a friend in both the interviews with young people and in the literature. Some people thought that if a person did not have a disability, then they were less likely to understand them and others preferred to seek friendship outside the disability community (McVilly et al., 2006; Stevens, 2015).
## Goals of music programs

Table 13 summarises the type of group that facilitators describe of their music program and the goals or focus that facilitators described of their programs. It also contains the background of the facilitator.

**Table 13. Summary of music facilitator's programs.**

<table>
<thead>
<tr>
<th>Type of group/setting</th>
<th>Music methods used</th>
<th>Goal/Focus</th>
<th>Background</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amir</td>
<td>Band &amp; performance</td>
<td>Participation/Having a voice</td>
<td>Support worker/musician</td>
</tr>
<tr>
<td>Patsy</td>
<td>Jamming, recording songs, performance through community radio</td>
<td>End product (performance, recording)</td>
<td>Support worker/musician</td>
</tr>
<tr>
<td>Maria</td>
<td>Psychodynamic Music therapy including performance</td>
<td>Identity. (Music is where I can be myself.)</td>
<td>Music therapist</td>
</tr>
<tr>
<td>Susan</td>
<td>Music and drama</td>
<td>Participation, include everyone</td>
<td>Community musician</td>
</tr>
<tr>
<td>Russell</td>
<td>Music video, jamming</td>
<td>Everyone involved</td>
<td>Support worker/musician</td>
</tr>
<tr>
<td>Angela</td>
<td>Singing</td>
<td>Everyone included/participation</td>
<td>Community musician</td>
</tr>
<tr>
<td>Katherine</td>
<td>Singing and instrumental playing</td>
<td>Self-expression (express something that is within them)</td>
<td>Community musician</td>
</tr>
</tbody>
</table>
McFerran (2008) found that community musicians tend to focus more on the music, or intrinsic goals where music therapists tend to have a para-music or extrinsic focus such as social, identity, emotion or communication goals. In definitions of community music however, the intentions have been described as valuing the social and participatory nature of involvement as equal or even greater than the music learning or doing (Veblen, 2008). I was aware that in focussing the groups’ discussions around my research outcomes to date, I was directing the course of the discussions and without this, the answers to my question of an intention or goal for the facilitators may well have been different, although no person used the words ‘social participation’ or connectedness.

**Program foci**

The goals of music programs could be broadly placed into five categories that I named, connecting, identity building, an end product, self-expression and a political goal. By far the most common category was connecting. Within the category of ‘connecting’ all nine participants used the related words, participation, include everyone, everyone involved and engaged. The two therapists (speech and music) emphasised self-expression and identity and there were two other goals described as ‘creating an end product’ such as a performance or recording and a political goal; “The end game here is to get their message out”, Thom.
The most cited words used in discussion of program goals were ‘participation’ and ‘included’. Six of the nine facilitators used the word participate or be involved or included.

- It’s just about making sure that everyone has a voice and is included. Amir
- My guiding principal has always been that it was about including everybody so everyone can participate in the room. Susan
- I was trying to get everyone involved as much as possible. Russell
- I think probably my number one thing is I want to see that they feel included and that they feel some level of um, participation. Angela
- We just wanted people to participate and have the experience of making music in a group. Kathryn
- Recently it is switched gears to really engage the clients and try to get them to participate. James

These answers came after I shared the literature on the social aspect of music participation from the critical interpretive synthesis. The way that people answered was not about how people interact socially specifically, but notions of participating in some way, as well as being involved and ‘feeling included.’

It appeared that the facilitators had different interpretations of the terms ‘participation’, ‘engaged’, ‘involved’ and ‘included’ or would use them interchangeably. Brujnulf Stige (2006) suggests two ways of thinking about participation as an individual activity and as a collective activity. Each of the facilitators appeared to be referring to collective activity.
Participants were asked directly about the social aspects of their programs. This included what they observed and also what they do (if anything) to facilitate social interaction. Participants mentioned different ways that they facilitate interaction between people in their music programs. They also described observations of another phenomena of people seemingly not wanting to interact with each other. I have used the word ‘connecting’ and ‘not connecting’ to categorise these themes.

**Connecting**

- It’s (music group) really supportive. It brings out a really supportive side. In terms of social stuff, I guess, I’ve seen people sort of sharing music, bring their ipods and its ‘Hey listen to this’.
- Yeah I noticed a feeling of togetherness, and yeah, supporting one another in the group with song writing it encourages, you know everyone to put in something…that nobody knows about someone and they discover an interest that they both have. Song writing is a really interesting one I think in terms of friendships.
- About friendship, in the moment you know when everything’s going really well and there’s been this moment of high and happiness that’s kind of jointly felt by most people in the room, people’s endorphins are all out there and they are more likely to say stuff about how much they love each other or love you or love this. So the music itself or the activity itself and the way that they participate in it sort of makes people more well disposed to sort of feel friendly and feel warm towards everybody else.
- The one activity that I do that I feel really feel builds the social interaction – and this is only from my perspective so I could be wrong, is a music
conducting activity…but what happens then is that a large number of the people observe each other and watch each other and they participate and stop and start and that is the most integrated kind of group thing that goes on.

Active facilitation of social interaction (community musicians)

- It is a community with a wide range of people, though I actually break the group up… and make or kind of help them make connections. I am really strict on circle, so it’s always a circle where everybody can see each other, so everybody feels equal.
- Every single time, I’m mixing people up I often can’t even identify who’s from each group sometimes because it’s taken me a long time to work out who is from each group, um, so I don’t really care, so I am always kind of mixing people up in different ways.
- It is like when you have so many people you don’t have the opportunity to work individually with people, then you can’t really do anything apart from observe and wave a little magic wand here and there and hope that something falls out, you know.

Not Connecting

Another category was facilitators’ observations of people not connecting in the programs.

- A lot of the younger people had all come from one school, and they all come to the service and they’ve all known each other for a long time,
um, so there was a bit of a clique, um, and sometimes when there would be new people coming from different services, I could see them finding it really hard to navigate sort of social groups within the service, because it was a bit cliquey.

- I am interested that people are still very stuck in their groups that they come. They come from three different day services and they stay in those groups. They are much more confident with the people that they know and a little bit suspicious of the people that they don’t know, apparently.

- I mean the only thing that I can observe is that there is opportunity, there is plenty of opportunity for people to connect with each other and most people are not interested or able, keen to take that opportunity. Even the people I think would be.

One participant offered an explanation for why she thought people did not always want to interact with people they did not know.

I always think it is like when I go to a festival with my like friends, we’re allowed to hang out together and sometimes you meet new people and you find an amazing new friend, but actually, I kind of want to be with the people I want to be with. If I go their on my own and my whole thing is to be there on my own and that’s a totally different story, and I do go with a group, and I think there is something really natural about kind of hanging with the people you know and the familiarity of them. And I think we have this goal, I don’t know, with people I’ve worked with that people have a goal that it’s all about
people getting to know other people, which it is, but I also kind of understand to hang with what’s familiar.

Perhaps this relates to the notion of choice. What choices do people have during the music programs and do they have a choice about whether they attend or not? If choice and control has found to be associated with social connectedness (Stokes et al., 2013), the example that the facilitator gives above refers to her ability to choose how she is going to interact with others at the music festival. If she goes by herself and chooses to meet other people, then as she says, ‘it is a totally different story’. Otherwise, she goes to be with her friends. If people’s membership of the music programs are on the basis of their having disability, then perhaps this is also not conducive with the desire to connect with others. Choice to attend a music program coupled with a desire to connect with others seems to be a factor in whether a group will afford opportunities to make meaningful social connections or not.

This same facilitator spoke of an activity in her program where she invites everyone to participate individually. She said,

I always offer it to everyone um and we help people to do it, who sometimes who look as if they don’t want to do it. The support workers do more of that than I do, because I don’t feel comfortable trying to make people do things it appears to me that they don’t want to do. But quite often the support workers will put it in their hand and wave their arms around and I go well, ‘whatever’.

Where there is an expectation that people will be made to do things that they don’t want to do, it is likely that the same atmosphere will not be conducive to developing the types of reciprocal relationships that could be described as friendship.
The facilitator of this group expressed being unsure of the expectations of the service organisations where her group members came from and was taking cues in some ways from the support workers who came with the participants. She said, “I do wish there was a collective plan and you know, a collective reflections process with everybody involved, including the participants”.

In the example of the community music group within the wider community, the facilitator indicated that she had greater levels of autonomy in the leadership of her program because she runs it independently. She describes how people come for a coffee afterwards and interestingly distinguishes people who come from a service organisation:

Some of the core group of us go for coffee at a local café and so we now have – not the people from (service organisation), because they have to scoot off early to catch buses, but a couple of the ones that come independently, a women in her wheelchair gets herself there by public transport, and she comes every week and so she comes to coffee, and we have to order for her and take her money out of her purse and help her with her straw and all of that so that’s an inclusive thing sort of thing.

She also gives two examples of how she is directive in her program to promote feelings of equality between participants. One of these strategies is through the seating arrangement. She said, “I am really strict on circle, so it’s always a circle where everybody can see each other, so everybody feels equal.” If there is resistance to this arrangement, she says,
“aw, just shift you chair back a bit and they might be a bit grumpy about that, but I think, tough luck, too bad, this is a community. This is one of the rules of this community and they’re mostly fine with it.”

Secondly, with membership payments,

“just a little thing I thought, OK if I’m treating everybody the same, I’m acknowledging that because everybody is coming in the day time, nobody has got that much money. You are on a pension or you are retired or whatever, so to keep the price down, we all pay, so the people with disability all pay $7.00.”

This facilitator describes ways in which she is directive in promoting feelings of equality in her program, but in contrast to the previous examples, does not extend this to the way that people participate in their music making.

*Artistic merit or ableism?*

“Artistic merit is a term that is used in relation to cultural products when referring to the judgment of their perceived quality or value as works of art” (Stands4network, 2016)

Discussion of this section is expanded, as I was particularly interested in the notion of what I have termed ‘artistic merit’. The definition above refers to the perceived value of the work and a conversation ensued in the workshops that explored this and revealed different ways that facilitators perceive that value. The concept of artistic merit has been brought up numerous times for me as a music therapist in working in the disability sector. In focusing now on the views of facilitators, I was very interested in deepening my understanding of this notion in terms of how music
therapists may find meeting points as well as points of distinction with other music facilitators in enabling collaborations and assisting young people to access music opportunities. In hermeneutic inquiry, “plurality of interpretations and understandings may at times collide and therefore bring inspiration and expanded learning opportunities” (Loewy & Paulander, 2016, p. 2567). In addition, Gadamer’s concept of a ‘fusion of horizons’ could be sought by moving back and forth between the conversations in the data and my own interpretations, feelings and philosophic standpoint.

As stated earlier in this chapter, a distinction has been drawn between music therapists and community musicians where community musicians may be more focused on intrinsic aspects of programs and the music and less so with aspects of para-musical goals such as relational and social aspects of music programs (McFerran, 2008). The discussion below however, draws a distinction between community musicians and support worker musicians in relation to this notion. It is a conversation between three of the facilitators about editing participant audio recording and is also an example of a conversation that is deepened by the process of a group discussion afforded by the focus group (Bradbury-Jones et al., 2009). In deepening the discussion, meanings could be extracted from the data about the different worldviews of facilitators. This would not have been possible in individual interviews. Participants 1 and 3 are support worker musicians and participant 2 is a community musician.

Participant 1. There were a couple of songs there I thought, oh I could put some keyboard under it, you know, right under it… you know to give it (recording) a bit of oomph, but then I stopped doing that because I thought I
probably shouldn’t be doing that because, I don’t know if I am stepping on the actual essence of…

And then later;

Participant 1 : I guess another problem with producing is that I am able to sweeten their voice.

Facilitator 2: You are able to? Oooh…(low, disapproving tone)

Facilitator 1: So I can add things to it, a bit of a delay and all of a sudden wow, it sounds kind of professional.

Facilitator 3: I think there is nothing wrong with that.

Facilitator 2: I’m not a fan. Have to say. Yeah, I think probably…

Facilitator 1: However, it is for their listening pleasure though. You know what I mean. It is a good experience for the guys to record and write a song, but I think the end game here is to get their message out. Is to get their performance out, because that is what we are doing ultimately is performing, but I know you need to be able to package it, and I know that is uncomfortable, but we tend to do that in society.

Participant 3 later added to the conversation by saying,

I’ve always wanted to do some recording but like as a musician, I feel like I want to steer it you know. I feel like I want to give them some guidance but, not so much that I am stopping giving them inputting into the piece, you know what I mean? I find that really tricky because otherwise I just find it is
patronizing bullcrap. You just give someone a drum and what are they doing? Because I am approaching it from a musicians perspective, you know you have a song, what is the song going to be about, who’s writing it, who’s contributing what bit, you know?

And earlier on hearing a performance by a group of people with disability;

Participant 3: What I loved about it was it was polished and it was cool. You could take it in as a musical spectator, you know. You could appreciate it for what it was. It was actually music. It wasn’t just random, you know. And I’m not saying that there is not a place for that but it sort of got me excited about the possibilities...

This conversation seemed to highlight differences in the worldviews of support workers and community musicians in this context. Community musicians come from a belief of ‘music for all’ and participant 2 may have a more inclusive view of people’s participation in music. Support workers who are also musicians may be combining the performance aspects of music, where ‘artistic merit’ is seen within a specific cultural norm including standards of playing and sound, with the stance of being a worker in a disability service sector with historic and cultural norms that accompany this position. Perhaps there is a tension for these facilitators between these two viewpoints of support worker and musician. For a support worker there is a motivation to share music with people with whom they work, but then what to do when the standard doesn’t match with an ideal?

I was struck by the use of the term ‘patronizing bullcrap’; not least because of its colourful turn of phrase - in describing the notion of accepting what might be
considered a sub-standard musical offering. I interpreted this meaning as referring to a critique of work in disability with the notion of a ‘mire of low expectations’ for people. Reporter, Stephen Bevis quotes dance artist, Claire Cunningham who aims to break down misconceptions about art and disability. She says,

“The most disabling aspect is low expectations, either from non-disabled people towards disabled people or disabled individuals being raised in a way that they have low expectation of themselves. That’s a conditioning that takes a lot of work to break out of.” (Bevis, 2016, p. 1)

There is a difference between low expectations however and a desire for normalising behaviour or corralling people’s actions and contributions into a format that may be seen as acceptable by a societal norm. This was raised in chapter 5 in the discussion on cultural appropriation and abelism where a dominant culture begins to normalise certain standards of behaviour and those cultural norms are then imposed on a marginalised people defining their ‘otherness’ (Campbell, 2008).

The notion of artistic merit is deeply embedded in our society, as illustrated by the distinction made by one community musician facilitator talking about recordings. She speaks as though to ‘do something’ would then create a product deemed acceptable by someone ‘non-disabled’. The sentence was not completed and that suggested to me the difficulty of this concept. The context for this community musician is in having to produce something for funders of grants in order to facilitate arts projects. She says,

I think it comes down to what is the purpose of the recording. Is it for the person to hear their voice and not judge it critically and just going wow, I am
on that recording or is it to do something that they would then pass on to a…

This tension is also illustrated with the comment, “I know you need to be able to package it, and I know that is uncomfortable, but we tend to do that in society”. The word ‘uncomfortable’ here implies that it is less than ideal, but it is what we need to do in order to ‘get the message out’. The facilitators go on to argue that any recording artist has a producer that works with the raw recording to make it into a sellable product. A counter argument might be that in many circumstances, the artist has some control over this process. The historical context of oppression of people with cognitive impairment situates this idea in a different light to the average recording artist.

Another facilitator who is a support worker expressed how her views changed over time in working musically with her participants;

Initially of course I had grand plans of amazing music and stuff but, I guess once it gets down to the nitty gritty, um, it’s just about making sure that everyone has a voice and is included, and has an opportunity to perform and shine, that kind of thing.

I came across two young people during cycle 4 who were not so interested in the ‘participation for all’ ethos in the group that was established in Geelong. These young people were interested in finding facilitators who could increase their music skills and help them to participate in more professional arenas. For these young people, finding a facilitator such as the support worker musicians would be an ideal match for their ambitions.

In order to enable participation in the broader community however, individual
skills are only one side of the coin. The other side is the capacity and willingness of music facilitators and the community to support that participation. There were several examples of broader participation being enabled through Angela’s community choir with its broad membership, people’s songs being played on community radio in Patsy’s program, Amira’s public performances with her band and Thom’s recordings of people’s songs for sharing outside the music program and performances at local council events. Further discussion of this is under the heading, ‘Political goals’.

**Recruitment and group membership**

The question of recruitment and membership of music programs in the community came after sharing the process of recruiting people for the collaborative music group in Geelong. This recruitment process occurred at the same time as I was recruiting for the facilitator workshops and the difference in the two processes was so stark that I found it meaningful to draw comparisons. Recruitment for the facilitator workshops involved sending a series of emails directly to facilitators and these were then forwarded to other interested people and I was contacted in a relatively short time by people wanting to sign up. This efficient method of communication is not widely established in the networks of young people with disability. The young people I spoke to in the interviews did not report using the Internet for communication. They were depending on family or the service staff to organise activity for them or to inform them of opportunities for program involvement.

The introduction of the NDIS in Geelong initially set up a competitive system where service organisations were endeavouring to retain service users for the maximum amount of time to receive funding. They were consequently resistive to passing along information about programs outside of their service. Service
organisations traditionally manage activity for their service users and act as brokers to community programs. Service users, or their family and advocates are therefore in the routine of liaising with service organisation rather than community groups directly in order to source programs. This is set to change with the introduction of the NDIS, but the problem remains in the meantime of how people can access information about community programs. Detailed discussion of this is given in chapter 9.

I recounted some of this experience in the facilitator workshops and asked participants what their experiences had been. The music facilitators were not working in areas where the NDIS had been rolled out at the time of the focus group discussions. Their experiences showed that regardless of this, they encountered difficulties in reaching people to let them know about programs in the community without the support of service organisations. The only successful example of a community group having diverse membership was established through word of mouth.

Three facilitators who spoke of challenges with recruitment were the three community musicians. Support worker musicians working with service users in their organisations did not have issues with building group membership. Patsy had recently attempted to start up her own community music group in Melbourne. She had experience working in the disability sector for some years and was also an accomplished musician. She said that she had encountered many barriers in recruiting people because she couldn’t get access to potential participants without an association with a particular service organisation. This resulted in her abandoning her plan. She said:
Challenges I guess it’s finding those people with disabilities and having to communicate with all those levels, you know, so you contact council and they then contact that person’s house and with the flyer and stuff and there is so much you have to get to sort of get in touch with those people that its almost like, um, there’s not many opportunities for people with disabilities to find out about stuff that’s going on in the community unless it’s sort of handed to them. Umm, with this group that I tried to start, that’s something that I yeah, that perhaps, yeah, I just found a bit strange, I guess.

Another facilitator spoke of her experience in finding members for her community group and said:

I don’t know that I have had a lot through formal channels, it’s been more word of mouth where people have brought their friend. You know and then the friends keeps coming and they might go off and do pottery for a year and come back, so it’s been going for a while and it has ebbed and flowed. I am really interested in this thing of how do people independently find out about it… that people know that this is a service they can come to and be looked after. It’s not like throwing them to the… poking them in the door and saying ‘good luck.’

Another facilitator spoke of running short term projects over a day or two, but found it ‘almost impossible’ to find people to join a program for a longer period.

Recruiting people and getting people to come out of their regular routine programs or something different is really difficult. Almost impossible if they haven’t got the support of the organisation behind them and then you end up
working with people for a day or a couple of days if you are lucky (in a project).

She described the challenge of limited time and meeting the expectations of funders.

Anyone who is learning needs time to play and experiment whether it is, (demonstrates random playing and then ‘oh’ and begins to play with a steady beat) so how long to give people to play and experiment. How much do you expect from people – or it might not be what you expect but it is what the general funder looking in is expecting a product or a coherent music piece, at the end of the day.

As far as starting a group from scratch, for the facilitators working in the community, it was not possible without support from a disability organisation. One facilitator said however, that there was a young person in her group who came with her mother.

This young woman doesn’t speak. She just wanders around and she’s got all these funny little quirky things that she does, she just doing her thing. She was completely comfortable with just doing her thing, I’d be going ‘oh, you’ve got my list, I might be needing that in a moment’, you know ‘oh, that’s yep, that’s my ukulele’, you know and she’s just wandering around hee, hee, hee, and the mum was just really, I thought wow, as a mother you would be really happy to see your child just be accepted for whatever he/she was doing.

This facilitator also said that it was something that you couldn’t necessary ‘manufacture’.

I tried to manufacture it (the all abilities group) via another community house
in the area and it just didn’t work. You know, a group came from (service organisation) and then there were maybe four other people from the general community and some of them just couldn’t handle being in a group with people with disability. So they came twice maybe and then wandered off.

**Political goals**

In describing findings from the critical interpretive synthesis of connections to the wider community, I shared that authors of these programs tended to report on political agendas for example, with Curtis and Mercado (2004) describing their choirs as “communities of resistance” in order to “enact social change” (p. 2), or a participant in Elefant’s (2010) Israeli choir saying of his performance, “so that people out there can see and hear what the disabled can do” (p. 200). Stige, (2008) discusses the political potential inherent in performances describing how they may go beyond the connections between performers and audience and extend to broader community values. “Concerts are part of the ecology of a community and may therefore change attitudes and expectations in relation to valued participation in that community” (p.135).

This was reflected in the data from the focus groups as facilitators appeared to recognise this potential in their programs. A goal of performance as well as recordings was described in terms of having political intentions such as ‘spreading the word’, or ‘getting the message out’. One facilitator said if she were able to have more time with people, she would be interested in including performances for this purpose. She said she would facilitate a process where people can, “find a way of expressing themselves that is meaningful to them, and then I think performance is an important part of spreading that message but it wouldn’t necessarily be my first goal”. A support
worker musician described this observation at an end of year concert:

Seeing his mum at the Christmas concert just beaming with pride and it’s just amazing, it’s absolutely amazing. You know and parents tearing up and seeing their daughter singing whole songs on stage by themselves and they can just see the benefits, absolutely. It’s amazing.

Similarly, with making recordings of participant’s music and performance, the theme of sharing something of a person is seen as important. One facilitator recognised the importance of, “getting a product that they can actually take away and feel proud of and show their family and friends ‘look this is what I have done’. This is me singing, I wrote that lyric, you know”. Two facilitators described this idea as an integral part of their work.

- They did a few performances at council events and that which is great, but isn’t that, as a musician what I am trying to achieve? You know what I mean. So if I can engage these fellows and the format is there to allow for them to do it and perform, whatever standard it is that we are doing it is awesome.

- I think the end game here is to get their message out. Is to get their performance out, because that is what we are doing ultimately is performing.

One facilitator spoke of getting a recording played on a community radio show.

It was like the biggest deal, it was talked about for weeks, um and everybody’s families were going to be listening in to that song and it sounded kind of terrible because our recording skills were very poor, but you know it was just this great sense of accomplishment

Me: Talk about wider audience, wider connections I mean…
Facilitator: Yeah I mean, it’s community radio so, (laughing) all sorts of different people listen.

**Feedback survey**

After a period of eight months, I sent an online survey to participants of the facilitator workshops seeking to find out how their programs were going including what they saw as ongoing challenges and successes and also whether they were utilising anything from the workshops or not in their programs (see appendix G).

Four of the nine participants returned completed surveys. The most united answer given by each facilitator pertained to the question of the most useful element of attending the workshops. Each person said that they valued the opportunity to connect with others;

- Sharing ideas and experience
- Meeting other facilitators and hearing their approach
- Inspiration from others and sharing ideas
- Peer exchange gives me encouragement and helps me to know that I am doing OK

Part of providing ongoing communication and support for music facilitators was to set up the Facebook page called ‘Music Action.’ Although eight of the nine facilitators joined this group along with others, very few have posted comments or information independently apart from me. It is possible to see how many people view the posts that I contribute and most people read them and often ‘like’ them but have
not utilised this as a platform for exchanging ideas. There was one exception to this where a facilitator asked for ideas to develop a feedback form for participants of her music program. This received many comments and suggestions. The opportunity to meet physically with others in a group context appeared to be a useful forum for peer exchange.

One of my research questions was, ‘does collaboration between music facilitators including attendance at the workshop result in increased capacity’? In terms of the value of connecting, it appeared to help. When I asked if any skills were being utilised from the workshop, one person said ‘no’ and three others said music skills, such as learning new songs or song writing. These were not skills that I taught but were shared among group members.

In terms of what was missing from the workshops, one facilitator said, “more specific techniques from music therapy”. The skills people said they would like to develop for themselves were,

- Sound production techniques
- Using music applications
- Having an individual focus while working with large groups
- Learning sign language
- Using electronic instruments
- Building music skills with people with varying abilities

This suggests that workshops designed specifically to build music skills and specific skills for including people with varying abilities would be useful. In terms of improving their programs, facilitators said variously that they need more one-on-one
time with people to build music skills, more adapted instruments, more paid time for
developing their program, more money, more instruments and a better venue to
conduct their program.

Conclusion

Findings from this cycle indicate that most people work in closed groups exclusively
with people with disability and one person runs a mixed group in the community of
people with and without disability. The goals of programs most commonly focus on
everyone being involved and participating and to a lesser extent, self-expression and
identity building, and political goal of ‘getting the message out’.

Music facilitators in this area are providing a number of varied opportunities
for people to participate in music groups. These were most often for people within an
organisation who are familiar with each other. From the interviews I had with young
people, it was found that most people’s social networks were limited to the people
they came in to contact with through the disability organisation that they attended. If
the person had friends in this organisation, then they were more likely to be satisfied
with their level of connectedness. If they did not have friends there, then they reported
feeling lonely and had a desire for meeting more people and finding friends.

The community groups offer further opportunities for meeting people by
bringing together people from different disability organisations, but in these
circumstances, it seemed that people were often staying with the groups of people
they were familiar with and they were reluctant to interact with different people. The
question of people’s choice for attending the music programs was not answered, but
may have been a factor in this. With the music group of people from the wider
community, the facilitator describes different methods she uses to ensure that people are treated equally and how she encourages interaction. Performance and recordings were one way of making connections with the wider community and reports of connections through this method were described as providing opportunities for showcasing talents as well as connecting with a variety of people.

Some differences in worldviews were found with support workers who were musicians and people who were community musicians and this difference caused some tensions between focus group participants. This was illustrated in discussions on varying ideas of artistic merit. Support worker musicians come from a place as musicians and offer their personal skills and see a part of their role as getting the message out. Community musicians are more focused on everyone playing together and having a ‘go’ rather than meeting a particular standard.

When reflecting on these findings, I have learned that there is significance for the way that music therapists could be referring people to community or mainstream music opportunities and vice versa. Understanding the goals of facilitators such as ‘everyone in it together’, or ‘building skills and focussing on the musical outputs’ are different ways that people may be interested in pursuing music. The skills and passion demonstrated by the facilitators who participated in the focus groups would be of great value to people who are looking to engage in music programs. Matching facilitator’s skills and focus with participants who are seeking these ways of appropriating music, will be a valuable health resource for young people. Within a transformative paradigm, actions that enable greater access to music should be prioritised as well as actions that ensure empowering conditions are encouraged and maintained for young people within those opportunities.
Reflection of music facilitator workshops

Our pragmatic view of epistemology and the nature of enquiry indicate that it is not the means of production of the evidence that constitutes the criterion we use to justify a knowledge claim. More specifically, it is the quality of the critical reflection on that evidence and the creative attempt to weave beliefs based on that evidence into the totality of beliefs held by the rest of the community (Freshwater & Avis, 2004, p. 6).

In this critical reflection of the findings from focus group discussion with music facilitators, I will expand on a discussion of different worldviews of the participants of the focus groups. I will then provide a critical discussion of the funding model, the National Disability Insurance Scheme (NDIS) within a human-rights based framework in light of people’s entitlement to access music opportunities. I will then conclude with some ways that music therapists may advocate for those rights by increasing and enabling broader musical opportunities.

Music facilitators

At the conclusion of investigating all abilities music groups from the perspectives of music facilitators, I was most struck by the fact that I knew very little about accessible community music programs in my geographical area and had not
considered that there were so few people doing this work. The differences in ideas and experiences of facilitators opened my eyes to the varied possibilities that may be available and fostered to increase opportunities for people to access music with their individual funding packages.

As described briefly in chapter 2, community music covers a diverse range of music making endeavours from around the world. Definitions are varied but authors tend to agree that it is a group activity where people join together to make music which “reflects and enriches the cultural life of its participants and their broader community” (Bartleet et al., 2009, p. 22). It may be characterised by “decentralization, accessibility, equal opportunity, and active participation in music-making” (Olseng, 1990, p. 59). The intentions of community music programs have been described as valuing the social and participatory nature of involvement as equal or even greater than the music learning or doing (Veblen, 2008). Higgins describes a commonality of community music practice as residing in a space of the ‘workshop.’ He conceptualises the workshop space through critical thinker, Jean-François Lyotard’s definition of ‘event’ which is something that “can disrupt pre-existing frames or contexts giving opportunity to the possible emergence of new form and voices” (Higgins, 2008, p. 392). The ‘workshop’ in the context of community music programs are places that foster and harness human desire to make music and additionally, may “be in the pursuit of equality and access beyond any preconceived limited horizons” (Higgins, 2008, p. 394).

The comments make by facilitators in the focus group discussions who identified as community musicians showed similarities to the definitions of community music above. The community musicians who participated in the focus
group discussions are also members of Community Music Victoria, a not-for-profit organisation. As stated in chapter 1, its vision and mission is,

High quality participatory music-making experiences to be available to all Victorians, and our mission is to facilitate the development of the skills, opportunities and networks necessary to bring this about. Making music together is a great entry point into creativity and results in profound benefits to individual and community health and well being (Community Music Victoria, 2016).

The ways in which facilitators understand this conceptualisation of community music translated to discussions in the focus groups. In particular in reference to the value of participant’s music contributions in what I termed ‘artistic merit.’ Notions of artistic merit have been explored in disability studies. In her book, “disability and contemporary performance”, Petra Kuppers says that her desire “aims towards a form of un-knowing that un fixes certainty about otherness, but that still remains able to act as a dialogue ground with our social and cultural reality” (Kuppers, 2013, p. 10).

Similarly, Bruce Gladwin who is director of Back to Back Theatre in Geelong, an internationally renowned theatre group of people ‘perceived as having intellectual disability’, describes the process of developing theatre with:

It takes time to make a new work; each requires a new route of immersive inquiry. Our theatre is not achieved through a particular technique or formula. Collectively we forge an inclusive path that allows all of the ensemble members and collaborators to travel together. Timeframe and process are considered to allow individuals to voyage with creative dignity, understanding
and the opportunity for meaningful contribution. (Gladwin, 2013)

And in another interview;

Just by stepping onto a stage, the actors signify their own disability. They can’t do otherwise. Are they aware of that? Are they in control of it? Gladwin’s not sure it matters: “When you’re making something, why not use everything to its fullest, including how an actor looks onstage? Why deny yourself half the palette?” There are, in other words, layers of meaning at work; one from within the work, one from outside of it. It’s problematic, yes, but that’s the beauty of it – and it’s why Ganesh… is so full of signs and icons. As Gladwin says: “I like watching theatre that scares me”(Gladwin, 2014b, p. 4).

Each of these artists tackles notions of value in artistic endeavours. For Kuppers, the value in her art is where it acts as a ‘dialogue ground with (our) cultural and social reality’ and similarly Gladwin, by allowing actors to ‘voyage with creative dignity’ values meaning making both from within the work as well as outside of it referring to the identity of the actors. In some ways, each is saying that there is not a masking of difference with the artist, but instead an exposition and a valuing of that difference including the space where it meets with the art or ‘cultural and social reality.’

In working as music facilitators with people traditionally marginalised and de-valued in society, the notion of music as empowerment may be a useful concept to consider in this context. Rolsvjord (2009) discusses the notion of empowerment in music therapy practice and writes that music skills and abilities may be needed for
participation in our culture and society but there is a paradox when thinking about how to help someone to appropriate these skills whilst maintaining or building a person’s sense of empowerment Rolsvjord (2009). If the aim is for a person to become more autonomous in their life, then this can be demonstrated by not intervening in the person’s decision making. If a person is helped to make decisions in order to participate, then that may lead to feelings of helplessness and dependence. In music programs, if we intervene in someone’s artistic endeavours with the intention of aiding their participation in society, are we helping or hindering in terms of empowerment?

Rolsvjord (2009) offers that this paradox may be addressed through thinking about interdependence instead of dependence and mutuality in relationships where the person both contributes to, as well as gains from the relationship. In music programs, the artistic bounds of the facilitator are broadened by contributions from the participant and participants gain from the contributions of the facilitator. Just as Maria says in the facilitator workshops, ‘we are journeying together’.

During focus group discussions after the conversation that I termed ‘artistic merit’, I recounted an experience of my own. The purpose of doing this was to contribute another perspective based on my experience and to invite further discussion. This experience was with a young woman in a long-term one-on-one music therapy program. Our sessions at the time consisted of song writing and recording so that the woman could give CD’s to her friends and family. She sang in a monotone, almost spoken word style by herself and when I sang with her, she sang in relative pitch and rhythm. When we did recordings, she would sing the verses independently with me on guitar and I would join her in singing the chorus. In my
mind, I was giving the songs musical structure and melody according to my values in music making. One day during the recording of one of her songs, she stopped and asked me if I would not sing with her. I was slightly taken aback, but went along with it and did another recording. I thought when I played back both versions, she might hear what I was trying to do and see that my way sounded better. When she did listen back to both recordings, she heard the one where I did not join in and she smiled and said that was the one she wanted. Her strength in speaking up for what she wanted taught me a valuable lesson. I told the group that since then, I have also begun to enjoy and value the unique way that she makes her music.

One of the community musicians responded with,

I think the voice is such a, I mean it is such a you know this is mine, this is me, when I speak to you or when I sing to you or whatever, this is, I guess in a kind of metaphysical sense it is my heart being made of sound and so really, I get that you know.

The ‘patronising bullcrap’ term, as colourfully stated by one facilitator, would indeed be apparent if people were falsely praised or kept in a disempowered position in music programs where they were not given the freedom to ‘voyage with creative dignity’ or opportunity to go beyond “preconceived limited horizons” (Higgins, 2008, p. 394). I have heard this criticism before at disability events where performances consist of a facilitator on guitar singing and other participants sit with hand percussion instruments, seemingly disengaged or described by one conference delegate who muttered next to me, ‘token participators’. The line between this perception and the value that a person might place in their own musical offerings as their ‘heart’, is what Gladwin might be referring to when he says there are, “layers of meaning at work;
one from within the work, one from outside of it. It’s problematic, yes, but that’s the beauty of it” (Gladwin, 2014b, p. 4). No matter how it is perceived by another person it offers a space of new possibilities and creative mutuality. The same support worker musician said on the other hand, that he was ‘excited by some of these possibilities’. Perhaps to take another quote from Bruce Gladwin, in terms of facilitating artistic endeavors with people,

At this beginning, as the person at the helm, so to speak, I feel directionless, like I have no idea how to do my job and the past work seems a complete mystery, not knowing how it was made. I’m envious of those practitioners that have a craft to fall back on. In this situation one can only hope for art to transcend craft. The aim is for curiosity to replace the anxiety (Gladwin, 2014a, p. 6).

In searching the literature to support this discussion I have referenced studies in community music and music therapy, but for the support workers who work with music, I turned to studies looking into the experience of these workers. Research is increasing in this field due to an acknowledgment of the influence that workers have on the people they support (Hastings, 2010). Much of the research has pointed to factors such as the work being underfunded, often stressful and not well supported (Jennifer, Hensel, Rikki, Carolyn, & Dewa, 2015). In an Australian study of support workers in community settings, researchers found that staff reported having favorable views on the job tasks, on interactions with the people they supported and with co-workers but felt dissatisfied with factors relating to autonomy in their work including decision making and utilisation of their skills including a “pervasive sense of powerlessness, isolation, and being undervalued” (Ford & Honnor, 2000, p. 359). A
certificate in disability support work in Australia includes “training and support to people with disabilities; enhancing their ability to achieve greater levels of independence, self reliance and community participation” (Intercaretraining, 2016).

To explore the support worker musicians’ views of their broader support work was beyond the scope of this study. The literature points to the fact that the job has numerous challenges and that motivation to work in the sector is grounded in a respect and interest in the people that they support. As well as their role as support workers, facilitators who attended the workshops were also variously a sound recording producer and bass player, a pianist, singer and songwriter and a guitarist, video maker, singer and songwriter. The role of being a musician includes an emphasis on skill acquisition and standards of performance. When combining these factors, it may be possible to surmise that the motivation for support workers is to place value on the music standards of the people that they support and to have certain ideas about artistic merit. This is illustrated by one person saying, it is a case of ‘approaching it from a musicians perspective’.

Ansdell (2002) defined music therapy and community therapy as having “shared territory but different maps” (p.10). He described the similarity as being ‘musicking as a way to work with people’ and the differences in ‘where they work, why they work including the goals of programs, how many people they work with – music therapists often work individually, the depth of work possible and the status achieved as professionals’. In this assessment, Ansdell was referring more to traditional music therapy work rather than CoMT, where the crossover is perhaps less well defined.
I have used these elements as headings to compare community musicians as well as support worker musicians with music therapists. Table 14 illustrates some of the differences based on the data from focus group discussions.

**Table 14. Similarities and differences between facilitators of music programs.**

<table>
<thead>
<tr>
<th>Who is worked with</th>
<th>Community Musician</th>
<th>Support worker musician</th>
<th>Music Therapist</th>
<th>Community Music Therapist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Groups</td>
<td>Groups and individuals</td>
<td>Groups and Individuals</td>
<td>Groups</td>
<td>Community centres, or service organisations including people who are not service users or staff.</td>
</tr>
</tbody>
</table>

| Where they work | Community centres | Service organisations, Group residential houses. | Service organisations, community centres, elsewhere | Community centres, or service organisations including people who are not service users or staff. |

| Why they work | Strengthening community through music | Get people involved with music, ‘get the message out’ through recordings or performance | Therapeutic goals | Strengthening community through music, therapeutic goals |

| Continuity and depth of work | May be ongoing or project based. Less depth | May be ongoing. Less depth. | Long and sort term. May be in-depth work | Long or short term. May be in-depth |

| Funding | User pays/grant funding for projects | Organisation pays | User or organisation | User or organisation |

| Training requirement | No formal | Disability training. No formal music. | Bachelor/masters in music therapy | Bachelor/masters in music therapy |

| Background | Musician | Musician/ disability support training | Musician/therapist | Musician/therapist |

| Philosophical tradition | Music for strengthening community | Quality music production, sharing music, sharing music | Music as therapy. Change at an individual or group level. | Musicking as an engaged social and cultural practice |
To think about this in terms of what people may appropriate from music as a health resource, for individuals interested in performing or gaining specific music skills or pursuing particular genres of music for listening or playing, they will be well matched with support worker musicians who value these goals. For those interested in “the social and participatory nature of involvement as equal or even greater than the music learning or doing” (Veblen, 2008), they may be well matched to community music programs. For those seeking therapeutic work, particularly in individual settings, then music therapy will be the best match.

In addition to the facilitators who were able to come the workshops, there were several others who could not come. I visited two of these groups as part of the recruitment period for the focus groups. One was a community singing group run by a women in a council run community centre in Melbourne. She said that a group of people from a day service close to her used to come, but following a staff change, they no longer attended. She said that this was very disappointing both for her and for the group members. Her group was then halved and membership now includes several people who access the community centre independently. If the NDIS provides funding for people to access services independently, then presumably these situations will be less common. This music group facilitator could be described as a community musician.

Another person working musically with people was a Salvation Army employee who facilitates a different type of group again. He told me that he has been running these groups for 16 years. He would not be described as a community musician in the traditional sense but perhaps as an entertainer or ‘disco DJ’. The
group is very well attended with up to 80 people at one time. They are in the format of a disco, but held during the day so that day service users can attend. The lights are turned off and coloured lights used. The facilitator is in a small booth and sings karaoke style to popular music from the 60 through the 80’s. He told me that after some years of experimentation, he had found that these genres maintained a happy and relaxed atmosphere with the attendees. The following is an extract from my reflexive journal after attending one of the discos.

*People were engaging in their own way. Everyone seemed relaxed with moments of heightened emotion with calling out or rocking/clapping. (The facilitator) said that he doesn’t’ use rap or metal because both can cause too much excitement or even violence. He seemed to find the right type of music to keep people contented and happy. There was interaction between people with eye contact, sometimes touching or more overt hand holding, or dancing together. A lot of obvious interaction was with the staff. I was put in mind of Anthi Agrotou’s study where the subtle communication between people that was only revealed through long and careful observation. I wonder what was going on here that was not obvious? The group has been going on for 16 years. Some people knew each other really well, I am guessing. Whatever was happening, there was little pressure on anyone to do anything. I offered around instruments at different times. Some people took them – some looked away or grabbed something and immediately dropped it. People seemed purposeful in their participation. They knew what this was all about and they took their place – much more than me who hovered about looking for a good way to ‘be’. (Should I try to assist or stay out of the way?) Some people danced, or rocked, some people were in perpetual walking motion around the*
room and in and out of the action. Everyone participated in his or her own way. It was an accepting and welcoming atmosphere. No one was asking me to do anything or to be anything. I could have jumped on a microphone I was happy to pick up a djembe and play some beats for a while. No-one seemed to take particular notice. If I had the urge, like some people, I could have been more extraverted. This is something that has evolved over years. It’s like (the facilitator) has hit the ‘sweet spot.’ There was a group of people from (another day service) with more complex needs in wheelchairs. Everyone appeared to be relaxed. Some people were happily rocking in their chairs and smiling.

This demonstrates a different kind of group and music experience again. In terms of participation with the activity, there were various levels demonstrated by people attending from listening quietly out of the way, to actively dancing and singing holding microphones. A distinction from other programs described in this context was a lack of reciprocation or co-creation (Stige, 2010a, p. 113) from the facilitator although he may have been adjusting the music choices to suit the mood of people in the room. What was also apparent was that there was no pressure or expectation on people to participate in any particular way. People could ‘be’ whatever they wished in the moment.

Brynjulf Stige (2006) distinguishes two main types of participation as individual and collaborative activity. The participation discussed in the workshops could be described as collaborative participation. Stige then defines two types of collaborative participation as communal experience and political action or citizen
participation and suggest that both communal experience and political action are integrated in this type of participation (p. 1340). He describes this as,

a process of communal experience and mutual recognition, where individuals collaborate in a socially and culturally organized structure (a community), create goods indigenous to this structure, develop relationships to the activities, artefacts, agents, arenas, and agendas involved, and negotiate on values that may reproduce or transform the community (Stige, 2006, p. 134).

The community music groups offer opportunities for communal experience, but data from these focus groups indicated that levels of participation vary considerably. In some instances, people often staying with the groups they were familiar with and they were reluctant to interact with anyone outside of that and although they develop relationships to the activities, this is not necessarily extended to other members of the group. In terms of negotiation of values in the various groups, it could be argued that this was apparent, even with the disco as the genre of music is determined by participant’s responses to it.

Findings indicate that all the facilitators had an ethos of including people and having people participate in their sessions but that the meaning and the outcomes of this was varied. I learned that community musicians come from a tradition of music for all and they are actively encouraging this to happen. I learned that support workers who are musicians offer people their specialised skills and that may be well matched with people who are seeking to develop that particular skill set. In the case of the workshop participants, it could be sound production and recording, or music video making and song writing.
I learned that the music facilitators from these workshops want to know more. They are interested in learning more skills and being able to articulate what it is they are doing and want to do. I also learned that there is openness to collaboration in this space between community musicians, support worker musicians, music therapists.

At the end of the facilitator workshops, I too was excited by the possibilities that may be available to young people looking to access music if these opportunities could be made known to them. The NDIS is providing funding to individuals to exercise choices in purchasing services to meet their needs, but few resources have been directed to building the capacity of the community to be able to meet this need. There seem to be few music facilitators doing this work and for those who are, they expressed challenges linking to potential participants as well as having adequate resources both in skills such as signing and music technology and adequate venues.

**The NDIS and people’s rights to access music**

The NDIS guidelines emphasise less reliance on specialised support and encourage peoples’ transitioning to mainstream supports through individual funding, but what does this mean in terms of accessing music? What are the opportunities being offered and are ‘mainstream supports’ currently realistic for everyone? It is possible that further disabling conditions may arise in expecting people to be a part of a group in the community that is unable to meet their needs or maximise opportunities for that person to participate meaningfully. As one of the facilitators said about a community program that is accessible, “it’s not like throwing them to the… poking them in the door and saying ‘good luck” (Chapter 6).

In the Shut Out report (Deane, 2009), criticism came from the fact that many
people had left institutions but remained in a state of being ‘shut out’ where they were living in the community but not given opportunities to contribute as equal citizens in meaningful ways. The NDIS presents a further shift by encouraging the transition of people out of another form of institution, namely the large service providers into community groups that may be currently ill equipped to facilitate meaningful inclusion. To withdraw or limit funding for specialised services where there is no active plan for ‘the community’ to take its place creates a danger of shifting into another form of marginalisation (Goggin & Newell, 2005).

The formation and realisation of the NDIS occurred following long campaigns by disability rights movements in Australia and in other countries including New Zealand, Great Britain and America (Productivity Commission, 2011). Australia was one of the first signatories to the Convention on the Rights of Person’s with Disability in 2008 (United Nations, 2006) and the NDIS has based its principals on choice and control as a basic human right. It is also based on a neo-liberalist ideology of consumerism where people who consume things also have “choice, participation, rights and redress” (Ramcharan, 2016, p. 1).

Young and Quibble (2000) distinguish negative and positive rights within disability studies. They describe negative rights as those that are concerned with quality of treatment (protection from harm, abuse, discrimination) and positive rights as, “equality that requires special treatment.” The former is concerned with that which must not be done to you and the latter with that which you must be given (Young & Quibell, 2000, p. 749). They suggest that negative rights are a “band-aid solution and far from stopping the injury in the first place, are often unable to even find the wound” (751). They say that what is made apparent in many cases of people with
intellectual disability is that rights cannot be used to empower people whose very participation in a legal framework (or societal framework) renders them powerless” (Young & Quibell, 2000, p. 753). If individual rights must be decided upon by people other than the individual, such as parents or caregivers, they “cease to be individual rights as intended and beg the question of being ‘rights’ at all. In short, to empower oneself, one requires rights, but to exercise rights, one has to be in an empowered position” (p. 753). Within this context, the question becomes whether the new system is about human rights or about the right to consume.

Within a neoliberal ideology, there is an assumption that if individuals are given choices to purchase what they need, then the market will respond by meeting that need. In fact companies and services will be compelled to do this in order to stay viable. This is based on the concept of ‘atomisation’, where people are initially separated and treated individually. They then cluster together where there is a common need, which in turn causes a reaction in the market to meet that need (Connell, Fawcett, & Meagher, 2009). There is an assumption embedded in this and that is the capacity of people to navigate the system and secure the supports that they need as autonomous individuals. The people most likely to benefit from such a market-based system are those individuals who have education, are English speaking, geographically well placed, and are in a strong socio-economic position (Connell et al., 2009). Those who don’t fall into this category are likely to be doubly disadvantaged. “If personalisation becomes aligned with individual responsibility, at the expense of social responsibility, advocacy and community capacity building, then strong cause for concern emerges” (Fawcett & Plath, 2012, p. 7).

In terms of service provision, a market based system works to make change
for needs that are being met by funding from the NDIS such as equipment, services for support including allied health and transportation, but does not create a change for the provision of non-funded services such as community services. There is no particular market incentive to make the broader structural changes needed to include people with disability. As disability advocate El Gibbs states,

The ordinary choice that any consumer gets is key to how (the NDIS) is being sold. But it is still a located within your ordinary, not mine. Your ordinary still has stairs to the train station, and it still stares at difference. How much of my individual choice can change this (Gibbs, 2013, p. 43)?

In moves to redress this situation, the NDIA have allocated funding towards a system called the ILC or ‘Information, Linkages and Capacity building’ (National Disability Insurance Scheme, 2016). This is a grants based system from which organisations or individuals can apply for project based funding to fill gaps in the market place. This tier of the funding model has recently begun its rollout with a national funding round allocated. The successes or otherwise of this system will take time to assess.

In considering the new market based system from a critical perspective, it has become apparent the capacity of the community and mainstream music opportunities are limited in number and not widely known about. In order for people to exercise choices and appropriate opportunities to access music, then action is needed in capacity building and linkages to programs, as well as building new programs. Music therapists may take up this broader role as a ‘music worker’ by using knowledge of the systems, as well as having the ability to respond to people’s individual needs for music as a health resource. This role could be similar to a social worker role except
with the focus on music. Social workers Barbara Fawcett and Debbie Plath (2012) described ways that social work could be used to counter the disadvantages of an individualized system by a “move beyond an individualised focus to facilitate community networking and advocacy in order to access appropriate services, promoting community responsibility for alleviating disabling social barriers” (p. 13).

**Music Worker Model**

A model of music therapy work could be developed for this fast-changing local context, encompassing knowledge of the current opportunities available for accessing music and the development of opportunities to meet the needs of people who have increased choices with their funding. Ansdell (2002) used the term “action therapists” where therapists could initiate “cultural and attitudinal changes (p.17). Within a CoMT framework, Ansdell describes the role as a balance between being the role as ‘musician’ to promote music opportunities for individuals and ‘therapist’ to work with factors that prevent access to these (p.28). Using linkages and capacity building as a way of working, a music worker could link interested young people with music therapists, community musicians or other music facilitators including participants of the NDIS who are interested in music group facilitation. This type of role is one that would require organisational support for funding and could fit within a business model of consumer led services.

A number of models have been developed in the music therapy literature looking at pathways between music therapists and community musician facilitators. Stuart Wood (2016) developed what he terms as a Matrix Model (Wood, 2016). This emerged from work in a neurological rehabilitation unit. He describes the Matrix Model as one that views music in a multi faceted way that acknowledges the social,
witnessed and political aspects of musicking (p.44). The model allows for fluid movements between different ways of ‘doing music’ such as music therapy participation, individual and group, or community music based on the needs and wishes of participants/clients/musicians as well as resources and opportunity.

Figure 15. The Matrix Model.


Within this model, Wood said that progression from therapy to community was not always the direction that people might take with some people taking the reverse trajectory. He described this as looking both at a person’s progress and a person’s progression in the matrix valuing both their rehabilitation as well as their artistic experiences (p.50).
Musicspace, in the UK, was set up in response to the deinstitutionalization movement in the UK and is supported by the National Health Service. Its vision was to create a space for music for all, encouraging all kinds of performance and links to wider cultural and social contexts (Bunt, 2004). It provides community based music therapy for individuals and groups, in house and outreach, training and support for postgraduate music therapy training, to workshops in therapeutic music making, development and supervision of research as well as performance spaces. Funding for the music space comes from a combination of government, private sources and community grants.

McFerran (2008) explored the roles of community music and music therapy in a participatory action research with adults with disability. She made one proposal of a rotating application of community music and music therapy to reduce monotony, provide varied and diverse experience and address different goals and contrasting opportunities. She quoted one participant who defined the differences as “community music is like going for a tumble in the surf whereas music therapy is like lying down in a cool refreshing river” (McFerran, 2008, p. 5).

O’Grady and McFerran explored similarities and differences between community musicians and music therapists through the lens of a health continuum looking at where on the continuum, people might access music and for what purpose. If someone was at an acute or crisis stage of their health, than they may need certain types of support in the music continuum. If they are at a well stage of their health, then their needs will be different. These authors discuss the power differential being most apparent at the acute end of the continuum where the health of the music worker is most different to the client. In the wellness end, the power differentiation is less.
These authors’ definition of health is that it is “not an either-or condition but a process involving physical, emotional, social, cultural, and spiritual dimensions” (O’Grady & McFerran, 2007, p. 68). The term ‘health’ might be used cautiously in this context given historic oppressive associations with the medical model. Although I have used the term ‘health’ in this writing I refer to the music as a resource rather than a person’s health status.

O’Grady and McFerran’s model becomes useful in this context considering the power differentiation between the person seeking music and the music facilitator. The young woman I worked with who told me to stop singing had developed a level of empowerment and self-advocacy to express her needs in that context. As the critical interpretive synthesis in chapter 3 showed, community musicians work across all areas of disability but the level of engagement with people appears to decrease, the more complex the disability.

Perhaps a level of engagement would a useful framework to consider with NDIS participants. At the very core is the level of music engagement that a person desires. Beyond this, opportunities could be appropriated where possible without hindrance from pre-conceived notions about what a person can and cannot, should or should not do. From an advocacy perspective, the core of this approach is predicated on individual choice. Figure 16 shows some of the ways that music may be used or appropriated by young people and others. It also shows some affordances that may be accessed by these different pathways. Facilitators of the various pathways are in the rectangles.
Figure 16. Music for health.

I have drawn connections between each of these different types of music pathways to demonstrate how a person might move back and forth and in between them, depending on their needs and choices and the availability of programs and facilitators.

As a concrete example, in the conclusion of this thesis, I have proposed just such a position with a large disability organisation. The proposal is culturally and contextually sensitive and positioned precisely between the relevant services and the service providers that exist. There is no single model of what a music worker would be, however in this context I have proposed a position with the aim of increasing people’s opportunities to access music, increasing the capacity of the community in
enabling these opportunities, facilitating music projects and conducting research to identify how the music worker model is best utilised.

The role would include four elements:

1. Work with service users to identify particular music interests such as:

Recreational/quality of life/well being

- Personal music for everyday listening
- Community music involvement (singing groups, bands, drumming)
- Music events (access to concerts and festivals)

Careers

- Performance
- Music education (tafe, university, music lessons)
- Music industry (Sound production, recording, composing)

2. Work with the community to increase access to music including building collaborations with:

- Music sector
- Community Music Victoria (capacity building workshops/connections and support for inclusive music programs)
- Music Therapists
- Music educators (teachers, tertiary music institutions)
• Disability support worker musicians (capacity building/connecting people to expertise)
• Arts organisations
• Community centres
• Advocacy groups
• Youth and social workers
• NDIS

3. Facilitating music projects

• One off workshops (compose or create a piece of music for performance)
• Continue with community music workshops
• Coordinating music events and festivals
• Marketing and PR
• Developing new ideas for projects

4. Research

• Conduct an action research to investigate the role of a music worker within the organisation with the aim of discovering how the role may be best applied to achieve positive, practical outcomes for the organisation and its service users.
• Cycles of planning, action, observation and reflection
• Use an emergent design focussed on practical knowledge generation.
• Analyse data at each cycle and use to inform subsequent actions.
• Report to key stakeholders each month with key findings
• Disseminate results through continued presentations and peer-reviewed publications.

DeNora writes that music’s role in health is dependent on how it is appropriated and what it affords through this process (DeNora, 2007). In this context, I am interested in what music may afford people, in other words, what they want and what I know from the research is possible and then how this may be linked to achieve the goals and aspirations of that person. I know that opportunities and resources are limited for the young people that I have encountered through the project. How will people access or appropriate what they need from music? Will music therapists and other music facilitators learn to locate affordances along with participants? The next cycle describes the process of establishing a community music program in collaboration with a group of interested young people.
CHAPTER 8

Community music program with young people

“Not even great talent and industry can ensure life success over adversity without opportunities” (Elder, 1997) as cited in (Bronfenbrenner & Morris, 2006, p. 822)

In this chapter, I describe the final cycle of the action research, which was to establish a community music program with a group of young people from Geelong. Geelong is my hometown and a regional city outside of Melbourne. The band currently meets weekly in a community centre in Geelong run by the Salvation Army, a protestant Christian church and international charitable organisation first established in London, U.K. in 1865 (Salvation Army, 2016). There are currently 10 members of the band and we are called ‘The Rockheads’. Three young men in their late teens and early 20’s who access services from the Organisation were the first provide consent to participate in the research project. They formed an organising committee in the beginning along with the Community Inclusion Team member from Geelong and a support worker. Since then, four more young people accessing service organisations have joined as regular band members along with two more support workers. In addition, there are two people who play with us occasionally who are community members of the Salvation Army: a trombone player and percussionist and singer.

The band did not begin rehearsing at this centre. At the first meeting with the three service users of the Organisation and the Community Inclusion person, I described two community centres that I had previously visited and found suitable in
terms of accessibility and cost for the music workshops to begin. One of the community centres, run by the local council, was a youth centre and had a recording studio and music room with a large store of instruments that were available for us to use. The other centre was similar but lacked the instruments. In that first meeting, I suggested that we might try the youth centre with instruments first and if it didn’t suit us, we could look elsewhere. Two of the committee who use speech gave their approval for this first step.

At the first meeting in this community centre, I had the instruments out around the room including electric guitars, basses, drums, hand percussion instruments and microphones. I began the meeting by saying that it was our music group and we could do whatever we liked. I asked people what they wished to do. Two of the men said they wished to try the electric guitars and the third man wheeled himself to a cymbal on a stand and began to scratch the surface. Previous to this session, the men were able to access a large music group in their service centre run by a community musician who played guitar and sang. The men were offered hand percussion instruments and were able to request songs. Neither men said that they had played other instruments before this. The support worker also said she did not play an instrument but was keen to try along with the men. The Community Inclusion member had some experience playing percussion and joined on a drum machine. Journal extracts from this first session, session 5 and a session 6 months later are included in appendix I.

The band rehearsed for six months at this centre, but on two occasions, we were unable to access it because of council staffing issues and I hurriedly found another centre to meet. This was when we first went to the Salvation Army centre.
When I asked band members what they thought about this centre as a place to rehearse, there was general consensus that they liked it. When I asked why, one member said, because there are more people. The Salvation Army provide a free lunch every week where anyone is welcome to come in and have a meal. Typically, there will be 30 to 60 people having lunch of all ages and milling around the common areas. The band rehearses in the afternoon and so coincides with some of this activity. When I asked whether we might stay at the centre, band members agreed that this would suit well and so we have continued there.

The request to include more people in the band had been raised much earlier during band discussions about how the workshops could be made better. In an early session, when asked what they though about the program, band members said that they enjoyed playing music and they enjoyed playing with support staff. When we discussed how it could be improved, one man said ‘more people’. Discussions ensued on how this might be achieved and band members then contributed to recruiting more people from their centre at other programs during the week.

I have included a brief description of the Rockheads here to give some background. The majority of my discussion however will be focussed on the ethics process, the recruitment process and interactions with service organisations in order to establish the program. The reason for this is the time taken to establish the music program ran well into the final year of this project. The band continues and has had several performances and I draw on some of these experiences to illustrate developments within the group. Once the opportunity was afforded to the band members, they took leadership, made decisions, embraced the opportunity to learn instruments and give performances. This included making decisions about where we
rehearse, who can be a part of the group, participation in steering aspects of the design of the program such as the music we play, the instruments people have learned, as well as taking up marketing and leadership roles and interacting with people outside of the service organisations. What I discovered was lacking was the opportunity for having this kind of experience and so I have focussed the discussion on challenges to providing the opportunity for young people to make the music workshops into what they need.

I used the word ‘workshops’ in the ethics application for the proposal for a collaborative music program with young people. The reason for this was in incorporating Higgins’ (2008) conceptualisation of the term in reference to community music making. He describes it as a place representing “a search for new means of expression and new rules of presentation (and it) has the potential to generate new genres of artistic discourse” (Higgins, 2008, p. 392). In this way, it resists a top-down approach and attempts to invite collaboration and equality. I use the word ‘program’ to refer to all the community music workshops together.

At this point in the project, the NDIS had been implemented in the Barwon region, which includes Geelong, as a trial site for two and a half years. Each person who had been assessed as eligible had transitioned to this scheme in Geelong. Eligibility entails being under 65 year of age, an Australian citizen and having “life-long disability that substantially impacts on everyday living” (National Disability Insurance Agency, 2016b). Each person who I wished to work with in the music program would therefore be a participant of the scheme unless they lived outside of the catchment area of Barwon. This meant that it was possible that a person may
choose to use funds in their individual package to attend a community group independently of service organisations.

The ethics application for this stage of the research (No.91/15) included the proposal for the music facilitator workshops in cycle 3 (see appendix F). In the application, I refer to the collaborative music program as ‘Section A’ and the music facilitator’s workshops as ‘Section B’. Figure 17 shows the form of the two proposals within the ethics application.

![Figure 17. Second ethics application. Stage 2.](image)

The proposal pertaining to Section A took significant time for approval. The reasons for this will be described later in this chapter, as well as in chapter 9. Once the application had been approved, the recruitment process was also significantly long and challenging. By the time there were a small group of interested young people who
had signed consent and were ready to begin, I was in the final year of the project. The time allocated to meet each week for group members accessing day services was restricted due to the routines imposed by the service. This meant that time needed to form the music group as well as the processes need to collaborate as co-researchers within a participatory framework (Bigby, Frawley, & Ramcharan, 2014), became too restricted in the time left for this research project. Consequently, the group runs as a community music therapy group. I videoed some sessions and recorded detailed descriptive field notes in the style of ‘thick descriptions’ (Geertz, 1994) and decided to focus the remainder of the thesis and ensuing presentations on investigating the barriers that I encountered in establishing the program.

The process of starting up the music program illuminated factors that I believe relate to some of the reasons that young people have limited social networks and why they report feelings of social disconnection and a lack of autonomy in their lives. Over the course of the investigation, my thinking changed from a focus on the young people at the centre of the investigation to the systems surrounding them and the influence that this has had on the ability or otherwise for young people to have equitable opportunities to access music.

One moment that is crystallised in my memory of this period, was after a meeting with a group of allied health professionals during the recruitment period. I am an allied health professional and although there were no music therapists among them, the relative proximity of the worldviews between us made the moment more poignant for me. I could not completely separate my profession and myself from the systems that I saw as restrictive and disabling for young people. The following is an extract from my reflexive journal after the meeting where I presented my proposal for
a community music group collaboratively run by young people. I was requesting that the therapists’ pass along flyers (see appendix H) about the program to any young people they worked with.

The allied health chairperson person asked whether I could send evidence and maybe a summary of the interview data analysis. It is like there is the invisible line up of gatekeepers standing between the young people and me and I can’t get to them. If I did, maybe they would wonder what I was going on about because only a select few people are allowed to offer anything at all. I feel so frustrated. When I do get to talk to a young person, such as at balloon football they say ‘yes, sure. I would like to be in a music group’ (10\textsuperscript{th} December).

I then emailed my supervisor with...

I was thinking more about our conversation yesterday and about my reaction to the therapists’ meeting I had and being asked for a written summary of goals and projected outcomes of the study in order for them to pass the information to young people...Did we have to have a music therapy assessment to be in a band or other music group? Did we have to justify some particular need to then get information about where to go to a gym or be in a sporting group? I can understand this justification for children in some circumstances, but with adults there has to be some way that options are freely made available and accessible in order for people to choose what they want to do with their insurance money. I guess at this early stage of people actually having choice, it will take time to sink in (email correspondence, 11\textsuperscript{th} December 2015).
At this point in the project, I began to sketch a diagram of the layers of systems that I had encountered surrounding the young people with whom I wished to work. I found that a useful way to think about this came from an early version of ecological systems theory, formulated by developmental psychologist, Urie Bronfenbrenner (1979). This framework led me to understand that the initial parts of the research involved an investigation into the microsystems of young people or those to whom the young person has direct contact – namely family, the people at their particular Organisation service and music facilitators. The latter part of the project would involve an investigation into the macro, exo and meso systems including, the service sector, government organisations, culture and society.

Figure 18. Ecological systems

Bronfenbrenner’s theory provides a framework to consider the ecology within which a person lives, how that influences their lives and how they, in turn influence their ecology. Ecological systems theories have been drawn upon to think about
context and culture within music therapy work (Rolvsjord & Stige, 2015; Stige, 2016). Bronfenbrenner’s framework consists of a series of four nested structures, each one being progressively further from the person but nonetheless having influence on their lives (1979, p. 3). The first is the immediate environment called the microsystem, which is made up of people with whom the young person has direct contact such as family, peers and staff at the day service. The next layer is the mesosystem, which is the interactions between those in the micro-system, such as the level of interaction between the family and the day service. For some young people this may involve a significant level of interaction and for others, it may be very little. The next is the exo-system, which is the larger social context surrounding the young person to whom they have no direct contact, but nonetheless influences the life and opportunities for that person. This comprises the local community, the upper levels of the disability organisations’ hierarchy, including the ethics board and also interaction between disability organisations and management levels of the NDIS. Finally, the macro-system comprising culture, the economy, law, government policy including the National Disability Insurance Agency, which oversees the scheme. Included in the macro system are the political systems and how they interact with the components of the exo-system.

Further to these layers of systems, Bronfenbrenner added the element of ‘time’ which he refers to as the chronosystem (1993). The element of time had been used to investigate child development by looking at the progression of age on an individual, but added to this was an acknowledgment of the influence of change over time in the systems and environment in which individuals live. This is a significant element in the current project as it relates to changes within the funding model of disability.
service provision over the course of the investigation and the trickling down effects and impacts this has had on the young people at the centre of the project.

In describing the project from an ecological perspective, I could describe the first 3 cycles of my investigation as being within the microsystem. What I found from interviews with young people was that their social networks were very small. Together we mapped out the people in their lives and found that most often, this was made up of family, with whom all the interviewees lived, members of staff and other service users at their day service. Only three of the 11 people I spoke to had contact with people outside of this. When I asked young people what they thought of this, I found that for those who reported having no peer friendships in their centre and no contact with people outside the service and their family, that they reported feeling lonely and had a desire to connect with more people.

Through the workshops with music facilitators, I found that most programs are held in disability services centres and therefore, they don’t offer the opportunity to connect with people outside of this. This was also reflected in the literature where over half of the articles on the social aspects of music programs reported on sessions within schools or disability services. For the young people who reported having friends in their disability organisation and said that they were happy with their social situation, than this could be seen as adequate from a social sense. For those who reported feeling lonely and wished to connect with more people, the opportunities for this to happen were limited.

The reasons for this limitation did not become apparent until I attempted to establish the collaborative community music program. The extent to which I encountered difficulties in establishing the program meant that the time for including
participants in the process as co-researchers became untenable. This was due to the
time restrictions of this project as well as time restrictions imposed by the routines of
the service organisations.

The group has formed and is continuing to run as a rock band called the
Rockheads. Instead of being a participatory project involving the young people as co-
researchers, the program could be described as a community music therapy group
where members make decisions about the day to day running of the program as
participants rather than as researcher/participants. Band members participation
includes leadership roles, marketing and promotion, shared decision making about
how the workshops run, who can belong, the music we play and where we play.

For this chapter, I have taken the field notes and reflexive journaling from this
period and woven them into a semi-fictional story in the style of a case study. Merseth
(1994) describes a case as “a descriptive research document, often presented in
narrative form, that is based on a real-life situation or event” (276). Three
fundamentals of a case are that they are real, they rely on careful research and study
and they foster the development of multiple perspectives by users. Related to cases
are the way in which they are used and how this might help to frame conversations, as
stimulants to reflection, as tools for professional evaluation, or to orient individuals to
particular ways of thinking (Merseth, 1994). Importantly for this project, the case is
created explicitly for critical discussion and includes “detail and information to elicit
active analysis and interpretation by users with differing perspectives” (Dooley, 2002,
p. 337). A case study, then can be understood as the study of a case in order to
understand a larger group of cases or population (Gerring, 2006). In this instance, I
have used the form of case study to convey my interpretation of a large volume of
data into a more digestible format as a case story or a creative non-fiction (Caulley, 2008) designed to shine light on a situation and to stimulate discussion. The technique of creating a case story from my field notes relates to the ethnographic endeavour of “an elaborate venture in” as described by Geertz (1994) where reflexive meaning is situated in the reporting and writing of events (Stige & Ledger, 2016). The story emerges after the initial efforts to ‘grasp’ are followed by a process of ‘render’ (Geertz, 1994, p. 6).

This case study is written in response to the process of gaining ethical approval, the process of recruitment through disability service organisations and others and liaising with the new government-funding model, the National Disability Insurance Scheme (NDIS) in order to begin community music workshops with young people. The proposal, with participatory and emancipatory aims, was to recruit young people living with disability who were interested in being in a music program. The young people would form an organising committee with me to decide what type of music group they wanted to be, when and where it would be, who could be a part of the group and how to evaluate it.

What I discovered was an irrational system of oppression when seen from the position of attempting to enact this proposal. What I have attempted to do is to describe the process as a therapeutic case study whereby the position of the clients (in this case the exo system and macro systems) is problematized, to flip the traditional hierarchical assumption that people with disabilities are the ones needing help. I suggest that the young people with whom I wished to work have the characteristics of a good therapist, being consistent, available, deeply caring and committed to process. In stark contrast, the pathological client displays frequent anti-social behaviour, is
resistive, rebellious and restrictive. Why not flip the tables? As Dan Goodley writes, disabled people have for too long been denied the opportunity to occupy the position of the modernist human, being rational, capable, responsible and competent (Goodley, 2014). The characters I describe who are the clients in this case are representative of whole systems; human resource ethical boards (Humres Ethcom), disability service organisations (Disserv Org) and Government funding models (Govdis Fundmod). Their actions are based on incidences that occurred during the process of establishing the community music program.

**CASE STUDY**

This case study describes a music therapy program conducted over a year. The three clients are aged between 60 and 70 years. They suffer long-term mental illness and live in a supported residential unit, referred to among residents as ‘The Bubble’. The three clients were due to be discharged from the Bubble sometime within the following year to a supported community based house and the long term aim was that they could become a support group for each other. The goal of the music therapy program was to begin to build trusting relationships between the men and therapist and to slowly introduce interested members of the community into the group with a view to independent living.
Figure 19. Humres, Diserv and Govdis
Images sourced from free images online (Image of faces, 2015).

My role in this case study is one of music therapist assistant. I had been given the task of arranging a time and day to bring the clients together to the therapy program and then to be an observer of the therapy process, learning by recording events through detailed notes. The therapist, Marla is represented by the young people at the centre of this picture. She has a long history of working with similar clients. Her particular theoretical framework is based on a humanistic and psychodynamic orientation facilitating non-verbal communication through the music, drawing on the client’s own strengths as a way forward towards health.

Figure 20. Marla and Mel
Images sourced from free images online (Image of faces, 2015).

The most important element of this program was that it was to be held outside the Bubble in order to challenge and work through some of the embedded patterns of behaviour noted with each of the clients. Methods employed in the therapy would remain open and flexible in order to respond sensitively to some of their complex
needs. They might include active music making, song writing and listening to music with verbal discussions emerging from the music processes.

Table 15. The clients.

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Humres Ethcom</td>
<td>60 year old</td>
<td>His clinical notes include attachment to ritualistic patterns of behaviour and retreats to oppositional and controlling conduct.</td>
</tr>
<tr>
<td>Diserv Org</td>
<td>64 years</td>
<td>Swings of mood, is self-isolating which manifests in anti social behaviour including rigidity and abandonment fears.</td>
</tr>
<tr>
<td>Govdis Funmod</td>
<td>70 years</td>
<td>His notes included identity disorder and lack of insight characterised by personality changes, involuntary escapes from reality with grandiose plans for the future.</td>
</tr>
</tbody>
</table>

Phase 1 – Coming together

My role as music therapy assistant in arranging for the clients to meet together was unexpectedly longer and far more involved than I could have predicted. The restiveness I encountered appeared to be the result of the complexity of the client’s illnesses and long term institutional living. It was Humres and Disorg, whose agreement to attend at the therapy program proved to be the most challenging. Humres’ notes show a general resistance to programs offered at the Bubble, particularly where the structure was not clear to him from the very beginning. This feature of his illness has been somewhat allayed with proposals of cognitive behavioural therapy in the past, as the concrete nature of the process was straightforward to communicate. This proposal was for a creative arts therapy program and was designed to address aspects of behavioural rigidity.
I first knocked on Humres’s door, and when he answered, I said that he had been referred for a new therapy group. He said that he would listen to my proposal, but then gave a time and day several days hence when I could come back and tell him about it. I came back at this prearranged time and described the music therapy program. I said that it would take place outside the Bubble in the community, would involve music making and that the process would be an evolving one led collaboratively by Marla and members of the group.

Humres’s initial response was to regard me sceptically. “So I just turn up without knowing what is going to happen and we all decide how the group runs together? It will never work.” I asked him how he thought it would work and he said he’d think about it and come back to me. In time, he did come back with a list of questions including:

- What if things get out that I don’t want people to know? How are you going to stop people talking outside the sessions?
- What qualifications does Marla have to run this program? I want to see a Curriculum Vitae and references.
- I need to know what the room looks like and what facilities will be there. How will I know if it will suit my needs?
- You haven’t told me anything about who might be there. I need guarantees of who will be in the room.
- What if people leave?
- What if new people join that I don’t like them?
- Who’s going to protect me? You can’t trust anyone else around here.
I was aware that this type of therapy was new to Humres. In our discussion, he said he had heard of music therapy and the manager of his unit told him it would be a good thing if he went and it was this that appeared to keep him cautiously open to the idea. I explained to him that the more structure put in place in the beginning, the less chance there would be for new and possibly helpful opportunities to emerge from the group. I explained that the therapist was very experienced and would skilfully manage any turns and changes that occurred within the course of the therapy sessions.

Despite the careful explanations and attempts at reassurance, he remained insistent with his requests and after some deliberation, I recognised that I would have to meet him half way if we were to have any chance of getting him to therapy. My concern with this was that the restrictions would limit the options for innovation within the group, so I would need to carefully keep avenues open for the group to move. I told him how the room would be set up, how many people would be there in the beginning, the music activity expected, in what order and even made a prediction of how we might interpret various actions and events that may occur within the session and included a description of Marla’s experience and qualifications. I wrote this down in detail and then waited for his response.

Humres took a very long time to get back to me. Staff in his unit described how he struggled, mulling over every aspect of the proposal and worrying about where things may unravel. Finally he came back to me, this time with a long list of questions and requests.

- *When will you be talking notes, on which days and at which points in the session?*
• You mentioned some people who would be a part of it, but what about if others want to join? What if I don’t like them?

• What will happen if they cause me do something I regret?

• What will I get out of it? You didn’t explain that clearly enough.

• Last time you said “session” and this time you said “sessions”. Which one is it?

• When will it start?

• When will it end?

• What if someone leaves?

• How much music making will there be and how much talking will there be?

• I want a watertight contract between Marla and me. In French.

I interpreted this fixation with structure as a way to maintain control over the process, but in responding, I felt that everyone including Marla was being drawn into his illness. I felt deeply compromised and wondered if things would ever progress. I had two choices, to continue with Humres to try and work through these issues, or to answer his questions, provide a contract in French and then hope that it would end there and that Marla could work with what was left.

Each time I saw Marla in the hallway she asked how it was going. I told her that I was persisting but that there was a fair bit of resistance. She regarded me with an understanding look and encouraged me to remain patient and persistent. She did not seem particularly surprised by this but after 7 months, I thought I had detected a slight air of frustration at the delays.

Again Humres went through the answers and came back to me with four more questions. These were quite simple questions and I interpreted this as I slight yielding
to the process. I replied straight away and Humres, perhaps asserting his power one more time, took 5 weeks to return a response of agreement to attend the therapy program. Marla and I considered that this was a break though for Humres and we were hopeful of seeing further change in the group therapy.

It was understood before we began that Disserv Org would not participate without Humres, so once I had him on board, I approaching Disserv with an air of optimism. I was very surprised initially that he began with a similar level of restiveness such as asking where and when it would be and what was going to happen? Again I repeated to him that it would be an evolving process where everyone could make decisions together and the details of the program would be worked out in a collaborative manner step-by-step. He responded by saying that it seemed highly irregular and he came up with many of the same reasons as Humres for why he couldn’t attend. I explained to him that Humres had been through the proposal in great detail and had covered every possible angle and that he was now satisfied and had agreed to attend.

Disserv came up with several of his own concerns for example, that it sounded boring, or that he had his own music, why would he need to listen to other peoples’ or that the thought of having to make decisions was going to take too much energy. He also expressed concern that if he went along, he might miss out on something else that would be more interesting. He was most concerned with what he would get out of it and how the therapist would be able to guarantee this? He wanted to know if I was able to guarantee a benefit balanced with the cost on his time and energy.

We later discovered that Disserv was responding to Govdis’ new personality and that this had manifested in paranoid behaviours, particularly in relation to any changes into his routine. He was particularly anxious about losing the support of Govdis who
was displaying signs of independence with his new personality. Govdis’s new personality had evolved slowly during the past couple of years and he was calling this one, Nashdis. Nashdis had materialised following involvement in another collaborative, creative arts therapy program.

Reports from the therapist of this program included that Govdis was demonstrating empathy and flexibility in his thinking. His general mood and had also improved and this was resulting in increasing sociability and friendship around the Bubble. However, as much as he seemed able to articulate these values, they did not always translate in his actions. The nature of this change was quite radical and although staff seemed hopeful, only time would tell if they would result in significant change for the better.

On the day that I approached Govdis about the music therapy program, he was in good spirits smiling and appeared receptive. He agreed immediately and even offered to assist with any logistics in establishing the program. I mentioned that Marla was going to run the program outside The Bubble and he was particularly enthusiastic about this. He said that the old Govdis wouldn’t have cared where the program was as long as Disserv appeared to be in control of the situation, but he was now of the opinion that therapists may have valuable ideas and that having the program outside The Bubble was an excellent idea. I contacted Marla saying we finally had everyone’s agreement to attend and she made a date to begin on the spot. A room containing instruments was booked at a community centre down the road from the Bubble, which was also used by other members of the community.
Phase 2. Trusting or not. Group processes emerge

During the process of the therapy, it was Disserv that continued to be most resistive. This manifested each week in small but significant ways. For instance, he wandered in late every week saying that he eats lunch at the same time every day and this could not be changed under any circumstances. He promptly left at 2.00pm sighting that he needed to use the toilet and that he could only use the particular type of toilet in his own room. The other men in the group who were accustomed to these behaviours accepted this, but after a while Marla began to gently challenge him and discuss alternatives, which were either ignored or met with ever more excuses.

The first few session’s involved explorations of various percussion instruments by the men with Marla attempting to provide containment through playing steady rhythms and reflecting some of the men’s initial music making. These first musical offerings reflected the various personalities of the clients. Humres faded into the background with barely discernable sounds, his energy seemingly be spent on getting to the program. Disserv either played separately to everyone else or following Govdis’s beats, whilst Govdis played the drum loudly over everyone else, whilst simultaneously denying that he was drowning anyone out. Curiously, all the men appeared to be ignoring Marla.

For example, at one point we needed another percussion instrument and knew that Disserv carried one in his bag. He did not use it in the session and so Marla asked him if it could be used. He was making eye contact with her, but seemed a little distracted. She asked again and got the same response. A little later in the session, she said the same thing and this time he looked at her a little longer. As he hadn’t
answered her, she decided to reach over to towards the instrument, but the moment she did this, he became very upset. A dialogue followed:

Disserv: “You can’t just pick this up without asking me!”

Marla: “But I have asked you several times already.”

Disserv, “I can’t just have anyone using it. What if something happens to it? I need a proper arrangement for this to happen?”

Marla: What sort of arrangement would you need?

Disserv retreated back into himself mumbling in an annoyed tone leaving Marla’s question hanging in the air.

Another time, Marla asked Disserv if she could start the group a little earlier the following week because there were to be some guest musicians joining the group. Again, she asked him directly and they made eye contact and it was assumed that he had heard her, but when she started the group earlier the following week, he again became upset and began speaking angrily and about decisions being made without consultation. It was almost like Marla was a blind spot. It was acknowledged that she was in the room and that the group existed only because of that, but so much of the time, it was as though she were completely invisible to them. I interpreted that in rebuffing Marla’s authority, the men attempt to maintain their positions of power, however tentative in the group.

I observed several occasions where the men would talk with each other, sometimes in deep conversation regarding the music group for example, who would play which instrument and what type of music they might listen to, but just between
themselves, leaving Marla out. Most of these conversations occurred between Govdis and Diserv. On the occasions when Marla spoke or tried to break in, there was barely a pause in their conversation with each other.

It gradually became apparent to me that Marla could only be acknowledged by the men in certain circumstances and that those circumstances were difficult to determine and were known only by the men. These patterns of behaviour which were founded in the Bubble however, were becoming increasingly dynamic, particularly influenced by the changing personality of Govdis. Govdis periodically confided in Marla before or after the session, offering assistance and telling her that the program was useful, but this connection was rarely observable once the session began.

**Phase 3. Break through**

One session, six months into the therapy, Marla suggested to the men that they might want to perform a song or two that they had been working on. The performance would be in the common room of the community centre and other people from the Bubble would be invited to attend. This seemed to get the men’s attention. There were enthusiastic conversations between the men about how this might work. Since the day and time of the performance was different to the rehearsal times, it took a lot of careful negotiation and encouragement to get everyone there on time.

The performance was a success according to both the performers and audience. There were many people there and members of the audience congratulated everyone involved but most particularly, Marla. After the performance, I observed that the men’s behaviour toward Marla seemed to have changed. When she spoke,
they began to listen and to become more open to her suggestions. Their gaze seemed to come in to focus, as though noticing her for the first time.

The next time the group met for a therapy session, Marla appeared to leverage this new level of openness in the group by initiating some small changes. For example, she made a suggestion that the group book a regular performance and the men readily agreed to this. They each smiled and acknowledged her idea. A shift in the group dynamics was becoming apparent. The performance seemed to allow the men to have their skills validated and to find broader acknowledgment of their abilities and this newfound confidence followed with a relaxing of their defences and a sense that they may be ready to begin working together in a new phase of therapy.

Marla had skillfully waited and listened for opportunities to move into openings in the men’s defenses and to demonstrate that she could be trusted and listened to. She continues to build on these opportunities and to leverage moments of openness in order to reinforce collaborative opportunities and to create moments of mutual empowerment.
CHAPTER 9

Reflection. Music Program

My advise to kids who have some form of disability is, don’t let it stop you.
Use it as your strength. Don’t use it as a weakness. One red light can lead to a
whole bunch of green lights and a few amber ones thrown in. The red light is
just a bit of a test, but there is definitely more green than orange. Spoken by
the lead singer of ‘Rudely Interrupted’, Rory Burnside (2010).

I wrote the case study in chapter 8 as a playful critique, partly in jest at the
farcical nature of negotiation with large bureaucratic organisations, but also as a
serious narrative in order to highlight the question of where the problem lies. By
turning the tables and taking a different view of events, the focus turns to the broader
systems and both the enabling and disabling conditions they can create.

I suggest in retrospect that the young people that I characterise as the therapist
may adopt therapeutic qualities as a result of the systems that bind them. The average
adolescent, young adult are not necessarily consistent, reliable and deeply committed
to process as I describe Marla. This is most clearly demonstrated by comparing
members of the group who come independently and do not depend on service
organisations. They might message me at 1.00 in the morning saying they are too
hung over to get to the band, or else they come early and hang out to chat while I am
setting up, or leave early if they have something else on. These are the realities of life
and belonging to a community group. The young people who attend services and do
not have individual support are there at the same time, they leave at the same time and unless they are sick, they are there every week. This is convenient for me as a facilitator and maintains a level of consistency, but there is no opportunity for these young people to be unreliable, to be absent with the unexpected disruptions that you might otherwise expect from members of a community group with varying commitments in other areas of their lives. I will give explanations for some of the circumstances that appear in the case study with reference to an ecological systems framework and later from a Foucauldian theoretical framework (Foucault, 1961).

**Ethics processes**

The character of Humres encompasses Human Research Ethical boards. Within an ecological framework, these institutions would be placed in the exo-system. The exo-system is defined as,

> “the linkages and processes taking place between two or more settings, at least one of which does not contain the developing person, but in which events occur that indirectly influence processes within the immediate setting in which the developing person lives” (Bronfenbrenner & Morris, 2006, p. 818).

The linkages therefore are between the ethics board and myself as researcher with advising persons such as the two supervisors of the project. In this case, interactions between the exo and meso systems have both advantageous and detrimental effects. The two main detrimental effects are the lack of opportunity to have input into research methods and the incomprehensibility of the participant information sheets in order for participants to give informed consent.
The aims of participatory research in empowering participants to have meaningful input in methodological processes were hindered by developments between the ethics board and myself as researcher. In addition, the fact that the application became so complicated meant that there was little chance that any participant would be able to give his or her own informed consent to participate. As a result the emancipatory aims of the project could not be realized. However, an advantage of the thoroughness of the ethics processes and reviews ensured that the protection and rights of people participating in the project would be upheld.

Also affecting outcomes of this process was the element of time. Within an ecological framework, this element is known as the chronosystem (Bronfenbrenner, 1993). The time taken to review the ethics application and the many revisions it went through hindered the opportunity for young people to learn about research processes and to participate as co-researchers, given the project was within the context of a PhD project.

Human Resource Ethical boards play a vital role in ensuring the rights and protection of people who participate in research, but how congruent is their current structure for proposals of projects with participatory and emancipatory goals where little will be known about the process of the projects before beginning? Cathy Warner (2007) described this situation as a Catch 22 (Heller, 1961). Being able to communicate the aims of the research and what it will involve is necessary as well as the voluntariness of involvement before people consent to participate (National Health And Medical Research Council Of Australia, 2007). Tensions arise when applying for ethical approval in participatory projects at the points of allowing enough flexibility for the direction of the inquiry to emerge from the process as well as the
level of detail required to meet regulatory requirements of ethical boards (McDonald, Keys, & Henry, 2008). Lincoln (2005) describes how the current system for gaining ethical approval for emergent, qualitative designed research projects is not “attuned to the needs purposes, concerns or relationships now being generated by postmodern and post structural critical inquiry” (p.179). During the process of gaining ethical approval, including the voluminous requests for detail, it appeared to me that the board was leaning more towards protection of its own institution rather than protection of the participants of the research (Christians, 2005; Lincoln, 2005).

Mary Brydon-Miller (2008) suggests that there are several assumptions that researchers might challenge when thinking about the main tenets of the Helsinki Declaration World Medical Association (1964), upon which ethical standards in Australia and elsewhere are based (National Health And Medical Research Council Of Australia, 2007). These tenets are respect, justice and beneficence. The National statement, used as a guideline in Australian ethical boards adds to these tenets, “research merit and integrity” (p.9).

Brydon-Miller suggests, in considering the notion of respect that it could go beyond giving people the opportunity to decline to participate in a project. It should encompass the belief that all individuals have the capacity to contribute to processes of research where it impacts on their lives. She questions the perceived need for protection accorded to those described as being vulnerable or having diminished autonomy, recognizing that these descriptions have also been used to control and disempower people. She states that assumptions about coercion between researcher and participants comes from an objectivist paradigm and that the relationships formed in collaborative projects need to be considered in their own context. Similarly,
Mertens (2007) states that within a transformative axiology, “respect is critically examined in terms of the cultural norms of interaction within a community and across communities” (p. 216).

In considering beneficence, Brydon-Miller (2008) posits that in order to maximise benefits for participants, research agendas need to be identified by participants themselves rather than others who may have conflicting interests. Mertens (2007) states that beneficence is defined in terms of the promotion of human rights and an increase in social justice (p.216). Beneficence in this project could be framed as opportunities for young people to participate meaningfully in the processes of research such as deciding on evaluation methods in addition to music-making.

Finally, with notions of justice, Brydon-Miller asserts that the roles of participants in action research should be extended to include decisions regarding the “generation, ownership and dissemination of knowledge based on this research” (p. 202) and Mertens (2007) states that within a transformative axiology, “an explicit connection is made between the process and outcomes of research and furtherance of a social justice agenda” (p.216).

Research that involves people with intellectual disability is often termed ‘inclusive’ (Walmsley, 2004), and Johnson and colleagues outlined a description of the types of inclusion that should be considered. These include that participants have ownership of research questions, that they collaborate in doing the work, and that the findings will further the interests of the people involved.

Researchers have found different ways of working within the requirements of ethical review boards in proposing participatory projects with people with complex
communication needs (McLaughlin, 2010; Milner & Mirfin-Veitch, 2012). They also demonstrate that there are different types and levels of participation (Conder, Milner, & Mirfin-Veitch, 2011) depending on the individual strengths and wishes of the participants (Bigby et al., 2014). In the music therapy literature, chapter five of Cathy Warner’s doctoral thesis demonstrates one method. In her participatory project with a group of men labelled with ‘severe challenging behaviour’ who did not communicate verbally, she set about gaining ethical consent from the men by using video footage. She said that she risked not being able to gain ethical approval by doing this, but did find a way to communicate her rationale in using this method clearly enough with the board. The video footage contained images of people participating in a music group (2005).

The music making element of the current project could have been communicated to participants in this way. Other aspects of the proposal such as the voluntariness of participation, details about decision making and evaluation would be very difficult to convey before the project began and yet it was a condition of the ethics board that it be included in the participant information sheets. Another way might have been to use consent forms to communicate research aims at the beginning of the project and then to proceed in a step-by-step manner where each stage of the project is applied for collaboratively with participants and submitted for review by the ethics committee. In this instance, because there was a time restriction on the project I did not think it was feasible to take a step-by-step approach. I ended up detailing different options that could be put to the participants as choices of evaluation. This included taking ethnographic style field notes in the form of thick descriptions (Geertz, 1994), summarised in an accessible form and reviewed periodically with participants or video footage reviewed periodically with participants. In other words it
was project with participatory aims, within a set of boundaries and limited choice.

Additionally, in describing these particular choices, the proposal became so long and detailed, that to participants, it may as well have been in a foreign language. In order for the participant information to be more accessible, they could have been translated to Easy English. Easy English is a simplified and concise form of writing where four or five ideas are presented on a page with an accompanying picture (Communication and Inclusion Resource Centre, 2016). To include the amount of information being requested by the ethics board however, the process of developing this could take months and would require dozens of pages of information. Presenting the approved information sheets and consent forms to participants seemed to be a disempowering action. I knew that participants would likely have great difficulty understanding the information. The very beginnings of the project set up a situation of an imbalance of power. Next-of-kin provided consent for most of the young people who became participants of the program and this satisfies the requirements of ethical guidelines.

Colin Barnes (1996) provides a critique of the notion of accessibility in place of rigour in participatory research that includes people with intellectual disability as co-researchers. He states that the level to which people may be meaningfully included may be overstated at times and that the value of the research should be measured by the practical difference that it makes in people’s lives. This includes the often-incomprehensible nature of academic writing to people outside of the academic world. Participant information for a research project however, needs to be in an accessible format to ensure that people are able to begin with a good knowledge of what they are agreeing to. This means that it is conveyed in a format that is as
accessible as possible whilst being adequately detailed (Goodley & Moore, 2000; Shakespeare, 1996).

In retrospect perhaps a more efficient way to manage the ethics process with a participatory project would be to have ongoing management throughout the project as it evolved. This could be in the form of an ethics supervisor to whom researchers may submit or discuss new requests and developments as they evolve, without waiting for the board to sit. In this way, participants could have more control over the process and evolution of the project and the ethics board could have assurance that the participants are being afforded respect, justice and beneficence along with the requirements of research merit and integrity. In terms of the impact of this for young people within an ecological framework, the opportunity for exercising meaningful choices as co-researchers is restricted by a process that is beyond their control, as approval needed to be sought before the recruitment process could begin.

The notion of accessibility of information brought to mind a theatre experience I had with two friends at an arts festival in Geelong in 2015. The theatre piece was conceived and performed by people ‘perceived as having intellectual disability’ as described by Back to Back Theatre (Creative Victoria, 2014). The play consisted of a series of rooms that the audience were required to pass through. In each room, there was a puzzling set of expectations that each audience member was asked to work out before they were permitted to move on to the next room. In one, we were handed a piece of paper and pens and told, via gesture from the actors, to do something. If what we put down on paper did not meet the actor’s requirements, we had try again…and again. Once we got it right one of the actors set about overlaying on the paper an elaborate and involved type of signature. Sometimes this meant that
friends who had come together to the theatre became separated, as one person was able to move forward without the other. Another room had an expectation for singing a song, doing a dance or reciting poetry, another to do with traffic rules using toy cars and people.

It was not made explicit as to what the theatre experience was about and my friends abandoned the play half way through saying it was too confusing and they did not understand it. I stayed, but found myself stepping into a disempowering and bewildering world that, in my mind, seemed to reflect the many life situations that people with intellectual disability might encounter. If I got something ‘right’ the first time, I felt a great sense of relief, but I still did not understand what I had done. My friends’ comments afterwards were most telling when I described what I thought the play was about; ‘Well why didn’t someone explain that to us in the first place?’ In other words, where was our accessible information?

During my research project, I met with one potential participant upon receiving ethical approval and I described the project to her and told her that information about it was contained in the booklet I gave her. She handed it straight back to me and said she did not want it, although she was interested in the project. I noted in my reflexive journal afterwards,

She’s not interested in bits of paper with information on it. Remember that.

It’s about talking and communicating in other ways.

Crossroads in the Research

It was tempting for me to pause in the project at this point and begin to develop ways of working more closely with the Organisation HREC to find
alternative ways of communicating the research project proposal to potential participants. I had to make a decision whether to move forward or stay at the point of ethics. My decision became one to move forward. I would accept consent from the next-of-kin and I would then communicate the project to young people gradually as it unfolded, asking their opinions and reminding them that their participation was voluntary in accordance with the national statement,

Where consent has been given by a person authorised by law, the researcher should nevertheless explain to the participant, as far as possible, what the research is about and what participation involves. (National Health And Medical Research Council Of Australia, 2007, p. 59).

I made the decision to move forward, as I had already spoken to participants involved in the first stage of the project about setting up a music group and time was running out. I would use my reflections from progressing through the ethics process to inform future projects. The HREC of the Organisation has since made changes in its processes to more efficiently manage research proposals.

Disability Service Organisations

Also contained within the exo-system are the disability service organisations from where I was looking to recruit participants. There are six large organisations and several smaller organisations in Geelong. I encountered restiveness from both the changing environment created by the NDIS and also from what I would describe as a ‘cultural abelist attitude’ that assumed that the young people I wished to recruit need an intermediary to decide whether the proposal was suitable for their consideration. Both of these affects could be placed within broader macro systems exerting influence...
on the ability for young people to have independent access to information about external programs or other opportunities.

I arranged to have meetings with representatives from all of the organisations in Geelong either in person or on the phone to describe the project and to ask them to pass the information along to the young people in their organisation. These representatives were either managers or community access staff. Their concern in passing along information appeared to be a result of economic uncertainty with the introduction of the NDIS. In the past when organisations received government block funding, they may have arranged for people to go to a community program during day service hours and the organisation would still receive that funding. Under the NDIS, if a person leaves the service independently to go to another program, then the organisation loses money for the time that they are gone.

The different reasons for not passing along information to young people by representatives in the organisations included the fact that they had their own music programs, or that information could not be passed along unless they knew when and where the program would be. One manager in an organisation said that service users in their program had already taken part in a participatory project and the result was that the young people did not like making decisions and would just get bored. After all the meetings and phone calls from the first few months, I did not have a single positive response or follow up from any of the organisations that I had contacted.

During this period, as described in chapter 8, I met with a group of allied health workers and asked whether they might pass along information to any people they worked with who may be interested in being involved in a music group. I described the proposal in detail and they had a lot of questions, which I found
encouraging. They then ended the meeting by asking me if I would send a report of evidence for the effectiveness of such a program before they would consider passing along the flyers.

Another encounter I had was with a leader in a large disability advocacy organisation who made a judgment about my status as a therapist by saying that he opposed the assumption that people with disability need therapy and so ‘no’, he would not pass along the flyers to anyone. My concern was that if young people cannot be approached directly, how do you reach them to describe the project in order for them to make a choice about participating?

The challenges for recruitment are not unique to areas in transition with the new funding model. Lennox and colleagues (2005) reported similar experiences for a large research project in Queensland. They attributed this in part to the sometimes numerous levels of management in large service organisation, issues of direct access to potential participants and issues of funding. Nind (2008) similarly described how gaining access to people usually requires going through gatekeepers and that often this includes convincing the gatekeepers themselves of the benefits of the research to potential participants as the gatekeepers assume the role of protector of the client.

My way through this dilemma was through my ongoing association with the Organisation and the ability to approach potential participants directly. I also liaised with the Community Inclusion person in Geelong who endorsed the program within the organisation and passed along flyers to young people who then took them home.

In considering this from an ecological perspective, I discovered a lack of interaction between the exo and meso systems. There was a missing link that
connected community programs with families and individuals. With the introduction of the NDIS, where people have their own funding to access programs, the mechanisms are not yet in place to enable free flowing information between community programs and individuals and their families. Disability service organisations have traditionally managed these connections in the past and in this initial stage of the NDIS, they have continued to do so.

*The National Disability Insurance Scheme (NDIS)*

The NDIS in theory is a revolutionary system with its emphasis on choice and control for people with disabilities and in many instances, it has provided new opportunities for people. However the way it is being rolled out in practice frequently falls into disabling modes of practice resulting in limitation on those choices for the recipients of its funding. It forces people to be categorised by their level of impairment and then compels them to emphasise their impairments and disability to gain an adequate level of support. This is continually reviewed each year in order for people to keep the support. This system strongly favours what critical disability theorist, Dan Goodley (2014) terms a neoliberal ableism where those who are the most outspoken or have advocates who are outspoken gain the most and those who are less able or have a limited network of advocates are making do with barest minimum. The scheme emphasises people’s choice and control, but there is currently a strict limitation on this level of choice bound by complex and layered regulatory systems that are constantly being reviewed and are open to a wide range of interpretation. The NDIS use a construct called ‘reasonable and necessary’ when deciding on whether to support a participant’s choices. Reasonable and necessary is based on the extent to which a support is related to the person’s disability, that it
represents value for money, the likelihood of its effectiveness and beneficence to the person and whether or not the support can be provided by other informal supports in the person’s life such as family or other carers (Australian Government, 2013).

Despite this, there are many reports of people who have had life changing experiences and new levels of freedom through funding provided by the NDIS. One advantage to the system is that those who are most able, or have strong networks of advocacy are gaining a good level of support from the system, and this in turn creates models of opportunity for those who may not have the same resources to advocate for themselves. For example, one member of the Geelong music group has secured her own apartment with 24 hour support staff. This was achieved with her family’s strong and persistent advocacy. Within the Rockheads, knowledge of this situation has been discussed and members of the band and their families have become aware of new possibilities and opportunities for independence.

There are also promising signs of greater collaboration between participants of the NDIS scheme and service providers, and also greater interaction between different service providers as it is emerging now that cooperative practises are proving more successful within the scheme. The beginning of this case study refers to conditions 18 months ago and even in this short time, there has been considerable change. Viewed from an ecological systems perspective, the chronosystem (Bronfenbrenner, 1993) or element of ‘time’ has exerted positive influence on processes within the ecology for young people. Changing practices through time have made explicit mutually beneficial elements such as collaborative practice among service providers, which in turn benefit participants.
In considering some of these factors from an ecological systems theory framework, it becomes apparent that there are multiple layers of complexity governing interactions between systems, how they respond to each other and how this in turn influences the opportunities made available to people who are using – and in many cases - depending on their services.

**Bio-power**

In attempting to make sense of this situation, my thinking turned to the reasons for the very existence of these ecological systems. How has this situation come to be and for what purpose? In my search for understanding, I turned back to French philosopher, Michel Foucault’s theory of bio-power (Foucault, 1982). According to Foucault, bio power is a series of governing practices constructed to manage and control populations. Foucault used the term ‘dividing practices’ to describe how during post-industrial times and the rise of medical advances, scientific discourse was combined with the practice of segregation and social exclusion. A system evolved whereby populations of people who might otherwise be largely undifferentiated, were classified, organised and managed; for example, mentally ill and mentally healthy, disabled, and non-disabled, homosexual and heterosexual. Through these classifications, ‘subjects’ as he terms them become tied to an identity. They then come to be known and come to know themselves according to a scientific classification. Along with this identity come possible modes of actions or choices. Foucault’s ideas have been drawn into critical disability studies (Tremain, 2001), feminist (Butler, 1990) and queer theory (Huffer, 2010) as a way to think about identity and power.
Feminist authors who have applied Foucauldian theory to critical disability studies include Canadian feminist author Shelley Tremain (2001) who said that “the ways in which concepts, classifications and descriptions are imbricated in institutional practises and social policy, structure possible fields of action” (p. 622). This is demonstrated in the way in which people are required to detail their impairments and the difficulties that these impairments impose in meetings with NDIS planners in order to generate a suitable individual funding package. Planners then take this information away and some time later, people are presented with a funding package attached to categories containing possible courses of action. The package is presented as an offering of greater freedom through choice and personal control, but in fact it is highly regulated. As Kumari Campbell (2013) points out;

“If the definitions of abled-bodied and disabled become unclear or slippery the business of legal and governmental administration would have problems functioning. Alarm would arise due to uncertainty as to how to classify certain people and in which category; the distribution of resources would unravel (p. 6).

British authors Margrit Shildrick and Janet Price (1999) suggest, “the body as abled or disabled has historicity and is constructed, not by once and for all acts, nor yet by intentional purposes, but by the constant reiteration of a set of norms. It is through such repetitive practise that the body as both disabled and abled is materialised and naturalized (p. 94). This materialisation is then central to the governance of them.

An illustration of this governance in the case study can be seen when members of the Rockheads try to act outside of these norms and fields of action beyond the
music group. I told the group that a much-anticipated visit from another band the following week meant that if we came a little earlier, we could hang out for a while before we rehearsed together. One of the band members told his taxi driver on the way to the service that morning to come back half an hour earlier to pick him up to take him to band. He told me later that he had asked staff in his centre several times during the week if he could come early to band, but no one took any notice of him. His taxi driver came early, walked in and collected him without anyone noticing and he arrived at band early. Predictably chaos ensued with a missing person in the centre.

The problem as defined by his service organisation was that there was a flaw in their security system, but from where I stood, the problem lay with not considering that one of their participants should be capable of making arrangements for himself and that there seemed to be no mechanism in place in order for him to do that. Foucault might say that choices were limited by his identity as a disabled person and service user. When he is in the centre, he can make certain choices, but he is not able to arrange his movements in and out of the centre.

In another example, we needed an extra keyboard for the group and one of the band members said there was one at his service centre. He said he asked staff during the week if he could borrow it and again, no one took notice of this request. When his taxi driver came to pick him up, he asked the driver to pick up the keyboard and the same thing happened. No matter how we tried to explain that the band member had been asking, it did not seem to make a difference to the idea that this man was not qualified to make a request for the borrowing of the keyboard. His choices for action were bound by his identity as a service user without the power to make this independent request.
Foucault (1982) suggests that to liberate oneself from these boundaries requires liberation from the type of individualization that is linked to governing bodies. Following this, Tremain (2001) states that demands should be formulated in terms of “‘what we want’ not ‘who we are’”(632). Maintaining attachment to categorisation only reiterates the need for the restrictions that governing bodies impose.

**Resistance**

Critical disability theorist, Dan Goodley and colleague (2000) suggest that university researchers may contribute to the self-advocacy of people with disability by telling stories of resistance. By illustration the authors re-count the story of a woman who had a note in her file from a psychologist saying that she would not be capable of crossing the roads independently. The woman was driven each day from her group home residence to a day service a short distance away. She would then wait for the taxi to disappear before crossing the road to get supplies for morning tea from the shops, as she was the designated tea person. The woman has since died and this story was told by a friend (p. 879). Goodley describe this as an example of ‘hidden resistance’ and adds that there is also danger in documenting these stories as they come to light because of possible repercussions for that person. The woman would no doubt have been prevented from this small act of independence in order to comply with safety regulations of the organisation. A possible way around this, according to the authors, is to present the stories in an anonymous and clandestine manner, similar to the ways in which the resistance is carried out in the first place.

Unfortunately for the young man in this project whose taxi driver brought him to band early, there was no opportunity to keep this act of resistance hidden. Kumari
Campbell (2011) in an interview with Dan Goodley on abelism speaks of phenomena where acts of resistance may create an increase of tensions between those seeking more independence and those who act as care-givers. She says that her work in this area is in building strategies for resilience for people with disability. For the young man in this project, he has asked to leave this particular service centre and members of the band who are able, are supporting him to do this. A further development since this incidence has been his joining of a self-advocacy group where he is continuing to make his voice heard.

Angie Hart and colleagues (2016) discuss notions of resilience and state that although there is little consensus to its meaning, resilience assumes adversity and is relative to it. Critiques of resilience research say that it places too much responsibility on individuals for problems that lie outside of their control, however these authors offer that young people can use their resilience to make changes that do not rely on individual responsibility. They say that researchers and practitioners make natural advocates for young people in achieving this. They can do this by working across both structural and individual levels and that research may be a way to build young people’s resistance. However, it must be co-produced to capture the complexities of power inequality.

The band, the Rockheads has afforded various opportunities for its members. This includes making decisions about where we rehearse, who can be a part of the group, participation in steering aspects of the design of the program such as the music we play, the instruments people have learned, as well as marketing and leadership opportunities and interacting with people outside of the service organisations.
The band rehearses each week in a busy community centre that offers a free lunch to anyone who comes through the door on a Thursday including the band members. Although band members who do not belong to service organisations have joined the band, most are not regular members. Part of this is due to the fact that band members from the services arrive after general community members have eaten their lunch and have left. Community centre staff have offered to make a space in the dining room for the band to play whilst people are having their lunch but this never happens because band members arrive when most people have gone. The day services cannot change their routines at the moment to allow for this opportunity but this is something that is a continuing aim for the music program.

A few times during the past year, the band has had to rehearse at one of the day services. When this happens it is immediately apparent that many of the restrictions we face are eliminated including the challenges of having too little time and fully accessible toilets. It may be that in the future, band members decide that rehearsing in a day service is preferable given the rush that occurs to get to the community centre and back in time for catching transport home. Perhaps having the choice to do this will outweigh the unjust nature of not having adequate choices in the past. Watts Jones (2002) as cited in Campbell (2008) points out that segregation is different to separation (p.8). If band members collectively decide to meet at a service centre each week, then the act of choosing may be viewed as an act of empowerment.

Music therapy

Music therapists can have a role in creating conditions for destabilising disabling cultures. Goodley and colleagues (2000) term this “radical professionalism” (p. 879). Rickson and Warren (2017) have begun some exciting research into enabling
access to a tertiary level music course in New Zealand for people with intellectual
disability. Schwantes and Rivera (2017) have recently published findings from an
action research project in a college program in the U.S.A. showing that the inclusive
program could help to build authentic relationships. Curtis and Mercado (2004)
similarly developed an inclusive creative arts performance in a university in Canada.
Sandra Curtis later explored a feminist approach to music therapy with community
music therapy and says:

Feminist music therapy provides a feminist understanding of the complex
interaction of multiple oppressions of unjust societies, of power and privilege
on one hand and of dis- empowerment and marginalization on the other. It
requires more, however, than understanding, even more than healing the
wounds caused by unjust societies; it requires no less than activism for the
transformation of those societies (2012, p. 212).

Similarly McFerran and O’Grady (2006) investigated links with feminism in
CoMT and describe opportunities for challenging patriarchal oppression within
constructs of health along a continuum. Stige (2002) advocates for political and social
responsibilities within CoMT in documenting a participatory project in Norway, and
Sue Baines (2014), explores anti oppressive practice and music therapy in her
doctoral thesis stating that “participatory arts agendas can be a radicalising process,
transforming, emancipating and encouraging resistance” (p. 64). Vaillancourt (2012)
investigates notions of social justice within (CoMT) and suggests that:

it provides a fertile and supportive ground for social justice to be voiced. In
my opinion, by making music accessible to a larger community, CoMT greatly
contributes to the societal integration of clients who face various physical,
psychological, cognitive, and social challenges, allowing them to partake in experiences of beauty and sharing (p. 19).

Kumari Campbell (2011) stated that a powerful way to counter abelism is to engage a detective lens to uncover and unmask it where possible. Once this is achieved, to question first what can be gained from abelism, where are the benefits and entitlements for certain groups? Whose interests are being served in this situation? Secondly to look at how abelism diminishes and oppresses possibilities for people.

Unmasking in this research project has included a process of critically investigating the literature reporting on music programs, young people’s feelings of social connectedness, the availability and nature of existing music programs in the local context and the process of establishing the band. Through this, I discovered that opportunities for the young people in this project to access music are limited and most often these are through music groups run by music therapists, community musicians or support worker musicians within a service organisation. Given my experience of starting a community group, it is understandable as to why this is the case. The current system of service provision is set up to make this the simplest option, where a music facilitator comes in and runs sessions within the centre, sometimes as entertainment or as a therapeutic session or participatory community music group. This in turn creates a situation where young people have limited access to social interaction in the broader community through the program. This is not necessarily a negative thing, if young people are able to choose this as an option.

Campbell (2011) points out that one development emerging from disability movements is a re-framing of disability away from being inherently negative and that
once this re-framing is internalised, then notions of inclusion and integration may not be so important. Belonging to disability groups may be perceived as a point of solidarity and elements of difference may be elements to celebrate. As mentioned previously, the late Stella Young (2012) said of the push to integrate the paralympics with the Olympics, “We get so few opportunities to publicly and raucously celebrate our community and the amazing contributions people with disabilities make. The Paralympics are ours. Hands off” (p. 4). The deaf community have demonstrated this and it there is a growing acceptance of neuro-diversity in the autism community (Bagatell, 2010).

One particular performance by the Rockheads was at a large disability conference run by and for people with disability and it was this performance that is referred to in the case story in chapter 8. Band members expressed excitement at the opportunity to go to a different place and to have a different experience. After the performance, members of the audience came up to congratulate band members and one person was approached by a recording artist who asked him if he would be interested in recording a song in his studio. Other interest in the band following this performance included people asking to join. This led to discussions among band members about the various attributes that prospective members may bring or not. One band member went out independently the following week and secured an ongoing gig with the conference organisers for the next few years.

The music group, the Rockheads meets each week in a busy community centre. The band includes people who have wandered in from the community and asked to join. One member is a trombone player who hadn’t played since she was in school and wanted to start up again. Another person is a singer and percussion player.
Support workers are also valued playing members of the band following requests from the young people who first joined. They have learned to play various instruments along with the young people. The band continues to meet up each week whether I am there or not. For members of the Rockheads, it was the social aspect initially that was of foremost importance. In early discussions of how to improve the group, members requested that we include more people and members then became involved in recruiting peers. Now that the group have expressed satisfaction with the social aspect of this 10-member rock band, the focus has turned to further developing the music side and for getting more gigs. Band member have said that the gigs provide opportunities to have new experiences and to go to different places.

According to McFerran (2010) the average teenager spends two and a half hours a day listening to music and they rate this as the most popular unstructured activity. Music is used as a resource for young people in constructing their emotional experiences, social experiences, identity and resilience. Most young people who are members of the band do not have access to this level of engagement with music and they may not wish to have this, but the opportunities for choosing a level of engagement are not available either way. The band members who attend service organisations don’t have independent access to the Internet or mobile phones with playlists of preferred music. As part of communicating in between sessions, a closed Facebook page was set up for all the members to communicate between rehearsals and for all but one member, this meant setting up a personal Facebook profile for the first time.

I find that the young people at the centre of this project are living in a dynamically changing situation. I have learned that their identity as people with
disability is culturally and politically constructed with an accompanying set of possible actions. Work from all fronts in the disability sector and beyond have provided enormous impetus to make changes for the better and this includes the introduction of the NDIS. However obstacles to adequate opportunities and independence arise through internalised norms and assumptions. As music therapists and others, our role may be to try recognise these and to challenge them. We need to think as broadly as possible about ways in which young people may appropriate music as a resource in their lives.
CHAPTER 10

Reflexive conclusion

“Whatever affects one directly, affects all indirectly. I can never be what I
ought to be until you are what you ought to be. This is the interrelated
structure of reality.” – Martin Luther King, Jr

I have begun to think about my PhD journey as shining a torch on a particular situation. The torch shining feels most appropriate because there was a strong sense that much about this situation is an old one; one that has existed long before I came along with my torch. Even though I have worked as a music therapist for a long time in the disability sector, it was in a very different context; in schools and day services and for this project I was looking through a different set of lenses.

Some of what has come to pass to create this situation is as old as human history and some of it is very new, particularly with the recent introduction of the National Disability Insurance Scheme. This scheme has thrown just about everything we have known about the disability sector to the wind in Australia and there has been a scramble on all fronts to try to adjust. It is the interactions between these elements that create the dynamic and changing picture that I attempt to illuminate in some way.

This metaphor has been used in various ways by researchers in describing the purpose of research; words such as making the invisible visible and illuminating the problem or issue. I think it is a particularly useful way to think about research. It ties in with my epistemology influenced by Freirerian philosophy (1972), particularly
where a previously obscured situation is illuminated and those who then see it, including myself may be empowered by this information and knowledge and perhaps either compelled or empowered to made change where possible.

The act of shining a torch in an action research can be to expose elements of a situation that are unhelpful or obstructive and to attempt to disrupt these in some way or to find alternative ways through. In addition, it can highlight the elements that are helpful in order to replicate or expand on them, or to appropriate them in order to move forward or improve a situation. I acknowledge that the various lenses on my torch through which I am viewing the situation are personal ones, constructed through my life experiences, beliefs about the world and about knowledge. The people at the centre of this picture are young people who may or may not identify with having a disability and they are transitioning between school and adult life. The setting is Victoria and the focus is on the role that music may play in the lives of these young people.

The focus for my investigation began within the microsystems of young people and the role that music might play in their sense of social connectedness. Through a process of four revolutions of planning, action and reflection, the focus for the investigation began to pan outward further and further to the systems and structures making up the broader ecology for those young people. Conducted within an environment of nervous anticipation with an overhaul of funding for the disability sector in Australia, the first cycle involved an investigation into the rationales, structure and reported benefits or otherwise of music programs involving young people across the world through a critical interpretive synthesis of the literature. The second cycle sought to reveal aspects of the current social situation for young people
through their own voices to learn about their feelings of satisfaction or otherwise with their sense of connectedness. Moving sideways in the third cycle, I sought to investigate aspects of current opportunities available for young people to access music from the perspectives of the program facilitators. Finally, through the process of establishing of a collaborative community music program, the picture began to transform and I was compelled to look outward to the interactions between layers of systems making up young people’s ecological setting and the influence this has on their lives.

Theories and models helped to shape the information that was trickling in at an ever-increasing rate over the project. A Freirean (1972) lens allowed me to view the situation though a critical consciousness or deepening of my understanding and in doing so guided me towards finding my role as an action researcher and music therapist in the materialising picture. This included being able to share my findings and ideas as they came to light in order to add in the perspectives of other participants of the cycles and to plant seeds for action and change. An ecological perspective gave me a way to think about the structural mechanisms at play and how young people at the centre of this context can influence and are influenced by their ecology. Foucauldian discourse (1982) as a theoretical framework amid critical disability studies (Campbell, 2008; Goodley, 2014; Tremain, 2001) showed me that the structures that I was examining were also constructed through language and societal governance and that these structures are evolving objects within an historical context. I could begin to conceptualise and recognise that although these constructs are as they are, they are not necessarily helpful but they are also not unchangeable. Music therapy and CoMT theory (Stige et al., 2010) showed me that the music flowing through this picture comes in many guises; music as a health resource (Ansdell & DeNora, 2012),
as empowerment (Rolvsjord, 2009), as a right (McFerran, 2008; Rickson & Warren, 2017) and as a political tool for action and change (Curtis & Mercado, 2004; Elefant, 2010).

Findings in relation to the research questions

At the beginning of the project, my overall question contained social connectedness as a focus as identified by Community Inclusion Team members of the Organisation. They had observed that feelings of social connectedness were challenged during the process of leaving school and difficult to re-establish for young people who accessed their services. They were interested in how music might play a role in improving this situation. My first question became:

How can music be used to address social connectedness for young people transitioning between school and adult services?

This question was later re-worded to:

What is the role of music in social connectedness for young people transitioning between school and adult life?

Looking back at the first question formulated by me, I can see a number of embedded assumptions. The word ‘services’ was replaced by ‘life’ later in the project, as I realised that the idea of transitioning to a service was an assumption based on my experience of working with young people within service organisations. The assumption was that people with disability would necessarily transition to a service once they left school. ‘Service’ in this context, as defined by the Cambridge dictionary is “a government or private organisation that is responsible for a particular type of activity, or for providing a particular thing that people need” (Cambridge
My thinking has now evolved to consider that each of us access services for things that we need at various times in our lives, such as public health services or recreational services, but we would not consider that our adult life would be wholly located in a service. The philosophies behind the NDIS and the disability rights movements in the past two decades are beginning to challenge this idea for young people with disability transitioning from school.

The other assumption embedded in the question was that music was a thing that can be used to ‘do’ something. This idea also stems from my training as a music therapist where music could be thought of as a tool for making changes in a person’s life or for being prescribed by an expert such as a music therapist as a panacea for a particular problem such as a lack of social connectedness. This assumes that the person needs an expert to provide a solution. The question changed again to use the word ‘role’ to re-frame my thinking towards a resource orientated (Rolvsjord, 2010) framework investigating how people were currently accessing music as a resource in their lives and where the barriers might be to access further opportunities if they were found to be limited.

My findings indicate that opportunities are limited. The Geelong music program from cycle 4 demonstrates that once an opportunity is made available, young people will draw on their own resources and abilities to take that opportunity and appropriate it in ways that they need. In this instance this is achieved through a collaborative process of journeying together with several integral parties; me as an experienced music facilitator, support workers invested in the actions of supporting the young people as well as making music, a person with the knowledge of community inclusion approaches, a community centre with an ethos of inclusion and
welcoming and an Organisation who values empowerment and equality. What emerges from this type of opportunity will be unique to each situation. What is demonstrated by the formation of the Rockheads is that if sufficient time, space and support is afforded to young people, then anything is possible in terms of resources afforded to those involved and the possible creative contributions to society. In the words according one facilitator from cycle 3, “the possibilities are exciting”.

I learned that far from assuming that the young people in this project need the help of experts, they themselves embody the role of ‘expert’ to help those around them as demonstrated in the case study in chapter 9. The fact that the young people who formed the Rockheads with me require support for many of their day to day functioning such as mobility and physical self-care, this might be framed as a contribution to the narrow ideals of a neoliberal, ableist society (Goodley, 2014). A society that assumes that independence and autonomy is the ultimate objective, when in fact many people crave greater interdependence and connection to counter feelings of loneliness (Cacioppo & Patrick, 2008). Dan Goodley (2014) suggests that non/normative lives extend the way we understand being human and counter the fact that “a whole host of norms are in fact limiting and stifling” (P.158). Disablism embodies the power to hold up a mirror to ableism and ask the question “Is that all you’ve got?” (p.156).

**Cycle 1**

Questions asked of the literature in the Critical Interpretive Synthesis included the types of music methods being used, methods of research, foci and reported outcomes, the use of participant’s voice and the types of social connections being fostered as part of music programs in the literature.
The data contained in the 27 articles indicated that participant’s voices are increasingly being included in research projects but that there is a lack of negative reporting. In terms of the social aspects to their involvement in music, young people reported more favourable outcomes than others involved in the research including family members and professionals. It also revealed that music programs reported with young people with more complex and multiple disabilities are solely facilitated by music therapists.

**Cycle 2**

My research question in the second cycle sought to understand how young people felt about their social connectedness in the local context. The question was:

How do young people accessing the Organisation services describe their own sense of social connectedness?

The maps of social networks that young people constructed showed that the majority are made up solely of family and people at the day service. Young people indicated to me through conversations in the interviews that they were satisfied with their sense of social connectedness when they reported having enough friends. People described as ‘friends’ could be peers at the day service, members of staff, or others outside of the service within their local community. Young people expressed dissatisfied if they reported not having friends or that the friendships they reported having do not fulfil their desired level of social connectedness and they wished to meet more people. Some young people indicated a reluctant acceptance of a ‘less than ideal’ situation, because they felt powerless to change it.
These findings indicate to me that different types of community or communities may meet a desired level of social connectedness for the young people. This could be within a day service or within families or communities outside of either, such as a community music group, sporting clubs, places of employment or further education. The crucial element is that people are given choices to seek the types of communities that fulfil their desired level of social connectedness. The ability to have the choice to pursue pathways of interest, independent of what others feel they should do, will ensure that young people can find the places and communities where they feel a sense of belonging and are valued as contributing members of society.

**Cycle 3**

My research question in cycle three sought to investigate the opportunities available for accessing music in Victoria. In addition, the aim was to begin connecting music facilitators to provide a support network as well as build links between their programs and the people who may wish to access the programs. My overall question was:

What are the current music participation opportunities available to people with disability in Victoria?

Findings from the focus group discussions showed that all but one person worked with groups exclusively with people with disability either within service organisations or in the community. This was also reflected in findings from the critical interpretive synthesis in cycle 1. The goals of programs most commonly focus on everyone being involved and participating but also on providing opportunities for self-expression, identity building and political goals of ‘getting the message out’.
Some differences were found with support workers who were musicians and people who were community musicians. The latter described coming from a place as ‘musicians’ where they offer to share their skills with the people they work with and also aim to ‘get the message out’ via recordings and performances. Community musicians described being focused on everyone playing together and being included. In addition, my observations of the Salvation Army disco illustrate another type of program where people come in groups from their services organisations and have the opportunity to freely participate without particular expectations. Music therapists may be described as coming from a place of training in different ways of practicing including in-depth work and thinking about how music may be used by a person as a health resource.

These different types of music programs indicate a variety of ways that people might access music as a resource in their lives. The NDIS potentially offers the choice to access these programs by providing necessary resources such as transport and support workers if needed. In the case of music therapy, the scheme will fund the service, particularly as a short term allied health intervention to build the capacity of the participant to access mainstream services. Current barriers to accessing music programs are threefold. The funding resources required to access music programs need to be justified to the NDIS as an economically viable support. Information linkages are limited between music programs and people who may wish to access them. Accessible music programs that do exist fall short of the number needed. The latest report shows that 105,000 people are expected to be participants of the scheme in Victoria by the end of the roll out in 2019 (National Disability Insurance Agency, 2016a). If a small fraction of people chooses to use their funds to access music programs, then the current opportunities will fall well short of meeting this demand.
Since reflecting on these findings, I have learned that there is significance for the way that music facilitators and interested organisations could be working to increase opportunities for people to access to music. Mechanisms that create a flow of knowledge between music therapists, other music facilitators and people interested in accessing music programs need to be increased. This will have the potential to build mutually beneficial opportunities for all parties. Music therapists benefit from the support of the NDIS to work with people to meet therapeutic goals and to increase the capacity of others associated with the person in building a desired level of engagement with music. This could include all levels from accessing personal playlists for everyday listening, community music participation or further education and a career in the music industry. Music facilitators working in the community, including community music therapists will benefit from the potential for participants to have independent access to their programs. This may now be based on individual desires to join programs, rather than decisions made by service organisations or others. Information shared between facilitators from different backgrounds has the potential to increase the capacity from meaningful participation of people from all walks of life, in turn enriching and broadening the scope of these programs. People interested in accessing music will benefit from having greater autonomy to choose their own level of engagement with music. This could be through access to adequate funding, increased knowledge about different opportunities to access music and provision of independent decision-making. Collaborative practices between facilitators and participants at all levels from the design to the running of programs will ensure that opportunities are created that take full advantage of the affordances that music has to offer.
Cycle 4

My research question in cycle 4 sought to investigate the process of establishing a community music program with a group of interested young people with a focus on social connectedness. Drawing on knowledge gathered from the previous three cycles, this collaborative music program was aimed at establishing a relevant and engaging platform for young people to be involved as co-researchers. The research question was:

How does participation in community music workshops address social connectedness for young people transitioning between school and adult life?

The band members placed a high importance on the social aspects of their membership from the beginning. When asked early in the program what could be improved, a band member said ‘more people’. Group discussions and recruitment drives at other service centre programs resulted in more people joining the band. Discussions about the venue where we originally met revealed dissatisfaction with the lack of people and this resulted in moving to another, busier venue. Attendees at the community centre where we now meet have joined the band and band members have expressed satisfaction with the level of social contacts afforded by the program. Support worker members of the band have reported observing increased closeness among band members outside of the music program. This includes members asking where people are if they are away and expressing a desire to stay together at different programs.

Another way to think about the affordances of a music program such as this is to consider the mutually empowering conditions that it creates. Young people are
afforded an opportunity by their advocates, support workers, music therapist and
community inclusion representative. Once the opportunity is afforded, young people
appropriate what they need from it. In this program, this has meant that new musical
experiences are created, people who had not otherwise played before are playing in an
open and accepting environment and have begun to identify as musicians. Community
members who access the centre independently are enthusiastically invited into this
music space. Young people along with me as the therapist invite support workers and
community centre members into a space where making music together is a natural and
perhaps even long-forgotten skill. Reintroducing this simple joy of shared musicking
nourishes the need for connection mutually felt by everyone in that space.

Many challenges were encountered when seeking to establish a community
music program and some of these continue to place restrictions on the freedoms of
band members. These include restrictions on the time we have to meet based on the
routines of service organisations, insufficient funding to support independent access
for each of the band members, and fundamental structural impediments to community
inclusion for people with complex physical needs including fully accessible toilets.
These challenges present opportunities for creating changes and small acts of
resistance to oppressive practices. Band members continue to challenge these.

Within a transformative paradigm of action research, the challenge remains for
how to create new possibilities within these changing institutional structures. Kemmis
and Taggart (2005) describe these as structures that have become “saturated with the
bureaucratic discourses, routinized practices and institutionalised forms of social
relationships characteristic of social systems that see the world only through the prism
of organisation and not the human and humane living of social lives” (p.572).
Elements of this are evident in service organisations, however calls for action brought about by disability rights movements and the changing funding model of the NDIS has created impetus for rapid changes and these changes coupled with the needs and desires of service users are creating new and exciting opportunities. Kemmis and McTaggart (2005) state that although participation may encourage growth and knowledge of a situation, it also may encourage growth in participant’s “capacity for action” (p.571). Within the Rockheads, member’s actions of speaking out and developing changed expectations for their situation is being demonstrated through small acts of resistance.

**Implications for the profession of music therapy**

Where does the profession of music therapy belong in this context within a critical disability studies discourse? To summarise my thoughts at the end of this chapter, I turn back to scholars who contributed to the special issue on music therapy and disability studies in Voices (Hadley, 2013). Sue Hadley asks the question of how music therapy might be utilised in a way that is enabling rather than disabling and she suggests that we could be equally working to create change among the non-disabled (p.10). To include changes in my own thinking and values following this scholarship, examples of change from the ‘non-disabled’ may be drawn from the support workers who journey with us through music therapy practise as well as examples of resistive actions stemming from participation in collaborative music settings.

A strong critique of music therapy within disability studies discourse is its position within the medical model through an alignment with other allied health professions (Straus, 2014). Music therapists are required by the NDIS to act in our allied health profession mode in working towards functional goals. We are asked to
facilitate functional change for individuals by assessing and identifying needs, making a plan and implementing it in the most economically efficient way before referring the person to non-specialised support in the community. In this way the NDIS espouses the ideals of the neoliberal society in which we now exist. People are now given the opportunity to follow the dream of independence and autonomy, to make the best of themselves by striving for a ‘normal’ life the same as everyone else. To frame this in another way however, the scheme’s aim of reducing people’s dependence on specialised and professional support could be seen as aligning with critical disability studies discourse, albeit from an economic standpoint rather than a human-rights standpoint.

Music therapists have been shown to foster relational goals alongside functional goals in music therapy programs. The language used, however in written assessments, goals and outcomes are often limited to the functional elements in order to meet institutional requirements for employment and funding (McFerran & Shoemark, 2013). CoMT practice in particular, moves explicitly into spaces outside of this, where the focus is less on functional goals and outcomes and more on the “communal reality” of music making (Ansdell 2002). Music therapists are familiar with these meeting places. Straus (2014) suggests that music therapists may work toward enriching and celebrating particular disability cultures such as the autism community by offering to “enhance their indigenous culture in an atmosphere of mutual respect” through shared music making (p.1).

Currently, NDIS guidelines state that allied health professionals must work within ‘evidence based practise’ in their field and impassioned discussions have surfaced in relation to the meaning of this in ensuring continued support of music
therapy within the scheme. Honisch (2014) suggests that in searching for points of contact between music therapy and disability studies discourse, that we search within music therapy for “consonant reverberation” (p. 8). Practices and theory within CoMT may constitute such a reverberation, although perhaps lie outside of insurance funding models as they currently stand.

Perhaps the best that we can do is become one of the allies or advocate or even skilled supporter (Walmsley, 2004). An ally to people within a disability studies perspective may mean that we do foster indigenous culture (Straus, 2014), that we do work with people outside of the disability community to affect change and values where it is required (Hadley, 2014) and that we do create opportunities for people to access music by working on structural and attitudinal barriers. As Jan Walmsley (2004) says,

Arguably for people with learning difficulties a skilled supporter is as vital as a wheelchair is to a person who is unable to walk, or a BSL interpreter is to a deaf person taking part in a hearing person’s event. As vital, and as unlikely ever to be discarded, though the nature of the support needed may alter as environments change, or as the person gains more skills and confidence (p.3).

Disability emerges from the neo-liberal ableist discourse not only as a site of oppression and marginalisation, but also as a place of resistance; a place where human nature may be reclaimed through the ideals of connectedness, dependence, interrelatedness, collectivism and vulnerability. Shared music making can offer spaces to foster these ideals outside of the allied health parameters.
In conducting this project I have come to know a group of people on the cusp of what I believe will be a brighter future. The Rockheads embrace opportunities afforded by belonging to a music group in which each person’s voice is valued. They have shown courage and determination to make the band what it is today and I think the future looks bright. The philosophic tenets that brought the NDIS to fruition are shared by community music therapy; the right to access music as a health resource on an equal basis to others and to have the opportunity for people to build their social network based on individual preferences and desires on an equal basis to any young person moving into adulthood.

As music therapists, we are in a prime position to advocate for the rights of people to access music by upholding the knowledge that access to the arts is a human right. If we work with people within organisations, we can foster opportunities for connections with the broader community through performances, or through community based groups. Within private practice, we can work with individual’s goals and aspirations ensuring that music as a health resource is accessible at the level that the person wishes. We can collaborate with community musicians, music teachers and others who use music to create pathways and foster opportunities for music access including further education facilities and the music industry to open up career paths for interested young people in music. We are in a prime position to invite young people with disability into the world of research through partnerships such as the one created for this project. These partnerships allow for opportunities to investigate questions and problems identified by participants and to optimise conditions for transformation and social justice.
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Appendix A

Link to video

Video containing the findings and interpretation of interviews data from cycle 2.

https://cloudstor.aarnet.edu.au/sender/?s=download&token=2a783076-33c6-faac-294b-2a19efcd37b0
Exploring the literature on music participation and social connectedness for young people with intellectual disability: A critical interpretive synthesis

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Abstract
Background: This article explores the literature on social connectedness and music for young people with disability. It then critically examines the level of congruence between the reported literature to date and current rights-based disability studies discourse. Method: A critical interpretive synthesis was used to examine 27 articles referencing the use of music for social connectedness. Areas of focus in the review are the nature of connections being fostered in music programs, the use of voice and collaboration. Results: The majority of music programs reported on closed groups. Outdated ‘expert’ models of working persist. The use of participants’ voice in the literature is growing, although there is a lack of collaboration and negative reporting. Conclusion: A shift in thinking heralds greater collaboration with participants, although this could be broadened to include decisions on research agendas, planning and evaluation. There is also need for active fostering of broader socio-musical pathways.

Keywords
disability, music, social connectedness, young person

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The evolving rights-based principles in disability studies along with policy changes in Australia following the ratification of the convention on the rights of persons with disability in 2008 (United Nations, 2006) culminated in the beginning of the roll-out of the National Disability Insurance Scheme (NDIS) in 2013. The NDIS shifts the funding model from a welfare model to an insurance model. This significant reform in disability support in Australia has been broadly welcomed and supported by both governments and the general population. One informing report for the change, shut out (National Disabilities and Carer Council, 2009), sought to highlight issues present in the disability sector in Australia by consulting people with disability, their carers, families and service organizations. What emerged revealed a profound dissatisfaction with the lack of choice and control in the provision of services for people with disability and that it was ‘characterized by a one-size-fits-all approach’ (p. 4). One outcome for this situation is a lack of social inclusion in Australian society where people are no longer ‘shut in’ institutions but now find themselves ‘shut out’. Emerging data generated by the scheme has shown that social participation is the most frequently documented category of goal in person-centred plans overall (National Disability Insurance Agency, 2015).

A review of the literature on independence and opportunity for young people with intellectual disability in Australia found that ‘having the capacity for choice and control is strongly associated with having strong social connections’ (Stokes et al., 2013: 5). For example, when people have the choice and control to pursue personal interests and aspirations, they have the opportunity to connect with others through a common interest, such as in the arts, sport or further education. Evidence from the shut out report (National Disabilities and Carer Council, 2009) and the review of independence and opportunity (Stokes et al., 2013) reveal that young people with disability in particular have very little choice and control in their lives and low levels of social connectedness.

For the purposes of this article, the concept of social connectedness developed by psychologists Lee and Robbins (1995) will be used. The authors developed their understanding and measures from psychoanalytic self-psychology theory (Kohut and Stepansky, 1984) and describe social connectedness as ‘an enduring and ubiquitous sense of the self in relation to the world’, and that it is built on experiences of relationships from early attachments and extending throughout the lifespan. The ‘aggregate of all these social experiences is gradually internalized by the individual and serves as the foundation for a sense of connectedness’ (Lee and Robbins, 1998: 338). The person views the social world through their individual lens and experiences it in a fairly stable way, although it is not rigid and may still be influenced by significant or long-lasting changes to relationships in life (Williams and Galliher, 2006). One of these changes may be the transition from school (Stokes et al., 2013). Crucially, problems are thought to arise in social connectedness when there is a ‘mismatch between the level of social connection desired and the level the environment provides’ (Cacioppo and Patrick, 2008: 23). As the most cited category of goals set by participants of the NDIS include further opportunities for social participation, it follows that the environment for many people with disability is not currently matched with the level of social connectedness desired.

The relationship between music and social connectedness for young people with an intellectual disability has been explored in music therapy, community music and music education disciplines. Music is regarded as highly relevant for young people and particularly shared music participation. Young people spend more time than any other age group engaging with music (Hargreaves and North, 2008). In music therapy literature, many articles and chapters are based on theoretical frameworks that predate more critical discourse about disability studies (Goodley, 2014) and community music therapy (Aigen et al., 2010), which is characterized by a
‘participatory ethos’ Stige et al., 2010 (p. 281). A recent publication of music therapy and disability studies in the journal, Voices (Hadley, 2013) signifies that it is timely for the music-based literature to be reconsidered with a more critical eye to identify the level of congruence between published reports of music participation and current disability rights-based principles. In beginning a participatory action research exploring music and social connectedness involving young people transitioning from school, the authors sought to critically examine published reports from around the world of music-based research and case studies with young people with intellectual disability, which have some focus on the social or interpersonal aspect of music participation.

**Design**

**Critical interpretive synthesis**

A critical interpretive synthesis was selected as the method to examine the literature in this article. This method varies from a traditional literature review or synthesis in that it does not begin with a fixed method, procedure or hypothesis but rather the process is ‘iterative, interactive, dynamic and recursive’ (Annandale et al., 2007). This allows the early analysis to inform the focus of the synthesis. Rather than synthesizing the literature to find common effects or outcomes, it involves a secondary analysis, which examines the interpreted and constructed nature of the research by authors and in turn leads the reviewers to reflexively examine their own construction of the analysis (Dixon-Woods et al., 2006). It includes a thorough search of the literature and may include both qualitative and quantitative studies. Importantly, it involves a critique, which may question any taken-for-granted assumptions or biases within the literature (Dixon-Woods et al., 2006).

**Method**

**Searching the literature**

Search terms employed included music, social connectedness as well as related terms: interpersonal connection, psychosocial, health, belonging and friendship and well-being; young people including teenager, young person, youth, adolescent, student and intellectual disability, including disabled, mental retardation, developmental delay, learning disability and developmental disability (McFerran et al., 2013).

Searches were conducted through the databases RILM, ERIC, PsycInfo, CINAHL, SocIndex, Proquest Central and Medline (Web of Knowledge), yielding an initial 1077 articles. The titles of these articles were then scanned for relevancy and a secondary search was conducted using the reference lists in the most relevant articles.

**Selection for studies for inclusion**

A purposive sampling technique (Charmaz, 2006) was used with the remaining data, which involved selecting articles designed to yield the most comprehensive understanding of the subject. This included articles from a range of disciplines and countries as well as newspaper articles, academic journals and books. Articles were targeted that included a social aspect to the music participation and young people who had cognitive impairment. The quality of the research in studies was assessed as part of the critical analysis. Articles were not excluded based on the quality of the research but rather included for their relevance to the subject. There was no limit on the years searched. The oldest study discovered was published in 1991. Four philosophic articles were...
included in the first review (Gooding, 2009; Gregory, 2010; Lubet, 2009; Stige, 2010a) and then excluded during the analysis in order to focus on research studies, including case studies. The age criteria for participants were secondary school students up to 30 years old with an intellectual disability, autism spectrum disorder or learning disability. The music element included all forms of music participation from listening through to playing and performing with instruments and/or singing.

The final selection numbered 27 articles that were entered into an Excel spreadsheet. Data extraction began under the following headings: title, author, year of publication, discipline, type of disability, music elements utilized, type of connection, age of participants, voice in the article, primary focus, social aims, social outcomes, study method and length of music intervention.

Findings and discussion

Of the 27 articles, the first appeared in 1991 with a growing number in the past 10 years. Figure 1 shows the years in which the articles were published.

The majority of articles were found in music therapy publications – six in music therapy journals, four in music therapy book chapters, two online music therapy articles, three music therapy theses and one publication from the Salvation Army in Melbourne (McFerran, 2008).

Music therapists dominate research identified on this topic and most of the work reported is music therapy based followed by music education, then community music. Seventy-four per cent of authors are female, 11% male and 15% mixed, where there are several authors. Seven studies originated in the United States, seven in the United Kingdom, six in Australia, two each in New Zealand and Greece and one each in Norway, Israel and Canada. Figure 2 shows the proportions of articles by their discipline type.

Articles were classified as music education if the study was designed and facilitated by music teachers or music educators. The one study classified as music technology (Adkins et al., 2012) was authored by two sociologists, a disability researcher, a computational artist and a musicologist. This study examined the relationship between inclusion and technology for people with an intellectual disability.
Types of connection addressed by the music intervention

Initial inductive analysis of the data revealed that the types of connections being investigated could be divided into four different categories. These categories revealed themselves organically through being immersed in the data and comprised gathering different sections from each article that described what the authors considered to be connectedness. In doing so, we were able to examine the frequency and type of connections being fostered by facilitators through music programs, and to begin uncovering the elements of these connections that were being explored through the research (Figure 3).

These categories are:

1. people with disabilities within a group where connections are built between group members;
2. individual therapy where the connection is built between the person with a disability and the music facilitator (one-on-one);
3. people within the disability community through community workshops;
4. people within the wider community through workshops or through performance.

Having categorized the data in this way, separate Excel spreadsheets were created for each category in order to extract more detail.

**Within a group.** Of the 12 studies looking at connections within a group, 6 explicitly stated the purpose of the study as focusing on relationships within the group:

- peer interactions (Hooper, 2001),
- prosocial behaviour (Rickson, 2003),
- changing pattern of relating (Fillingham, 2007),
- attitude towards and relationships with peers (Hillier et al., 2011),
- peer relations and self-management (Gooding, 2011),
- peer relations and self-management (Gooding, 2011).

The remaining six studies focused on:

- effect of long-term therapy (Agrotou, 1998);
- inclusion (Lapka, 2006);
- musical attainment, communication skills, self-perception of skills (Macdonald, et al., 1999);
- changing patterns of behaviour (Warner, 2007);
- choice and agency (Adkins et al., 2012);
- value of long-term group music therapy (Pavlicevic et al., 2014).

The four pre 2006 studies focused on social skill attainment in the United States, United Kingdom and New Zealand, with the exception of the one long-term psychodynamic study from Greece (Agrotou, 1998). In studies post 2006, three focused on social skill attainment within the therapy group from the United States and the remaining five focused on relationships within the group from a social inclusion (Adkins et al., 2012; Fillingham, 2007; Lapka, 2006; Pavlicevic et al., 2014) and participatory action research framework (Warner, 2007). It is only in the United States that social skills have continued to be measured with this population of young people after 2006.

The validity of social skills acquisition is now questioned from both a practical sense and from a social model framework (Crow, 2010). Robertson et al. (1984) reviewed the literature on social skills training for people with disabilities and found a lack of evidence that the programs were related to successful independent living. The measuring of appropriate personal space, tone of voice and facial expression in the data as social skills are assumptions around a particular set of ‘ruling norms’ (Hadley, 2014; Young, 1999). These norms may appear acceptable and universal, but they are based on assumptions of normative behaviour and imposing them results in privileging some people over others and those ‘others’ may then become further disadvantaged (Hadley, 2014). Warner (2005: 80) stated in her participatory action research that ‘I am not so interested in determining whether music therapy helps participants move to a different developmental level, but rather what sense they make of it, and how other participants also learn from this’.

Each of these studies focused on factors occurring within the group with the exception of the study by Pavlicevic, which explores the value of long-term music therapy group work (Pavlicevic et al., 2014). This study took a more collaborative approach in line with a social model of disability.
which draws the focus away from the person’s impairment to the disabling systems and mechanisms surrounding the person (Crow, 2010). This study analysed data from two focus group discussions and the results of the study suggested that:

rather than leading to developmental change, long term, shared musicking provides young adults with ongoing opportunities for experiencing confidence and self-esteem with feelings of shared acceptance and success, and also provides young adults and their families with opportunities for developing and sustaining friendships (p. 5) and ‘real-life’ experiences of ‘getting to know others’ and to find relief from relentlessly disabling environments (p. 16).

Interestingly, the authors stated that they had originally intended to include the participants in focus group discussions in this study but were discouraged by some parents of the young people, who were concerned that they may disrupt the focus groups. The ‘absent voices’ were represented by the parents in one focus group and by professionals associated with the young people in another focus group, exploring the value of long-term music therapy for young adults with severe intellectual disability. This led to a questioning of ‘voice’ and whose voice is privileged in these discussions. Our curiosity was piqued when reading this study and it resulted in a deeper exploration of the data, focusing specifically on the use of voice. This is in a separate section following.

Of the 12 studies looking at relationships in a group, three reported outcomes of social interactions outside the music group, which were attributed to the influence of the music program. One aspect of community music therapy draws on ecological systems theory (Bronfenbrenner, 1969) as cited in Pavlicevic and Ansdell (2004: 280), where it posits that ‘if therapy leads to change, there may be a ripple effect in that the environment reacts, both positively and negatively – to the changes in the individual’. Each of these outcomes was reported in the discussion section of the article. One study was a case study of a school band that included students with a disability (Lapka, 2006). Discussions with parents revealed other benefits of relationship building in the band. One parent said:

I can’t tell you how many times we have been downtown and a band member has come over to talk to my son, or just passes by and says ‘hey (name of son) how’s it going?’ These are kids who would never had said that before, if they hadn’t been in the band together.

A student without disability said that ‘when you are forced to spend time with someone, you learn to understand the person’ (Lapka, 2006: 58).

One study reported increased interaction and cooperation between group members in an occupational therapy session following the music group (Hooper, 2001) and one reported that young people met up outside the therapy program (Hillier et al., 2011). By including these anecdotes, the authors of these articles demonstrated an acknowledgment of social benefits that extended beyond the therapy group, whereas in contemporary community music therapy practise, this ‘multi-system approach’ is ‘active’ and ‘consciously directed’ (Stige et al., 2010: 280). Within this framework, partnerships and networks are actively fostered and the level of this action is dependent on the resources and needs of participants in each context. A fostering of wider networks for young people through music programs will be of benefit for those with a desire for greater social participation, for example, fostering ‘social–musical pathways’ (Pavlicevic et al., 2014) to community groups such as choirs or other music ensembles.
Connection between young person and therapist, or one-on-one sessions. Six studies describe the connection between the person with a disability and the music facilitator, and each is a music therapy program. Four of these studies examined therapy sessions with people described as having multiple and profound disabilities and no verbal language. One study was with a person described as having a moderate disability and limited speech and one with a person who was described as having severe autism and limited verbal language. Table 1 summarizes some of this data along with the aims and outcomes of each of these six studies.

Each of these studies explicitly aimed to describe or measure the interpersonal relationship between the therapist and person with a disability. Five programs used a primarily non-directive, psychodynamic or humanistic approach describing the process of therapy and the interpersonal relationship and one study utilized cognitive behavioural techniques such as 'praising the desired behaviour' and stated the aim as increasing social skills (Clarkson, 1991).

Four of the six studies discussed some generalizing of the experience of the therapeutic relationship outside the session, to build a social network. The authors from two studies included anecdotal reports of 'improvements in temperament and social behaviour' (Toolan and Coleman, 1994: 443), and 'improvements generally in their communicative and social skills' (Graham, 2004: 27) following the music therapy program. One author discussed having the intention of introducing opportunities for social contacts outside the session (Clarkson, 1991) and one discussed the significance of this step saying:

> By actively striving to generalize positive experiences of relationships beyond the therapy room, music therapists will be able to make a more significant contribution to the young person’s well-being while simultaneously acknowledging the strong emphasis they place on the development of relationships with (a person) who has profound intellectual disability. (McFerran and Shoemark, 2013: 12)

Connection with the disability community. Studies that look at connections to the community were divided into the disability community and wider community to explore the purposes of each project and how decisions were made to facilitate these connections.

An Australian study of friendships with adults with intellectual disability (McVilly et al., 2006) found that some participants believed that having a disability was an important factor for friendship. They described this as being ‘at my level’ and qualified it by saying ‘It’s hard to be friends if they ain’t got a disability. They just don’t understand’ (p. 699). In contrast, Lippold and Burns (2009) described how some authors measured successful integration as friendships between people with and people without disability. The nature of these friendships has been explored in several other studies (Amado, 1993; McVilly et al., 2006; Rickson, 2014) and it was a subject that was raised in a recent conference held in Victoria by people with disability. One young woman gave a talk on her experience of a friendship with someone without an intellectual disability. She ended the talk by saying, ‘don’t give up hope. It is possible’ (Stevens, 2015).

Six studies were categorized as focusing on connecting groups of people with disability with other people in the disability community. Five of these were music therapy projects and one was a community arts project. These studies were published in the past 6 years, with the exception of one study (Ely and Scott, 1994). This study was ahead of its time in exploring a connection to the community in what might now be described as ecological or community music therapy (Ansdell, 2002; Stige, 2002).

The following list shows an extract from each study that described some purpose or outcome in extending the social networks of participants and creating connections:
<table>
<thead>
<tr>
<th>Year/duration of program</th>
<th>Research method</th>
<th>Aim/question</th>
<th>Reported social outcome</th>
<th>Evaluated by</th>
</tr>
</thead>
<tbody>
<tr>
<td>1991 2 Years</td>
<td>Case study</td>
<td>Increase direct eye contact, increase signing to indicate choice, increase toleration of physical contact.</td>
<td>Eye contact is steady. Physical contact is tolerated through dancing. Signing for communication is increased.</td>
<td>Music therapy clinician (Clarkson, 1991)</td>
</tr>
<tr>
<td>1994 30 Sessions</td>
<td>Quantitative</td>
<td>To examine how changes in the levels of engagement and avoidance within music therapy shed light on the therapeutic process.</td>
<td>A deepening rapport over time and a containment of capacity for the therapeutic relationship.</td>
<td>Music therapist researchers (Toolan and Coleman, 1994)</td>
</tr>
<tr>
<td>1994 3 Years and 9 months</td>
<td>Case study</td>
<td>In the beginning: connect with breathing (the young man’s sole output). The article describes the process of the therapy as a two-way phenomena.</td>
<td>Clear musical communication is continuously increasing, asserting a misdiagnosis of deafness.</td>
<td>Music therapy clinician, independent observers of video footage (Agrotou, 1994)</td>
</tr>
<tr>
<td>2004 Not specified</td>
<td>Case study</td>
<td>To describe music therapy with a pre-verbal client where vocalization is used to establish an interactive relationship.</td>
<td>Vocalization can play an important part in establishing and developing a therapeutic relationship in which clients’ communication skills can grow.</td>
<td>Music therapy clinician (Graham, 2004)</td>
</tr>
<tr>
<td>2013 2 Years</td>
<td>Qualitative</td>
<td>How does music stimulate the development of the relationship between a child with a profound disability and a music therapist?</td>
<td>Spontaneous initiation is sought from the young person and the relationship is built over time.</td>
<td>Music therapist researchers, independent observers of video footage (McFerran and Shoemark, 2013)</td>
</tr>
<tr>
<td>2014 Average of 4 years</td>
<td>Qualitative</td>
<td>What is the experience of the interpersonal relationships between five music therapists and their adult clients with profound and multiple disability?</td>
<td>The process requires mutual effort over time and the relationship fosters psychosocial well-being for the client.</td>
<td>Music therapist researcher (Lee, 2014)</td>
</tr>
</tbody>
</table>
1. ‘To increase social networks and opportunities for social interaction for clients’ (Ely and Scott, 1994: 10). One future program goal for this project was for the sessions to be held in a community setting to further extend the social network to general members of the community.

2. ‘Social interaction was considered to be a significant outcome of this community service, where different adults from different services came together’ (McFerran, 2008: 29). (Summary of group leaders comments. The Salvation Army participatory action research project compared community music and music therapy.)

3. ‘The festival brings people together for company and cultural purposes’ (Stige, 2010b: 116). (Summarized speech by the Director of Culture in the opening ceremony. Participants come together from local communities once a year.)

4. ‘Create an opportunity to be in contact with a broader community’ (Elefant, 2010: 190). Written by the author on the purpose of bringing together two choirs of people with disability to perform.

5. ‘The choir gives its members an opportunity to meet new people and make friends’ (Rhongzhi, 2010: 54). (Summary of comments made by participants. Community choir for people with disabilities.)

6. ‘The groups have developed and cemented friendships’ (Stickley et al., 2012: 255). (A summary of comments by organizers.)

Connection to the wider community. Four articles explored a connection between people with a disability and the wider community through music. One study described a music therapy project and three described various community music projects. A music therapist authored one of the community music projects (Rickson, 2014), another included an author who is a music therapist (Dingle et al., 2012).

Analysis of the nature of the connection was explored in the data to discover people who made up the ‘wider community’ in each of the music projects as well as the reported outcomes. Table 2 summarizes this in each of the four articles.

Three studies described a connection between the audience and performers. Of these, two studies described this connection from the perspective of the audience and one described the connection from the participants’ perspective. A brief description and relevant quotations were drawn out to illustrate the nature of this connection.

Audience response to performance

- Rickson’s (2014: 10) study of the orchestral performance measured audience responses through interviews. Three audience members were interviewed who did not have an association with the performers and were described as ‘outsiders’. Their responses were summarized as being, ‘genuinely moved by the creativity, expression and artistry demonstrated by the learners’.
- Curtis and Mercado (2004: 9) reported 100% positive responses to audience enjoying the performance and 100% said they would attend another event by performers with disabilities. Some comments were ‘it was far better than I expected’, ‘it is wonderful what you have done’, ‘they can do so much more than expected’ and ‘this is testimony that people will achieve when given the opportunity’.
Dingle et al. (2012: 415) reported that a sense of connection to the audience was a common theme of the social impact of choir singing. ‘A lot of people were standing around and listening. It was a good feeling’. ‘It make you feel better – a good reaction from the audience’.

The data did not reveal who made the decision to foster these particular connections. It did reveal that connections made with the disability community tended to report more on the formation of friendship and social interaction. Rhonzi (2010: 58) reported, ‘The choir gave members opportunities to meet other members in their ages and their levels’. Connections made with the wider community, particularly through public performance, had more of a political agenda as well as extending the experiences of participants and widening social connections (Curtis and Mercado, 2004; Rickson, 2014). Curtis and Mercado (2004: 2) described the participants in their choirs from the university as ‘intentional’ and that they created ‘communities of resistance’ in order to ‘enact social change’. The authors said that while some argue that disability arts groups may ‘ghettoize’ disability artists, they also create opportunities to challenge society’s views by performing or exhibiting to the public. Disability advocate, Stella Young (2012), summarized this in her views on the proposal to integrate the Paralympics with the Olympics:

We get so few opportunities to publicly and raucously celebrate our community and the amazing contributions people with disabilities make. The Paralympics are ours. Hands off.

**Voice**

A separate analysis was undertaken to explore articles that utilize young people’s voice. Eleven of the 27 articles used the voice of participants with disability to explore the experience of their music participation.
participation. Each of these studies was published in the last 10 years, the majority in the past 4 years. The analysis began by exploring the methods of eliciting the participants’ voice, the questions that were being asked and how this related to their sense of social connectedness. In Table 3, italics formatting are used to indicate foci specifically related to social aspects of participation in these 11 articles.

Six articles were qualitative, three quantitative and two employed mixed methods. Of the mixed method studies, quantitative methods were used for participants with disability and qualitative for others involved in the project (Curtis and Mercado, 2004; McFerran, 2008). Direct quotes from participants with disability were also reported in one article in a response to the implied question, ‘what was your favourite activity?’ This suggests there was a qualitative element to the interview (Curtis and Mercado, 2004).

Of the quantitative studies capturing the participant voice, pre and post self-reported questionnaires were used with participants (Gooding, 2009; Hillier et al., 2011).

In the remaining six articles, participants’ voices were elicited using different qualitative methods. The various methods were as follows:

1. Brief informal interviews before and after sessions (Stickley et al., 2012).
2. Individual interviews before the project regarding current music use and then group interviews after the project (Adkins et al., 2012).
3. Individual qualitative interviews with participants (Dingle et al., 2012).
4. Seven individual and two group interviews with participants. Of the individual interviews, the participants had a parent or carer present to assist them with the interview, for instance, repeating questions (Rhongzhi, 2010).

<table>
<thead>
<tr>
<th>Year</th>
<th>Discipline</th>
<th>Method</th>
<th>Country</th>
<th>Study focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>2007</td>
<td>Music therapy</td>
<td>Qualitative</td>
<td>England</td>
<td>Thoughts and feelings on relationships and quality of life (Fillingham, 2007).</td>
</tr>
<tr>
<td>2009</td>
<td>Music therapy and community music</td>
<td>Mixed</td>
<td>Australia</td>
<td>Quality of life and session satisfaction (McFerran, 2008).</td>
</tr>
<tr>
<td>2010</td>
<td>Music Therapy</td>
<td>Qualitative</td>
<td>Israel</td>
<td>Satisfaction with performance (Elefant, 2010).</td>
</tr>
<tr>
<td>2011</td>
<td>Community music</td>
<td>Qualitative</td>
<td>England</td>
<td>Enjoyment, skill development, relationship building, social inclusion (Stickley et al., 2012).</td>
</tr>
<tr>
<td>2011</td>
<td>Music education</td>
<td>Quantitative</td>
<td>United States</td>
<td>Attitude towards peers (Hillier et al., 2011).</td>
</tr>
<tr>
<td>2011</td>
<td>Music therapy</td>
<td>Quantitative</td>
<td>United States</td>
<td>Social Skills functioning (Gooding, 2009).</td>
</tr>
<tr>
<td>2011</td>
<td>Music therapy</td>
<td>Quantitative</td>
<td>United States</td>
<td>Social skills functioning (Gooding, 2009).</td>
</tr>
<tr>
<td>2013</td>
<td>Digital music</td>
<td>Qualitative</td>
<td>Australia</td>
<td>Descriptions of use of digital tool (Adkins et al., 2012).</td>
</tr>
<tr>
<td>2013</td>
<td>Community music</td>
<td>Qualitative</td>
<td>Australia</td>
<td>Connectedness, personal meaning, health benefits (Dingle et al., 2012).</td>
</tr>
</tbody>
</table>
5. Semi-structured interviews before and after the project. Interviews were also conducted with key workers and residential staff (Fillingham, 2007).

6. Participant voices were gathered via interview in a participatory action study (Elefant, 2010).

Of the 11 studies, 5 specifically measured an aspect of social benefit. In Rhongzhi’s (2010) US study, for the question, ‘what do you like about being in the choir’ (p. 27), all members indicated they liked being with people, being part of groups and developing friendships. For the question ‘Do you like the people in the choir?’ (p. 29) every participant said yes. There was no reporting of negative aspects of choir participation and there was only one question that included a negative option as a response, ‘How do you feel when you come to the choir? Happy, bored, (circle yes or no)’. No participants circled ‘bored’. (p. 27)

In Hillier et al.’s (2011) study measuring peer relations, the results indicated improved attitude towards peers from self-report questionnaires. Parents of the participants completed the same questionnaire and although there was an improvement measured with these results, it was less significant (p. 0.049).

In each study where a comparison is made with others, the young person’s evaluation of their social participation is consistently more positive than others questioned. Whether this demonstrates the phenomena of ‘acquiescence’ (Lewis and Porter, 2004) or that young people were simply more satisfied than others were able to perceive, is difficult to determine from the data. For instance:

Jean names two service users and five staff as friends and her key worker says, ‘Jean talks a lot but they’re not friends’. Maggie names two staff members as friends and Maggie’s home leader said she has ‘no friends, as such’. (Fillingham, 2007: 81)

In Hillier et al.’s (2011) study of young people with autism and Gooding’s (2011) study of young people with learning disability, parents, case managers and teachers report less improvement in peer relations and social skills than the young people themselves.

The inclusion of participants’ voice in the reporting data is provided only in the past 10 years. Having a cognitive deficit may hinder understanding of concepts in questions and some people may have other ways of communicating than verbally (Finlay and Lyons, 2001; Rabiee et al., 2005), which means that effective ways of reporting and including the opinions of participants needs to be explored further and given equal or higher priority in the literature. It is through hearing directly from participants that facilitators of music programs can learn how best to design and evaluate programs, and through this collaboration, give greater choice and control to participants. In a broader literature review of young people with disability, the authors found that ‘the extent to which decision-making processes acknowledge and include young people playing a role in studies highlight the “lack of voice”. Young people with a disability are not properly involved in decision-making at crucial points in their journeys to adulthood’ (Stokes et al., 2013: 16). As research ultimately aims to affect the lives of people with intellectual disability, having active participation in program and research agendas is an important consideration (Nierse and Abma, 2011). The catch-cry of the disability rights movement in the United States in the 1990s summarizes this with, ‘nothing about us without us’ (Charlton, 1998).

In the ‘making music, making friends’ study (Pavlicevic et al., 2014), the purpose was to explore the value of long-term music therapy for young people with severe and profound disability.
As stated earlier, the authors discuss the unfortunate lack of participant voice in this study and explain that difficulties were encountered when attempting to involve the young people. Their lack of inclusion in the research indicates an assumption that participant’s voices are not required to give an evaluation of their involvement, and their exclusion sends the message to other young people with disability that they are not the ‘experts’ in their own experiences.

When participants are non-verbal. Within the data, another category of voice was created where participants have multiple and profound disability and do not use speech to communicate. Their opinions are very often absent in research because of challenges in communication (Morris, 2003; Pavlicevic et al., 2014; Rabiee et al., 2005). In several of the studies, participants’ voices are ‘heard’ through the rich descriptions of behaviours and responses during the music sessions. Using this method, researchers attempt to make the opinions and choices of the young people explicit in the data gathered and therefore represented in the results of the studies. Three of the five identified studies examined the relationship between the therapist and young person and two examined the relationships between group members of people with profound disability as well as with the support people closely involved with the participants. Each of these articles describes a music therapy program.

Of the five studies, two are contained in Lee (2014) (Agrotou, 1998; Lee, 2014; McFerran and Shoemark, 2013; Warner, 2005). I extracted a reported communicative behaviour from the participant(s) to illustrate voice and in particular one that indicates intentionality for instance:

Again Pamina chooses to combine her two repertoires and starts another two ‘phrases’ of foot-beatings: a four-note phrase, followed by a nine-note phrase. This time it becomes clear that she makes some delay over some of her foot-beatings, causing the group music to slow down, but also making it more difficult for us to keep our turns in a clear dialogue form. It may be that she was checking, in this way, the predictability of our responses to her. (Agrotou, 1998: 160)

All five of these studies were unique to music therapy. In the study by McFerran and Shoemark (2013: 11), four key principles of musical engagement are identified in long-term music therapy practice:

- the music therapist listens,
- the music therapist takes responsibility for structure,
- spontaneous initiation is sought from the young person, and
- the relationship is built over time.

As these authors discuss, benefits will be made for the young person if these communications are shared with people outside the group so that social opportunities for the young person may be broadened. Agrotou (1998) and Warner (2007) include carers in the therapy program in order to build their knowledge of communicative techniques and to draw significant others involved with the young person into the musical relationship. Music therapists are in a unique position to take this knowledge and disseminate it in new ways to benefit young people so that future ‘principles of musical engagement’ may commonly include another bullet point:

- collaborative musicking is shared beyond the session.
Conclusion

Through exploring the published literature in this way, the authors were able to ask specific questions of the data relating to the types of social connections being fostered, the level of collaboration with participants and voice. Current disability studies discourse as well as community music therapy theory (Pavlicevic and Ansdell, 2004) over the past decade have influenced this particular interest.

Through this lens, the synthesis revealed persistence in working from a medical model framework with some studies including developmental goals such as social skills acquisition, with its implied aim of normalizing behaviour. It has revealed a lack of any critique of programs from individuals participating as well as a marked discrepancy between the perspectives of young people and others regarding their social interactions. It has revealed a shift in thinking during the past 10 years to include a more collaborative approach, particularly in community programs as well as an acknowledgement of the need to foster music opportunities in broader areas of the person’s life but needs to go further. Collaborative decision-making in the design of programs, setting agendas and evaluation in research will all provide opportunities for young people to exercise greater choice and control in their lives. There is a need for music programs’ facilitators to ‘embrace diversity rather than normalcy’ (Rolvsjord 2014: 16) to contribute to the creation of a welcoming music culture in which people of all abilities can take part and flourish.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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References


Dear Melissa

HREC Project: Scope 78/14 – Linking in and Grooving Out:

*The use of music to address social connectedness for young people transitioning between school and adult services.*

Approval Status: Approved to proceed.

The HREC has reviewed your response and is satisfied all items have been adequately addressed and therefore your research project has been approved to proceed.

The approval period is from the date of this letter until 1st July 2015.

Terms of approval include:

- The submission of a bi-annual progress report every 6 months from the date of approval
- The submission of a Final report within 3 months of the project completion date
- The Scope HREC must be notified immediately of any adverse events
- Amendments should be submitted and require approval before any changes are made
- A Self-audit must be completed and submitted annually, along with the 2nd progress report

Please refer to our website for further details, including reporting and audit forms.

Yours sincerely

[Signature]

Dr Stella Koritsas
Head of Strategic Research
Chair, HREC

HREC: EC00428
ORG: ORG0554

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F (03) 9843 2030
E contact@scopevic.org.au
www.scopevic.org.au
Participant Information
Young People able to give Consent

Linking In and Grooving Out; The use of Music to Address Social Connectedness for Young People Transitioning between School and Adult Services

Why Did I Get This Letter?
This letter is to ask if you want to be in a study.

What is the study about?
The study is looking at how young people are going in their social life once they leave school. We are interested in how you meet people, how you meet friends, how you are involved in your community and with your family. We want to know how many people you know and how close you feel to those people.

We also want to find out about your music interests. What music do you like? What music don’t you like? Would you like to be involved in music workshops? What sort of workshops? Singing groups, rap groups, a rock band, jam sessions?

We are interested in looking at how joining in music workshops can make a difference to your friendships and connections.

The music workshops will be in the next stage of this project. Not this stage.

Who is doing the Study?
These are the people doing the study.

Melissa Murphy: She is a *music therapist and will be doing the interview. She is a masters student at Melbourne University.
Dr Katrina McFerran: She is a music therapist and is the head of Music Therapy at the University of Melbourne. She will be supervising.
Dr Nick Hagiliassis: He is the Scope Manager of Evaluation and Practice Enhancement and will also be supervising.
*A music therapist is a trained musician who works with people to improve their well being using music.

August 2014
What is the name of the study?
Linking In and Grooving Out: The use of music to address social connectedness for young people transitioning between school and adult services.

Who is paying for the study?
A scholarship called a Strategic Research Australian Postgraduate Award from the University of Melbourne is funding the study.

What will happen if I am in the study?
If you decide to be in the study three things will happen.

1. We will make a time with you to have the interview and arrange a good place that suits you where it is quiet and we won’t be disturbed.
2. You will sit with Melissa, the Music Therapist, and she will ask you some questions about your music and your friendships. This will take up to one hour.
3. Melissa will write down your answers and also record your answers on an iPad so she can listen back after.

What will happen to the information that I give?
Melissa will make sure that the information is kept confidential. That means that we won’t tell anyone whose information it is, even when we talk about the study at a conference or write about it in a published journal.

We will keep the information in a locked filing cabinet so that only the researchers will be able to see it. 7 years after the study is finished, the information will be destroyed.

How can I get a copy of the results?
If you do want a copy, Melissa will send one to you once the study is written up. Just circle the ‘yes’ on the consent form.

What good or bad things might happen to me if I am in the study?
You will have the chance to talk about your social life and about music and what it means to you. Your answers will be looked at and will help us to set up some music workshops that may be interesting and fun. The music workshops will be in the next stage of this study. Not this stage.

By doing this study, it does not mean that you have to do the workshops. This is separate.

If you would like to be part of the music workshops, you can let the researcher know, or your support worker.

Whether you participate in the workshops is up to you. They may or may not be near
where you live.

We don’t think that being in the study will be upsetting, but if it is, we can have someone come and talk with you.

**Who decides if I am in the study or not?**
You do.

It is up to you to say if you want to be in the study or not.

It’s also okay to say you don’t want to be in the study. Either way, it won’t make any difference to the services you receive at Scope now or in the future. It won’t make any difference to your relationship with Scope or anyone doing the research.

You can even say ‘yes’ now and then change your mind later. If you change your mind, just let one of the researchers know or tell one of the staff at Scope before the day of the interview.

**What if I want to ask some questions about the study?**
If you want to ask some questions, you can call us. The phone numbers are below. You can also ask a staff member at Scope to call us and make a time to meet so that we can talk about the study before you decide if you want to do it.

Melissa Murphy – 0448 313462  
Dr Katrina McFerran – 0407 350251  
Dr Nick Hagiliassis – 83114013

**What do I do next if I want to be in the study**
Just sign the consent form at the end of this letter. Put only that page in the envelope we provide. That envelope has our address on it. Then put it in the post or ask a staff member to post it for you.

**What if I don’t like something in the study?**
You can complain.

**How can I make a complaint?**
You can phone someone from the ethics committee. The Scope person’s phone number is 98432065. Say to that person:

“I want to complain about a project.”

Tell them the project number: “*insert project number*”, and the project name: “Linking In and Grooving Out; The
use of music to address social connectedness for young people transitioning between school and adult services.”

This will make sure the person knows the project that you are complaining about.

You could also send a letter. The address is:

Stella Koritsas  
Cair. Scope Human Research Ethics Committee  
830 Whitehorse Rd  
Box Hill Victoria 3128  
Telephone (03) 9843 2065  
Email: skoritsas@scopevic.org.au

**Project clearance by HREC: YES**
Consent Form

YOUNG PEOPLE AT SCOPE ABLE TO PROVIDE CONSENT

Linking In and Grooving Out; The use of Music to Address Social Connectedness for Young People Transitioning between School and Adult Services

Student Researcher: Melissa Murphy. Supervisors: A/Prof Katrina McFerran, Dr Nick Hagiliasss

I have read the explanation about the study. Someone has answered my questions about the study.
I understand that by signing this form, I am giving my consent to do the interview.
I understand that doing the interview means:
• I will be asked about my social connections such as my friends, my family and my community and I will be asked about music and what I like.
• Melissa will write down my answers and also record them on an iPad.

I also understand that I can decide later that I don’t want to do the interview anymore.

Please circle yes or no.
I wish to have a copy of the study once it is written up. Yes No

Name: ___________________________________________
Signature: _______________________________________
Date: _________________________________________
Contact Number: _______________________________
Email: ________________________________________

August 2014
Appendix E

Deciding on the Capacity for Consent
(Completed with the support worker and a researcher)

The person is able to understand what the study is about when it is explained to him/her.

Yes  No

The person understands what s/he will be doing.

Yes  No

The person knows that it is up to him/her only to decide to be in the study.

Yes  No

The person understands what benefit s/he might have from being in the study

Yes  No

The person understands the risks and inconvenience involved in being in the study.

Yes  No

The person knows s/he can withdraw at any time or decide not to do certain things.

Yes  No

The person knows s/he can complain about the study to any one of the following people:

   someone s/he knows well, one of the researchers or the Ethics Officer

Yes  No

The person usually makes decisions about participating in activities such as this study or use of services.

Yes  No
6th October 2015

Melissa Murphy
The University of Melbourne
151 Barry Street
Parkville, 3010

Dear Melissa

HREC Project: Scope 91/15 - Linking in and Grooving out: The use of music to address social connectedness for young people with a disability transitioning between school and adult services (Phase 2)

Approval Status: Approved to proceed

Thank-you for providing the amendments requested by the HREC.

I have reviewed your responses and am satisfied that all queries have been adequately addressed. Your research has been approved to proceed.

The approval period is until 31st December 2017.

Terms of approval include:

- The submission of a Final report within 3 months of the project completion date
- The Scope HREC must be notified immediately of any adverse events
- Amendments should be submitted and require approval before any changes are made
- A Self-audit must be completed and submitted annually

Please refer to our website for further details, including reporting and audit forms.

Yours sincerely

Stella. Koritsas

Dr Stella Koritsas
Head of Strategic Research
Chair, HREC

HREC: EC00428
ORG: ORG0554

making it happen
| Q1: What music sessions are you facilitating? | Weekly music group for people with disabilities in the area |
| Q2: How often do you meet? | Once a week |
| Q3: How many people attend on average? | 10 |
| Q4: How would you describe the people who attend your group? e.g. people from the general community, people within a day service for people with disability, other. | People within a disability day service |
| Q5: What constitutes a typical session? e.g. Warm up, singing, instrument playing, recording, jamming etc. | Instrument playing, singing, rehearsing songs as a band |
| Q6: What would you say is going well with your program? | Band dynamic - getting many gigs in the community, engagement and enjoyment is high |
| Q7: What would you say are the main challenges with your program? | Trying to build on musical skills with varying degrees of abilities |
| Q8: How would you say your music group is going overall? | Fantastic! Performing many gigs in the community, recorded a dvd, the opportunity to perform in public has given many people with a disability the opportunity to express themselves on stage as well as building confidence |
| Q9: Are you utilizing any ideas or techniques you learned in the facilitator workshop? If yes, could you list them here. | Tailoring songs to include all participants, eg, "The hello song" |
| Q10: What have you found most useful from attending the workshop? | Sharing of ideas and experiences |
| Q11: Were there elements missing from the workshop that you would have liked to be included? | More specific techniques used by music therapists to engage people with a disability |
| Q12: If there were something you could improve about your own program/s, what would it be? | More one on one time to assist people to build their music skills, eg, drum lessons, singing lessons, guitar lessons |
| Q13: Are there specific skills you would like to learn to enhance your program? | Sound technician skills, mixing levels for the PA for gigs in the community |
Q14: **Do you think you receive adequate support for your music program? E.g. financially, awareness from the community or organisation about your program. Yes/No Comments.**

No, I need more support particularly when performing in the community to adjust levels. Also need more paid time to provide music lessons to individuals.
#2

**COMPLETE**

*Collector: Email Invitation 1 (Email)*  
*Started:* Monday, November 14, 2016 4:42:51 PM  
*Last Modified:* Monday, November 14, 2016 4:49:52 PM  
*Time Spent:* 00:07:00  
*Email: IP Address:*

## PAGE 1

**Q1:** What music sessions are you facilitating?  
private music therapy  

**Q2:** How often do you meet?  
once a week  

**Q3:** How many people attend on average?  
individual setting for one person  

**Q4:** How would you describe the people who attend your group? e.g. people from the general community, people within a day service for people with disability, other.  
disability  

**Q5:** What constitutes a typical session? e.g. Warm up, singing, instrument playing, recording, jamming etc.  
singing, instrument playing  

**Q6:** What would you say is going well with your program?  
instrument playing, rhythms  

**Q7:** What would you say are the main challenges with your program?  
client can not speak, sometimes not clear how she is going  

**Q8:** How would you say your music group is going overall?  
sessions overall ok  

**Q9:** Are you utilizing any ideas or techniques you learned in the facilitator workshop? If yes, could you list them here.  
no  

**Q10:** What have you found most useful from attending the workshop?  
meeting other facilitators and hear about their approach  

**Q11:** Were there elements missing from the workshop that you would have liked to be included?  
no  

**Q12:** If there were something you could improve about your own program/s, what would it be?  
know more songs  

**Q13:** Are there specific skills you would like to learn to enhance your program?  
know music App for songs or other IT programs that work  

**Q14:** Do you think you receive adequate support for your music program? E.g. financially, awareness from the community or organisation about your program. Yes/No Comments.  
payment is just ok, could be better though
**#3**

**COMPLETE**

Collector: Email Invitation 1 (Email)  
Started: Monday, November 14, 2016 4:41:03 PM  
Last Modified: Monday, November 14, 2016 4:50:08 PM  
Time Spent: 00:09:04  
Email:

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**PAGE 1**

**Q1: What music sessions are you facilitating?**  
Currently 1:1 with man in his late 30s with an ABI

**Q2: How often do you meet?**  
Once a week

**Q3: How many people attend on average?**  
Client and sometimes family members

**Q4: How would you describe the people who attend your group? e.g. people from the general community, people within a day service for people with disability, other.**  
Client who receives individualised care and doesn't attend day service

**Q5: What constitutes a typical session? e.g. Warm up, singing, instrument playing, recording, jamming etc.**  
Keyboard playing - before his accident the client could play piano well. We are redeveloping those skills with exercising and songs played by ear and then practising reading music. Then we play guitar and sing together song and chosen by him.

**Q6: What would you say is going well with your program?**  
The most exciting outcome so far has been the redevelopment of the persons musical identity. Also his mood improve a greatly after sessions.

**Q7: What would you say are the main challenges with your program?**  
Keeping the individual stimulated. Trying new things - client wants to do activities that are familiar.

**Q8: How would you say your music group is going overall?**  
Good!

**Q9: Are you utilizing any ideas or techniques you learned in the facilitator workshop? If yes, could you list them here.**  
Yes we have been trying simple songwriting.

**Q10: What have you found most useful from attending the workshop?**  
Inspiration from others and sharing ideas

**Q11: Were there elements missing from the workshop that you would have liked to be included?**  
More jamming !

**Q12: If there were something you could improve about your own program/s, what would it be?**  
How to have more of a structure

**Q13: Are there specific skills you would like to learn to enhance your program?**  
Working out how to have an individual focus in a big group

**Q14: Do you think you receive adequate support for your music program? E.g. financially, awareness from the community or organisation about your program. Yes/No Comments.**  
**Respondent skipped this question**

---

4 / 6
**Q1: What music sessions are you facilitating?**

Disability music sessions for inclusive community singing groups.

**Q2: How often do you meet?**

Group twice per week, other groups weekly or monthly.

**Q3: How many people attend on average?**

Has 30 people on Fridays, 18 on Wednesdays. Groups have between 6 and 15.

**Q4: How would you describe the people who attend your group? E.g. people from the general community, people within a day service for people with disability, other.**

Group is people form 3 day services coming together. Groups are open to anyone.

**Q5: What constitutes a typical session? E.g. Warm up, singing, instrument playing, recording, jamming etc.**

Warm up, singing, listening, dancing, percussion, drama. Other groups: warm up, singing, improvisation.

**Q6: What would you say is going well with your program?**

All the participants are slowly increasing their confidence, trust and levels of participation including the carers.

**Q7: What would you say are the main challenges with your program?**

Venue is not really great. No financial resources for equipment (I have to provide instruments etc)

**Q8: How would you say your music group is going overall?**

Great!

**Q9: Are you utilizing any ideas or techniques you learned in the facilitator workshop? If yes, could you list them here.**

A couple of songs.

**Q10: What have you found most useful from attending the workshop?**

Peer exchange gives me encouragement and helps me know that I am doing OK.

**Q11: Were there elements missing from the workshop that you would have liked to be included?**

Respondent skipped this question.

**Q12: If there were something you could improve about your own program/s, what would it be?**

Some really useful instruments that people with limited motor capacity can play.

**Q13: Are there specific skills you would like to learn to enhance your program?**

Yes! Sign languages commonly used in disability work; Use of electronic instruments.
Q14: Do you think you receive adequate support for your music program? E.g. financially, awareness from the community or organisation about your program. Yes/No Comments.
Research on social connectedness with young people transitioning between school and adult services using music.

- Are you someone with disability aged between 16 and 30 years old in the Geelong area?

  Or

- Do you know someone with disability aged between 16 and 30 and could let them know about this project?

If so, we would like you to get involved in setting up a community music group.

Why are we doing this research?
Young people with disability may face challenges with making friends and feeling part of their community after they leave school. The aim is to:

- Get involved in community music making and
- Enhance social connections

Who are we?
The project is being undertaken by a music therapist and PhD candidate from the University of Melbourne in partnership with Scope. It is being funded by a Postgraduate Award Scholarship and Scope.

If you are interested and would like to know more about the project, please contact

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Journal extracts

Session 1

25th February 2016
1.00 until 2.00pm

Three men and supporter, Susan –(or Susan 2) and Matthew came for the last half hour.

Ben arrived first. He was wheeled in by the taxi driver. The driver seemed happy to come in and say hello. He seemed familiar with Ben and invested a little in his well-being – indicated by his smile. Chatted with Ben for a bit. I asked if he had been before and he said he hadn’t. I asked whether Oliver and Ethan were coming and he said they were and that Matthew would come in his car when I asked him. I asked him if he sang and he said yes and he also said Susan was a singer.

There was another group of young men and a facilitator in the main room and Jane said they had been coming for a while. She described the men having challenges in going to other programs and that it was an education program. The men looked in the late teens/early 20’s. Jane said they may change their times or day and so we may be able to use the big room sometime. It was the facilitator that knocked on the door a couple of times and told me the men had arrived.

So next, Oliver and Ethan came with Susan. I had come to the room half an hour early to set up. I was a bit disappointed that the keyboards were missing power chords. I will bring my own next time. I pulled out mics and set them up on stands and two drums and a cymbal from the drum kit as well as two electric guitars and an acoustic and plugged them in. I tuned the guitars to an open tuning and set everything up around the room.

When the men came in, I had their chairs positioned so that they could see the instruments. I told Susan that Ben said she was a singer. Everyone had a laugh at this when Susan said she definitely wasn’t and that Ben was telling fibs. I said that I was so happy to see them here and asked Ethan and Oliver if they had been here before. Oliver said ‘no’ and Ethan burped loudly when I asked him. Ben laughed heartily followed by Oliver at this. I said I thought I would interpret that as a ‘no’ to which there was more laughter.

I started by saying I was so happy to see everyone here and that we could have a music group together. I said that it was their group and they could choose what they wanted to do. I suggested we might spend the first few times trying everything out and said we had guitars, and drums and microphones to begin. Susan talked about Ethan and the keyboard and said that his mum said he plays at home and knows how to operate the buttons independently.
I told her and Ethan that they weren’t working and that I would bring mine in next week. So I said to Ben, do you want to start with mics or instruments? He said instruments. I then asked drums or guitar. He said guitar, so I got one of the electric ones and gave it to him over his lap. Susan assisted by holding it for him. I then asked Oliver what he wanted and he also said the guitar, so I grabbed one for him as well and he held on to it. I told them both I hadn’t switched them on yet. I then offered a drum to Ethan with a stick and he immediately began beating the floor Oliver? I said I wondered what we could do to support the guitars on the men’s laps because they were slipping down and Susan suggested straps. Genius! I went and found a couple of straps and put them on. Problem solved. Both men said they were comfortable with this arrangement when I asked. I went over and switched on the amps and sat with my electric and away we went. The men on guitars were strumming them very easily and Ethan was hitting the drum. At one point I asked Susan if she would like to play – she had been occupied with assisting the men with their instruments. She said yes straight away and I offered the ukulele. We all make random sounds finding and experimenting with the instruments. All a little in our own worlds getting our heads around this new idea of playing together. The open tuning in E gave us some semblance of harmonic unity.

After a bit, I began to softly put in a 12 bar blues progression and started singing. We’re all here, playing some music x 4 Oliver, Ethan, Ben and Susan
We’re all here playing some music.

I paused and put in people’s names leaving gaps. Ethan had stopped playing the drum and threw down his stick. He was grabbing hold of the fret board of Oliver’s guitar. I moved him back a little because I thought it might have been annoying him pushing into his lap. But he just reached out grabbed it again.

I asked him if he wanted to play the guitar and he smiled and rocked his head around. I asked Oliver if he would mind swapping and going on the drum and he said ‘yes that would be fine.’ When Ethan got the guitar, he immediately started strumming rhythmically with his finger across all the strings. We started up again and Oliver played sporadically on the drums. I had given him all three including the cymbal, but he just played one drum when he was reminded. He didn’t seem to play for more than a couple of seconds at a time and then sit back.

After another jam, we started a bit of a chat about music that they liked. Susan said the men had music with Shane and that Oliver liked ‘Mellow yellow.” He laughed and said mellow yellow.” I asked Ben what he liked and he said ‘achy breaky heart”. Oliver started to talk about his mum and a water bottle and phone and listen to some music. He had had this conversation with me before at the meeting. It sounded like things his mum didn’t want to forget when she was leaving home. Susan asked if he was thirsty and he said ‘yes.’ I asked Ben as well and he said yes. We had a bit of a break while I found cups and a jug in the kitchen. While we were drinking and chatting, Matthew came in. This was about 2.00. He started chatting and joking with the men and seemed happy to join in as
well. I suggested we might have one more jam and then put the instruments away and have a go on the mics. Is that OK? And Ben and Oliver said yes.

I asked Oliver if he wanted to play the guitar again and he said yes. I offered the stick back to Ethan to see if he wanted to swap but he didn't take it. HE was playing a purposeful base note on the botOliver E string over and over. I asked Ben if he wanted to swap and he said no. I said maybe we could have one more jam and then swap. 12 bar blues – the guys were more into it this time and all had a jam and solo break including Susan on the ukulele and Matthew on the cymbals. – Ben loved the verses for the staff. – laughing and making a high pitched squeal.

We finished with a flourish and I suggested we put everything away and have a go on the mics before finishing. I set up three mics on stands in front of the men. Ethan still had his guitar. He seemed keen to continue. I started up with the 12 bar blues again while the men made various vocal sounds and called out words. Ben kept saying Susan, and Oliver was saying hospital. Susan was saying he really loves that word. Ethan kept playing the guitar but didn't make any more vocal sounds for the mic. At one point I slowed down the beat and phased into From Little things. Ben immediately started saying 'grow' and plugged the word in each time at the end of the line in time. He smiled with the eye contact and acknowledgment of his musicking with me. Meanwhile, Ethan had bent over and was extricating himself from the guitar and strap. Matthew helped him out of it. Matthew was playing a cabasa near him, but he wasn't interested in playing. He was rubbing his eyes and they were very red. Matthew and Susan commented that he might be really tired.

Finished off when I saw the taxi drivers looking through the window. They really seemed interested in what the men were doing. They were smiling and waving. I wished I had asked them in and got them to join in. I think Ben – who also noticed them and smiled and vocalised – would have loved that inclusiveness. We wound up by having a bit of a chat about what we would do next week. Matthew suggested they could listen to specific songs to get used to them before the next session. We all had a bit of a laugh about the songs they chose, achy breaky and mellow yellow. – And then they were gone. Susan said she would drive them in the bus next time and would text me when she was outside so I could come and help bring people in.

Loved how Ethan was so clear in his communication and wishes – trying drums, then trying guitar and loving that, then finished after a while and pulling himself free of it. Lots to discover musically with this young man. Looking forward to his sharing and exploring. Oliver and Ben I think are going to hit it off. I wonder how much they see each other at the moment?

Session 13
Taxis all rolled in at 1.00. Everyone was there including Gabriel. I moved people into spots where they have begun to settle and I have noticed that there is a
familiarity beginning. There was a congenial atmosphere. The support people
seemed relaxed and there expectant for some music making.

James came bowling in. He had high energy and was talking non-stop, saying
how he nearly died and all these things that had happened to him including that
he had broken up with his girlfriend and that he was heart broken. He said that
his support worker had encouraged him to come today. He barely stopped
talking the whole time. I had set up the video recorder for the first time and so
made an announcement that it was running. I think I will show footage from it
next week so that people are clear on what is happening and what it means to be
recorded and will have the opportunity to withdraw consent if they wish.

So Gabriel smiled at me when I suggested the keyboard which I took to be a ‘yes’.
Susan wheeled him over and set him up in front of it. He was playing more
independently this time. Matthew sat next to him and was playing a little as well
as positioning it for him.

I picked up the bass guitar and said that I had never really played one before but
that I reckon we could work out a few notes on it to James. I had a strap on it
because he was so restless I didn't know if he would want to be sitting, but he
said straight away, he didn’t want the strap over his head. He attempted to put it
on and got confused. I pulled a little stool over to him and said it would be much
better to just sit, which he did. He seemed content to hold it and have a little play.
I showed him the three bass notes of the 12 bar blues and he began playing some
notes. I felt so pleased that he was giving it a go. It was the first time he had
played anything at all in the session.

Ben was set up with the electric guitar. He strummed the first notes and Matthew
and a few others jumped and said ‘woah’. Ben laughed. Ethan was in front of the
cymbal. He seemed was smiling and straight into playing. He tipped it over a
couple of times in the session and I thought he might be wanting to stop playing.
When it was straightened, he resumed his playing again. He took the drum stick
from Deb once or twice and beat a few notes competently before hurling it on the
floor. This provoked laughter from the group and he smiled. I interpreted his
disrupting as intentional and rebellious. James told me that Ethan is his favourite
band member so I guess that might be why.

Oliver had the microphone and was straight into it. Hospital. Hospital. (Gotta
learn the hospital song) He was smiling and cheerful.

Susan was on the drum machine, Deb on the snare and Matthew went on to the
snare also later in the session. He has a good sense of rhythm and seems as
though he is experienced at playing drum, although he has never said this before.

Gabriel was playing a few notes of the songs today on the keyboard. He made me
stop in my tracks once he had done it a couple of times. I think he has a good ear
and was playing intentionally. All his movements take a long time to happen
including looking up, but he had time to find some of the notes we were playing.
He definitely seems to be tuned in. Matthew told me his mum says he has been playing since he was a kid.

Just a great session. We had a discussion later about coming up with a name for the band. A number of suggestions were bandied around, - “the potatoey lemonheads” got a run for a bit. Eventually people seemed to settle on the Rockheads. In amongst all the chatter, I missed who first suggested it. I was interested during the band name conversation that Susan said that we were a band of 9 people. She had counted all the staff as well. I love that there is beginning to be a sense of ownership in the group including all the support staff. I asked Ben later if we needed more people and he says ‘no’ for the first time. I asked if there are too many people and he said ‘no’ as well. Maybe we are getting somewhere.
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Author/s:
Murphy, Melissa Amy Irving

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From social connectedness to equitable access: an action research project illuminating the opportunities and the barriers to accessing music for young people with disability transitioning from school to adult life

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