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WHERE ARE ALL THE DISABLED MUSICIANS?

AN EXPLORATION OF THE ATTITUDINAL AND PHYSICAL BARRIERS
THAT IMPACT ON THE IDENTITIES AND LIVED EXPERIENCES OF
MUSICIANS WITH A PHYSICAL IMPAIRMENT

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PhD

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DECLARATION

This thesis has been composed by me, is my own work and has not been submitted for any other degree or professional qualification.

George Alexander Low

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ABSTRACT

According to the UK Government, ‘disabled people remain significantly less likely to participate in cultural, leisure and sporting activities than non-disabled people’ (Department for Work and Pensions & Office for Disability Issues, 2014). Despite this fact, much of the research that relates to disabled people and music is focused on the therapeutic benefits of music and there is a deficit in research that explores disability and music from the perspective of the musicians themselves. The aim of my PhD project was to fill this gap by examining the lived experiences of disabled musicians in order to ascertain what might cause the perceived under-representation of disabled people in the music world.

As a musician and music student with mobility and sight impairments, I have first-hand experience of the challenges that can face disabled musicians and these experiences inspired me to explore this area of concern. Consequently, my PhD project is centred on the lived experiences of disabled musicians as they engage in performance and work towards qualifications in music. Thematic analysis was used to analyse data that was collected through 11 semi-structured interviews with disabled musicians and an autoethnographic analysis of my own experiences, both as a disabled musician and PhD researcher.

My PhD project shows that disabled musicians encounter a wide range of barriers as they engage in music making or journey towards a qualification in music and that these barriers create significant physical and emotional challenges for disabled individuals. Most of the issues disabled musicians experience occur during performance or while they work towards a qualification in music; these issues are the result of negative attitudes, discrimination and imbued misconceptions. Consequently, there is a need for the lived experiences of disabled people to be better understood by both non-disabled individuals and institutions who provide facilities and services. This improved understanding would allow both service providers and individuals the means to establish and maintain better access to music

and music education through the implementation of reasonable adjustments and more positive attitudes towards disabled people.

CHAPTER 1: INTRODUCTION

1.1 Overview of the project

The focus of the research outlined in this thesis is centred on the factors that impact on the experiences of musicians and aspirant musicians with physical disabilities. Existing studies related to music and disability tend to focus on music therapy and as such stem from the perspective of medical clinicians and scientists. Consequently, they focus on cures, alleviating symptoms, and ‘improving’ physical or mental well-being. In other words, they are rooted in the medical model of disability. In contrast, my PhD project contributes to the field through views and experiences of disabled musicians themselves. A result of this approach, although not a deliberate strategy, is that my project is more aligned with the social model of disability because it explores the barriers disabled musicians face, one of the main tenets of the social model.

The purpose of Chapter 1 is to provide background and context to my project and to describe the structure of this thesis. The chapter begins with a short explanation of the language I use which is, followed by a personal account of the inspiration for the project in order to explain how the research was shaped and the direction it takes. I then proceed to set out the structure of the thesis and introduce the research questions my project seeks to answer.

1.2 Terms and language use

In writing up this thesis, I wanted to avoid as far as possible the use of terminology and language that is impenetrable or confusing. I feel very strongly that writing should be designed to ensure the reader understands as quickly, easily, and completely as possible what is being said by the author and have tried to do adopt a writing style to reflect this ethos. However, as with most academic writings some subject specific terminology is unavoidable, so I have provided the following glossary of terms in figure 1.1:

Access: Suitability of a building or other structure for use by people with disabilities. In a broader sense, access also included making forms and information accessible to people with visual or cognitive disabilities; making alarms and signals accessible to people who are deaf or hard of hearing; and making services such as education and transport accessible to people with disabilities.

Accessible: In the case of a facility, readily usable by a particular individual; in the case of a program or activity, presented or provided in such a way that a particular individual can participate, with or without auxiliary aid(s); in the case of electronic resources, accessible with or without assistive computer technology.

Access barriers: Any obstruction that prevents people with disabilities from using standard facilities, equipment and resources.

Affirmative model of disability: The view that, through the affirmation of a positive identity of being impaired, disabled people can actively dismiss the predominant views of normality. The affirmation model also focuses on the value and validity of life as a person with an impairment (Swain and French, 2000, p.578).

Assistive technology: An umbrella term that includes assistive, adaptive and rehabilitative devices for people with disabilities. Assistive technology promotes greater independence by enabling people to perform tasks that they were formerly unable to accomplish, or had great difficulty accomplishing, by providing enhancements to, or changing methods of interacting with, the technology needed to accomplish such tasks.

Amputation: Removal of a limb or other appendage from the body.

Amputee: Someone who has had one or more limbs amputated.

Barrier: Obstacle preventing a person with disability from living independently, working, travelling and/or having access to buildings, services, forms and information.

Braille: System of embossed characters formed by using a Braille cell, a combination of six dots consisting of two vertical columns of three dots each. Each simple Braille character is formed by one or more of these dots and occupies a full cell or space. Some Braille may use eight dots.

Cerebral palsy (CP): A group of disorders that affect a person's ability to move and maintain balance and posture. CP is the most common motor disability in childhood. Cerebral means having to do with the brain. Palsy means weakness or problems with using the muscles. CP is caused by abnormal brain development or damage to the developing brain that affects a person's ability to control his or her muscles.

Communication device: Hardware that allows a person who has difficulty using their voice clearly to use words or symbols for communication. May range in complexity from a simple picture board to complex electronic devices that allow personalized, unique construction of ideas.

Congenital condition: Condition present at birth.

Deaf / hard of hearing / hearing impaired / hearing loss: The deaf and hard of hearing personal and may reflect identification with that community, the degree to which they can hear, or the relative age of onset. Some people believe that the term “people with hearing loss” is inclusive and efficient. However, some people who were born deaf or hard of hearing do not think of themselves as having lost their hearing.

Disability: The result of the interaction between persons with impairments and attitudinal and environmental barriers. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, when in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.

Disabled musician: A person who engages in music making who also has an impairment.

Discrimination: Refers to any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field.

Environmental factors: The physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person’s functioning. (World Health Organisation: International Classification of Functioning, Disability and Health (ICF) - Definitions in the context of health, Exposure Draft, Oct 2013).

Exclusion: The process in which individuals or entire communities of people are systematically blocked from (or denied full access to) various rights, opportunities and resources that are normally available to members of a different group, and which are fundamental to social integration within that particular group (e.g., housing, employment, healthcare, civic engagement, democratic participation, and due process).

Facility: All or any portion of a physical complex, including buildings, structures, equipment, grounds, roads, and parking lots.

Harassment: Occurs when the actions of a person violate the dignity of another person or create an intimidating, hostile, degrading, humiliating or offensive environment for him/her. The actions may include; spoken or written words or abuse, imagery, graffiti, physical gestures, facial expression, mimicry, jokes, pranks.

Hearing impairments: Complete or partial loss of ability to hear caused by a variety of injuries or diseases including congenital defects.

Impairment: A permanent or long-term characteristic of an individual that can result in a limitation in specific functions.

Integration: The inclusion, participation and acceptance of people with disabilities in society at large.

Interpreter: Professional person who assists a deaf person in communicating with hearing people.

Inclusion: The inclusion of people with disabilities, with or without special accommodations, in programs, activities, and facilities with their non-disabled peers.

Medical model of disability: The medical model focuses on individual pathology and attempts to find ways of preventing, curing or (failing these) caring for disabled people (Marks, 1997, p.86).

Mobility impairment: Disability that affects movement ranging from gross motor skills such as walking to fine motor movement involving manipulation of objects by hand.

Non-disabled: Person or people without a disability and preferred antonym for disabled.

Participation: Involvement in a life situation. (World Health Organisation: International Classification of Functioning, Disability and Health (ICF) - Definitions in the context of health, Exposure Draft, Oct 2013).

People-first language: Aims to avoid perceived and subconscious dehumanization when talking with or about people with disabilities. The basic idea is to impose a sentence structure that names the person first and the condition second, for example 'people with disabilities' rather than "disabled people" thus acknowledging the person before the disability and shifting the focus away from the condition.

Personal tragedy model of disability: The presumption that disabled people are dependent, abnormal, and cannot live a happy and fulfilled life (Swain and French, 2000, p.578).

Physical or mental impairment: Any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive; digestive; genito-urinary; hemic and lymphatic; skin; and endocrine; or any mental or psychological disorder, such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities (Americans with Disabilities Act of 1990).

Positive discrimination: (in the context of the allocation of resources or employment): The practice or policy of favouring individuals belonging to groups which experience discrimination.

Quadriplegia or tetraplegia: Partial or total paralysis of all four limbs and torso.

Reasonable adjustments: To avoid as far as possible by reasonable means the disadvantage which a disabled person experiences because of their disability.

Screen enlargement: Hardware and/or software that increases the size of characters and text on a computer screen.

Screen reader: Software used to echo text on a computer screen to audio output, often used by people who are blind, with visual impairments, or with learning disabilities.

Screen resolution: Refers to the clarity or sharpness of an image. For computer monitors, this term indicates the number of dots on the screen used to create text and graphics. Higher resolution means more dots, indicating increased sharpness and potentially smaller text.

Sensory impairment: A disability that affects touch, sight and/or hearing.

Service or assistance animal: Any animal trained to provide assistance or perform tasks for the benefit of a person with a physical or mental disability.

Social model of disability: locates disability in an excluding and oppressive social environment as opposed to the individual. The social model is a theoretical explanation that was developed out of endeavours for independent living and civil rights for disabled people. Advocates of the social model believe that many of the restrictions experienced by disabled people are a product of a social environment which fails to take account of their differences as opposed to being a natural consequence of their impairment (Marks, 1997, p.88).

Speech impairment: Problems in communication and related areas such as oral motor function, ranging from simple sound substitutions to the inability to understand or use language or use the oral-motor mechanism for functional speech.

Visual impairment / visual disability: Fully or partially reduced functioning in one eye's or both eyes' ability to detect and/or process images. Caused by a wide range of biological and environmental factors, loss of vision typically arises in young people from a genetic / biological condition or injury to part/s of the eye.

Wheelchair: Mobility aid used by people with physical disabilities that make walking difficult or impossible.

Figure 1.1: Disability terminology glossary. Adapted from Equality and Human Rights Commission website (2017), and the Glossary of Disability Terminology (Disabled People's Association, 2015)

The glossary in figure 1.1 is not exhaustive but will hopefully explain my interpretation and use of the most frequently used terms in this thesis.

With my 'plain language' tenet in mind, I have chosen to use specific terms in this thesis in order to keep the writing as clearly and consistent as possible and to avoid repetition. When referring to the disabled musicians who were interviewed in my PhD project to gather data, I use the term 'participant'.

To avoid repetitious use and confusion with other research, when referring to this PhD project I have tried to keep referring to it as this or my ‘project’ and research undertaken by others is either referred to as their ‘study’ or ‘research’. Likewise, rather than referring to ‘overarching themes’, and ‘subordinate themes’ I have tried to minimise the use of analytical terms in Chapters 4, 5 and 6 specifically as these chapters are the main platform for the discussion on the findings of my project. All allusions to other works are referenced using the Harvard System of Referencing; however, in some cases no date or page number is available, so I use the abbreviations- n.d. for ‘no date’ and n.p. for ‘no page’. In addition, throughout this thesis I present extracts from the interviews with the project participants. As I was the only interviewer, any references to George in these extracts are references to me.

1.3 The Inspiration for this Investigation

I am a musician. I have played a variety of musical instruments since I was 6 years old; from drums, cornet, euphonium, guitar and piano, to 4 different types of bagpipe over the course of my lifetime. Music runs in my family: my grandfather was a renowned Highland piper, my father was a Highland piper and harmonica player, and my mother played piano. My life therefore is steeped in music, musicianship, and all of the things that accompany life as a musician. In 1991, the onset of a progressive spinal condition began to impact on my ability to stand and walk. For the first few years I was able to walk with the aid of crutches and sit on a perch-stool to play my Highland pipes, so I was able to continue as a competing piper. It was at this point I began to understand how difficult life for a disabled person in the music world can be and I wondered whether other disabled musicians encountered the same experiences. I also noticed that I was the only disabled piper on the competition circuit, as far as I could ascertain, there were no other disabled pipers, something I had not thought about before I became disabled. Therefore, I began to wonder ‘where are all the disabled pipers?’.

Honisch argues that ‘...the most obvious barriers to the inclusion of people with physical impairments into the mainstream of Western art music are structural’ (Honisch, 2009, p.2). This became apparent to me during the period when I was competing as a disabled musician (approximately 4 years). I began

to encounter issues that impeded my ability to take part in competitions and perform in general; barriers emerged, both physical and attitudinal, that impacted on my life as a musician. Difficulties in accessing stages, practice areas and even performance arenas began to arise, as did issues with the attitudes of others towards me and my decision to continue competing. The comments and stares as I struggled on stage made me feel uncomfortable and the pain I was experiencing walking from the practice area to the stage impacted on my concentration levels when I eventually did get on stage. These barriers chime with those found in a previous study undertaken by the Arts Council of Northern Ireland (2007) which identified various barriers to the performing arts encountered by disabled people. These barriers were found to be similar to those identified by disabled audience members: difficulties of getting to and from venues, a lack of support to meet access requirements, and issues related to the accessibility of venues were all identified as barriers to participation (2007, pp.7-9).

Eventually however, as my spinal condition progressed I became unable to walk or stand and began using a manual wheelchair and, as I could no longer play Highland pipes, I was forced to stop competing. Consequently, I concentrated on Scottish Smallpipes and Border pipes which are customarily played in a sitting position. At that time, I also decided to improve my music theory and learn new instruments in order to keep my interest levels in music up and boost my music teaching credentials, so I began a Degree in Music course with the Open University which meant I could study from home. I immediately began to experience issues that impacted my ability to study and attend tutorials. Due to my pain levels, I had problems sitting for long periods and had issues with concentration. I was supported through my studies by the Student Awards Agency Scotland (SAAS) who provided a desk, chair and ergonomic keyboard and mouse to make me as comfortable as possible while studying. I was also awarded funding for travel expenses to tutorials. These adjustments did alleviate some of the problems I encountered but the main issue that emerged as a challenge to my progress was time. As can be seen in my PhD project, time is a major factor for disabled people. It can take a person with an impairment longer to do simple tasks than someone who does not have that

impairment. In my case, this problem was eventually exacerbated by the onset of a progressive sight impairment that makes reading and writing difficult.

All of these issues made for a stressful journey through the music education system that inspired me to try to find out how common such experiences are. As a result, I decided to apply to a university to be considered for a placement on a PhD by research programme; my plan was to try to ascertain why my experiences as both musician and student were so negative and difficult and whether other disabled musicians encountered similar difficulties. This was to be achieved through what has consequently developed into this PhD project. Most universities in the UK expect PhD students to attend their campuses regularly, for example, the University of Edinburgh states that ‘Students must attend and participate as required in all aspects of their programme of study. This includes being available for teaching sessions, assessment, examination and meeting Personal Tutors, Programme Directors or supervisors face-to-face and/or electronically’ (University of Edinburgh, 2017, Degree Regulations and Programmes of Study Undergraduate Degree Programme Regulations, 2017/18, paragraph 23), so I did not have the option to study from home this time. I was assured by staff at the University of Edinburgh that I would receive the necessary support I required while on campus and that every effort would be made to minimise problems with access to learning materials, seminars and tutorials. This would be in accordance with the university’s duty to make reasonable adjustments which the university state as the duty to ‘...avoid as far as possible “by reasonable means” the disadvantage which a disabled student experiences because of their disability. The duty requires the University to take positive steps to ensure that disabled students can fully participate in the education and other benefits, facilities and services provided for students’ (University of Edinburgh, 2017, Duty to make reasonable adjustments, paragraph 2).

From the outset, it was apparent that my journey through the PhD programme would not be easy and in fact would mirror the experiences outlined by Hannam-Swain in her article ‘The additional labour

of a disabled PhD student' (2018, pp.138-142). Like Hannam-Swain, despite the implementation of various adjustments and reassurances, my days on campus consisted of continual problem solving and complaining about poor access, negative attitudes, apathy and avoidance. I persevered with my PhD project for two years despite the stress and frustration I was experiencing but eventually things came to a head and I felt I could no longer fight against all the barriers I was encountering. I decided to withdraw from the PhD programme. I informed my two PhD supervisors that I was leaving and they both said they were shocked to learn of my decision. This was puzzling to me as, throughout all of the difficulties I experienced, they were constantly informed by email and in person. A meeting was arranged between myself and both supervisors to talk about my decision, during that meeting one of my supervisors suggested that I take some 'time out' away from the PhD before making a final decision. I reluctantly agreed and so began a three-month period away from the university and the problems associated with it.

During the three months away from the university, I was constantly urged by friends, relatives and other students not to give up on my PhD project. I received many suggestions on how to circumvent the problems I was experiencing in order to finish my project and after a great deal of thought I decided to try to work on a plan to finish this thesis. The data had already been collected and partially analysed, so the only major task to do was the writing up process. I concluded that the only way in which I could resume my PhD project was to make some drastic changes to my working environment and, because my experiences as a student were being mirrored in the data of my project, I decided to incorporate them into my project. The other major component of my plan to return to my PhD project was to change schools within the university and both supervisors. The reasoning for this was predominantly emotional; I felt a 'fresh start' was required, otherwise I would feel nothing had changed. Moving schools also made sense because my thesis was no longer centred in music despite involving musicians, instead, the focus had moved more towards disability and music education and was more in keeping with the work of the School of Education than in the School of Music. My decision to

change supervisors turned out to be more controversial, emotional and stressful. My existing supervisors were understandably disappointed that I felt I could no longer continue under their guidance and were concerned about changing supervisors at such a late stage in my project. However, I felt that my supervisors were inextricably linked with all the issues I had experienced under their guidance since they had not been able to resolve the problems I was experiencing. I concluded therefore that I could not continue researching my project under their supervision. In addition to these facts was the change in emphasis of my project, I was no longer focusing on musical identities which is an area of special interest to my previous supervisors, but on disability identities and education.

To continue my project at the School of Education nonetheless meant I would need two new supervisors. Fortunately, through my role as the coordinator of Disability Research Edinburgh, a research network I had formed at the start of my PhD programme, I knew my current principal supervisor Professor John Davis whose research chimed with the subject of my PhD project. Following some discussion Professor Davis agreed to guide me through the remainder of my project and recommended Dr Marlies Kustatcher for the role of second supervisor. This has proved to be an exceptional supervisory team who have made the remainder of my PhD project a pleasure to work on. I believe the combination of a supportive and engaged supervisory team in combination with my decisions to change school and write about my time as a PhD student in my thesis have resulted in a richer, more purposeful and directional PhD project than would otherwise have been produced. To follow this retrospection of the inspiration for my project, the next section outlines the structure and design of this thesis.

1.4 Research questions and design of the thesis

This introductory chapter is followed by Chapter 2 in which relevant literature is reviewed to provide context and locate my project in the field of disability and music. The chapter begins by discussing the pertinence of language in relation to disability, particularly the impact of terminology on how

perceptions of disabled people are often shaped and maintained. Chapter 2 describes issues such as the tensions that can arise in disability studies as a result of opinions on descriptors such as ‘disabled people’ and ‘people with disabilities’, the latter being an example of the ‘person first’ ideology which some believe puts the person before the disability (Snow, 2009, p.1). The chapter then moves on to consider the various models of disability and their relevance to the lives of disabled people. The medical model and its view that disabled people should seek a cure and are in some way ‘in need’ (Davis et al., 2003, p.192). Related to the medical model of disability is the personal tragedy model which reflects the general assumption in modern societies that disabled people live their lives striving for normalcy (Swain and French, 2000, p.2) and includes notions of inferiority, inadequacy, pity, sadness, evil and disgust (Swain and French, 2008, p.4). Chapter 2 then considers the social model of disability which seeks to counter the medical model by highlighting the need for the dismantling of disabling barriers denouncing the practice of seeking medical cures or promoting rehabilitation strategies (Shakespeare and Watson, 2002, p.4-5). The discussion then moves on to consider the concept of reasonable adjustments and the Equality Act (2010). Reasonable adjustments are measures that should help negate barriers to participation and avoid putting disabled people ‘at a substantial disadvantage compared with a person who is not disabled’ (Equality and Human Rights Commission, 2016, ‘Are disabled people at a disadvantage?’).

Following the discussion on reasonable adjustments, Chapter 2 presents an exploration of social identity with attention to Tajfel’s Social Identity Theory (Tajfel, 1970, pp.96-103) which proposes that the groups that people belong to are a source of pride and self-esteem and provide a sense of belonging to the social world (McLeod, 2008, paragraph 2), and to boost their self-image, individuals aim to raise the status of their group. Tajfel argues that the self-image of an individual can be enhanced by discriminating against and holding prejudice views of groups they do not belong to which Tajfel describes as the ‘out-group’ (1970, p.96). Consequently, based on which social groups individuals belong to, societies are divided into ‘us’ and ‘them’.

The exploration of social identity is followed by the introduction of avoidance, and the bullying of disabled people, phenomena that are consequences of social interaction and identity maintenance. The discussion on avoidance includes concepts drawn from studies by Park et al. (2003, pp.65-88) and Snyder et al. (1979, 2297-2306) and includes a consideration of the reasons behind the tendency for some non-disabled people to avoid disabled people. Disabled people are more likely to experience bullying than non-disabled people (Hollomotz, 2012, p.487) and writings by Hollomotz (2012, pp.477-493) are used to set up the discussion on bullying which is discussed in full in Chapter 5 as it emerged as a topic of concern for many of the participants in my PhD project.

The way in which disabled people, and disabled musicians in particular are perceived is the next topic prefaced in Chapter 2 and this topic is considered in more depth in Chapter 5 through a consideration of work undertaken by Lubet (2016, pp.1-234), an interview with Rick Allen, drummer with the rock group Def Leppard by Terri Saccone (2011, pp.1-8), and the experiences of participants in my PhD project. Chapter 5 continues with a look at the relationship between disability and musical performance with reference to the work of Lubet and the interview with Allen with the addition of examples from Honisch (2009, pp.1-28), Goffman (1963, pp.1-173) and Staniland (2009, pp.1-103) among others. Chapter 2 ends with an outline of the aims of this PhD project and a summary of the key research questions.

Chapter 3 presents the methods used to gather and analyse the data and provides background on my reasons for using the chosen research design. The rationale behind the choice of data collection methods is discussed along with the theoretical framework and an outline of the chosen method of analysis, thematic analysis. Chapter 3 concludes with a description of the Braun and Clarke (2006, pp.77-101) framework, a set of guidelines provided to assist researchers conducting thematic analysis

which was used to guide my analysis, a consideration of ethical issues, sources of bias, and finally a summary of the chapter.

Chapter 4-6 are the findings chapters. These chapters are constructed in a manner which addresses the 5 research questions in turn with Chapter 4 focusing on the first two research questions: Question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** And Question 2: **How do disabled musicians meet the challenges that arise when impairment impedes their ability to play their favoured instrument?** Chapter 4 is divided into two main sections in order to address these questions. There is at present a dearth of research into the way disabled musicians are viewed by others and how disabled musicians manage and negotiate both these perceptions, and their own challenges in relation to their impairment and their musical instruments. Chapter 4 extends current literature by answering these research questions.

The second findings chapter, Chapter 5, is dedicated to just one research question: Question 3: **How does interpersonal interaction impact on the lived experiences of disabled musicians?** The issues that can result from interpersonal interaction emerged as an area of major concern for the participants in my project, concerns that I share. There is at present no research that considers the interpersonal aspect of disabled musicians' lived experiences, so I decided therefore to commit a complete chapter to this topic in order to explore it fully and fill the gap I perceived to exist in current disability studies literature.

Chapter 6 is the last findings chapter and it focuses on two closely related research questions: Question 4: **How do disabled musicians experience institutional discrimination?** and question 5; **How effective are reasonable adjustments at combating institutional discrimination?** Question 4 refers to the difficulties experienced by disabled students as they attend colleges, conservatoires and universities in addition to organisations that manage and issue music qualifications such as the

Associated Board of Royal Schools of Music. Question 5 addresses the lack of research into reasonable adjustments in relation to disabled people and music education.

Reasonable adjustments are measures put in place to ‘avoid the disadvantage caused to disabled people by practices, criteria, or provisions or physical features of the environment’ (Fredman, 2011, p.98). This concept is considered and defined in more depth in Section 6.2 which focuses on the issues surrounding reasonable adjustments and consequently contains more data drawn from my personal experiences as a disabled musician and student than Chapters 4 and 5. As with the other research questions in this thesis, I am seeking to fill a gap in literature which does not consider the difficulties disabled people experience as they attempt to gain an education in music.

Chapter 7 concludes this thesis and begins with a review of the literature chapter, Chapter 2. It then summarises the findings of my project and in doing so revisits and answers the research questions in turn. This is followed by a brief summary of the findings and an outline of how my PhD project has contributed to the field of disability and music. Chapter 7 also contains a consideration of what the implications of my findings mean for future research.

1.5 Contribution to the field

Much of the existing research into the lived experiences of disabled musicians emerges from a music therapy frame of reference or with a focus on ‘the significance of disabled people’s presence in the history of music [and] the difference that disability makes in the production of the art form itself (Mitchell, 2017, n.p.). For example, MacDonald et al. (2002, pp.1-224) approach the subject with an emphasis on the benefits of music and includes a chapter on the therapeutic value of music. Lubet approaches the subject of music and disability by considering the historical aspect of disabled people in music and the impact of impairment on the music produced by disabled people (2010, pp.1-234). As opposed to these works which concentrate on the impact of music on identity, or disability on

music, I have taken a different approach. My PhD project is focused on the external forces that impact on disabled musicians such as the perceptions and behaviour of others, the impact of these phenomena on disabled musicians, and the barriers disabled musicians face both in music education and the music business. This focus is achieved by looking at the lives of disabled musicians from a purely experiential standpoint and without an emphasis on the benefits music making or the impact disability has on their music.

Key conclusions gathered from my PhD project show that negative perceptions of disability and impairment play a major role in creating barriers to music making, both in the music industry and in music education. Established perceptions engendered at least in part by the media (Barnes, 1992, pp.1-29; Shakespeare 1999, pp. 164-172) and the use of language (Clark and Marsh, 2002, pp.1-17) have created attitudes and approaches towards disability and impairment that impede access and progress to music facilities and qualifications in music. Data from my PhD project show that disabled people experience physical barriers to music making such as difficulties with access to music venues and finding ways to play their preferred musical instruments, but regard the role played by the attitudes and perceptions of others as a greater obstruction on their journey to becoming a musician. The data also shows that impairment is perceived to be a more significant impediment in the music world than in most everyday life with the result that people with impairments will experience lower expectations of their abilities and skills in music education and the music world in general. A consequence of these low expectations is the tendency for disabled musicians to believe they must work harder than non-disabled people to achieve the same status as a musician.

My PhD project also reveals issues related to the provision of reasonable adjustments in music education facilities and music qualification organisations. Although efforts can be made to provide physical adjustments and adaptations to buildings, evidence in my PhD project shows that these are not always adequately maintained. In addition, the perceived duty to adhere to established practices

such as holding events in a particular venue because they have always been held there, and structuring curricula in rigid forms, act to impede the progress of disabled people through the music education system.

This thesis was four years and four months in the making, longer than usual for a PhD thesis. Due to the limitations caused by my impairments and the issues I encountered throughout my PhD programme, I was awarded extensions and was forced to take time out from the programme to recover from the impact the barriers I faced as a student had on my mental well-being. Consequently, my PhD project is not only an investigation into the lived experiences of disabled musicians and music students, it is also a lens through which the reader is given a glimpse of my life as I journey through what transpired as one of the most difficult periods of my life as a disabled person. However, given the wealth of data and findings resulting from my PhD project I believe the end result goes some way towards compensating for the difficulties experienced during the process.

I make no apologies for the negative tone that pervades the thesis as it is an accurate representation of how my life was during my time as a PhD student at the University of Edinburgh. The negativity is also the result of careful and rigorous analysis of the accounts of the participants in my project, most of whom were keen to express their anger, frustration and disappointment at the way society and individuals behave towards disabled people and disabled musicians in particular. That being said, I have made every effort to ensure my thesis is a fair and accurate representation of the facts by adhering strictly to the process of reflexivity.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

To provide context for the methodology and findings of my PhD project, this chapter presents a review of existing literature and the most pertinent arguments related to the topics of disability. Researchers have examined and discussed many aspects of disability and there are numerous universities which provide teaching, qualifications and research opportunities in disability studies in the UK, including Sheffield Hallam University, the Centre for Disability Studies in the University of Leeds, The Disability Research Centre in Goldsmiths, University of London, and Liverpool Hope University. Likewise, extensive research on identity has been undertaken, especially following the publication of Erving Goffman's works 'Stigma: Notes on the Management of Spoiled Identity' (1963) and 'The presentation of Everyday Self' (1956). However, despite efforts to unify opinions on various aspects of disability, tensions still exist between the viewpoints of disability scholars on many aspects of the concept of disability such as the impact of language, the purpose, relevance and usefulness of the various models of disability, and the relationships between disability, impairment and identity. This chapter outlines the most dominant arguments and theories pertinent to the concept of disability and the experiences of disabled people as they engage in music making.

The chapter presents a review of the pertinent literature to provide a suitable background against which the issues raised in chapters 4, 5 and 6 can be set. For example, Goffman's theories on stigma and 'spoiled identities' are primarily based on individual interactions between "the normals" and "the stigmatized" therefore his conception of stigma helps to characterise the prejudice and stereotypes disabled people experience in interpersonal interactions (Bagenstos, 2000, p.438). In addition, the inclusion of references to the chapter in *Hearing the Voices of Children: Social Policy for a New*

Century by Corker and Davis (2003, pp.75-90) helps to contextualise issues such as bullying which is an interpersonal interactional phenomenon that Adam, a participant in my PhD project, experienced over a protracted period.

To establish context for research question 1: **‘How is impairment understood and how does this understanding impact on disabled people as they engage in music making?’** which is addressed in Chapter 4, a consideration of the models of disability was deemed beneficial as the concepts of disability and impairment are central in discussions on the models of disability in the field of disability studies. Therefore, Section 2.2 forms a consideration of the models of disability including the medical, social, personal tragedy and affirmative models of disability and reveals some of the tensions that exist in the understanding and positioning of ‘disability’ and ‘impairment’ in the field of disability studies. The treatment of disabled people is built into our language and as such has the power to construct or break down stereotypes (French and Swain, 2004b, p.5; Vash and Crewe, 2004, p.26), therefore Section 2.2.7 looks at issues related to the use of language which is notable in its appearance throughout my PhD project. The discussion has been positioned in Chapter 5 because language is the primary mode of communication between individuals and many of the most significant difficulties for disabled individuals that stem from language use can arise during interpersonal interaction. Section 2.2 concludes with a discussion on the role of language in relation to how disability and impairment is understood, and a consideration of the specificity of impairments.

Research question 2: **How do disabled musicians meet the challenges that arise when impairment impedes their ability to play their favoured instrument?** is the focus of Section 2.3 and the second research question addressed in Chapter 4. In order to understand the methods and strategies disabled musicians employ to meet the challenges they face as they engage in music making with their favoured instrument, Chapter 4 looks at factors that emerged from the data in my PhD project such as changing techniques and styles in music delivery, instrument adaptations and alternatives, and phenomena such

as passing as non-disabled to avoid the consequences of negative perceptions of disability and impairment. Section 2.3 discusses extant literature in order to set a background for the discussion on these techniques and strategies.

A major theme that has emerged from the data in my PhD project is the issues that can arise from interpersonal interaction. As a result, Chapter 5 of this thesis is dedicated to one research question, question 3: **‘How does interpersonal interaction impact on the lived experiences of disabled musicians?’** and Sections 2.4-2.6 review the literature related to topics that are pertinent to the issues that can arise from interpersonal interaction in relation to disabled musicians.

With a view to expanding the discussion on interpersonal interaction in Sections 2.4-2.6, and also research question 3 **‘How does interpersonal interaction impact on the lived experiences of disabled musicians?’**, Section 2.4 looks at the concept of social identity by introducing Tajfel’s Social Identity Theory (1970, pp.96-102), the concept of social comparisons (Anderson et al. 2002, p.159), and avoidance, which is another element of interpersonal interaction that can cause difficulties for disabled people. Section 2.4 ends with a consideration of bullying through the work of Hollomotz (2012, pp.477-493) and Corker and Davis (2003, pp.75-90).

Section 2.5 also introduces a topic that comes under the heading of interpersonal interaction, the influence of perceptions on a disabled individual’s identity. In Chapter 5, tensions between Magee’s idea of transcending impairment (2002, p.180) and the actual experiences of disabled people are discussed, and Section 2.5.1 provides some background to this topic along with the introduction of concepts such as ‘supercrips’ and what I identify as the ‘perception of disability spectrum’. Sub-Section 2.5.2 marks the end of Section 2.5 with a look at self-perception through research undertaken by Gibson et al., (2005, pp.502-524), Charmaz, (1983, pp.168-195) and Wendell (2001, pp17-33).

Section 2.6 is related to Chapter 6 which considers concerns voiced in my PhD project about disabled individual's journey's through the music education system. Discussed in this section are topics such as the tensions that exist between the increasing number of disabled students enrolling at universities and colleges, and the actual experiences they have (Barnes et al. 2009, p.6; Beauchamp-Pryor, 2007, p.ii), and issues related to the implementation of reasonable adjustments, staff knowledge and the interpretation of the Equality Act (2010) by education institutions.

This literature review chapter concludes with an outline of the aims of my PhD project, and a summary of the research questions and how they relate to the data in chapters 4-6.

2.2 Understanding disability and impairment

2.2.1 The medical or individual model of disability

Related to the factors that induce the perception of difference between disabled people and non-disabled people is the historic medicalisation of disability. Since the 1970's, many disabled people have resisted the idea that disability is a medical condition and disabled people should be 'cured'; disabled people also challenged the concept that disability resides within the individual by pointing to the barriers constructed by society. These arguments gave rise to what are now referred to as the models of disability.

Two major conceptual models of disability, the social and medical models, have formed a large part of recent debate in disability studies. Llewellyn and Hogan argue that the medical model of disability 'views all disability as the result of some physiological impairment due to damage or to a disease process' (Llewellyn & Hogan, 2000, p.158) while Davis et al. indicate that medical assumptions view disabled children to be 'inevitably passive, 'vulnerable' and in 'need' (2003, p.192). Additionally, Oliver argues that 'The medical view of disability tends to regard disabled people as "having something wrong with them" and hence the source of the problem' (2004, p.20). Therefore, the medical model view is that the issues disabled people face appertain to them as individuals and it fails to take

into account the ‘economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment’ (Oliver, 2004, p.23). Examples of the environmental and cultural barriers Oliver refers can be seen in the implementation of social policies and legislative hierarchies that sustain the environmental barriers that disabled people encounter. For example, the Equality Act (2010) does not override other legislation such as listed building or planning legislation; in their guide *Managing Change in the Historic Environment: Accessibility*, Historic Scotland recognise that ‘It is recognised that full equality of access may not be achievable in every circumstance due to practical, technical, financial, conservation and/or other constraints’ (2010, p.6), which means that some buildings cannot be made more accessible. This legislative hierarchy is a consequence of social policies and attitudes fostered by the medical model and one importance repercussion for disabled people is that they are expected to adapt to a near impossible set of circumstances. Often the only choices open to the disabled people are to have their dignity compromised by being physically carried into a building or venue, or effectively become debarred from that venue altogether. An example of this scenario is described in the extract of Rose’s interview in Section 6.2.3. The life of a disabled person therefore can be directly affected by the alignment or otherwise with the social model by legislative and administrative organisations. Viewed through the lens of the social model it is the poor design of stages and recording studios that are seen as the obstacles that must be removed or rectified to enable disabled people to perform, not the abilities of the individual. Legislation can also impact on the life of a disabled musician in other ways. Much of today’s legislation relating to disability is based on the medical model and social misconceptions, thus physical barriers prevail as a result. For example, the Equality Act states that ‘a person has a disability [...] if he has a physical or mental impairment’ (2010, Ch.1, section 6). Here the document states that the individual has the disability so the language used points to the disability as residing within the individual; in contrast to this individualistic approach, the social model challenges this ideology and attempts to counteract the common understanding of disability that is underlined by Masala and Petrello who state that ‘in

common language, disability most probably refers to the lack of a bodily part or function' (Masala & Petrello, 2010, p.1).

2.2.2 The personal tragedy model of disability

A major consequence of perceiving disability as an individual issue, as reflected in the medical model of disability, is the fact that disabled people are often viewed as victims or 'token examples of the tragedy of disability, involved in consultations or wheeled out to highlight the problems' (Shakespeare, 1996, p.7). This negative view of disabled people has been identified as the 'personal tragedy model' and reflects the general assumption in modern societies that disabled people live their lives striving for normalcy (Swain and French, 2000, p.2). Swain and French inform us that 'The tragedy model of disability encompasses many perceptions of disabled people, which are nearly always negative. These include notions of inferiority, inadequacy, pity, sadness, evil and disgust (2008, p.4). Therefore, the main hypotheses of the personal tragedy model are the assumptions that disabled people want to be other than as they are, that they cannot enjoy an acceptable quality of life, and that 'the disabled person's problems are perceived to result from impairment, rather than the failure of society to meet that person's needs in terms of appropriate human help and accessibility' (Swain & French, 2000, p.573).

The personal tragedy model is 'infused throughout media representations, language, cultural beliefs, research, policy and professional practice' (Swain & French, 2000, p.572) and as such forms the one of the main points of interaction between societies and disabled people. Consequently, disabled people commonly have a devalued or low status in society resulting in people with obvious disabilities trying to 'pass' as 'normal' (Darling, 2003, pp.881-895; Shakespeare, 1996, p.7; Goffman 1963, pp.41-42). Passing is more difficult when the individual is in public view, so performing musicians will inevitably have a higher risk of exposing their impairments, making them more susceptible to being ascribed the low social status ascribed to disabled people. Being in public view also brings the issue of low expectations to the fore; as will be shown in Chapter 5, disabled musicians regularly encounter low

expectations as they work to establish or maintain a career in music and have to develop strategies to help overcome the effects of such attitudes.

Therefore, being perceived in the way that the medical and personal tragedy models set out, as tragic, inadequate individuals who are limited by their impairments, has significant implications for disabled people and their lived experiences, which is evident in the findings of my PhD project. It is attitudes and preconceptions like these that drove disabled people to challenge how they are perceived and treated by the society in which they live, and the social model of disability followed by the affirmative models of disability were developed as part of that challenge.

2.2.3 The development of the social model of disability

Shakespeare argues that the social model of disability has developed into the ‘ideological litmus test of disability politics in Britain, used by the disabled people’s movement to distinguish between organisations, policies, laws and ideas which are progressive, and those which are inadequate’ (Shakespeare and Watson, 2002, p.3). Shakespeare and Watson (2002, p.4-5) argue that the social model has become an important factor in the lives of disabled people for two reasons. First, it highlights the need for the dismantling of disabling barriers to advance inclusion for disabled people and denounces the practice of seeking medical cures or promoting rehabilitation strategies. Second, the social model ‘remains liberating for disabled people’ as it diverts blame from the individual to society. Disabled people can now see that they do not need to change but it is society that needs to change (Shakespeare and Watson, 2002, p.5).

The foundation of the social model of disability is a policy statement adopted by the Union of the Physically Impaired Against Segregation in 1974 (UPIAS, 1976). Their main aim was to have issues such as inadequate public transport, unsuitable housing, and inflexible work routines addressed in order to enable disabled people to achieve ‘maximum possible independence’ (UPIAS, 1976, p.1). Contrary to the medical model which is constructed around the premise that disability is located in the

individual's impairment, the social model ascribes the responsibility of disability to the existence of barriers constructed by societies and cultures which in effect 'disable' people with impairments (Dewsbury et al., 2004, p.3; Barnes & Oliver, 1993, p.17; Thomas et al., 1997, pp.2-3).

The British social model was developed from the ideas outlined in the UPIAS document, *Fundamental Principles of Disability*; Oliver (1996, p22) has provided an edited version of which is quoted here at length:

'... In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this, it is necessary to grasp the distinction between the physical impairment and the social situation, called "disability", of people with such impairment. Thus, we define impairment as lacking all or part of a limb, or having a defective limb, organism or mechanism of the body and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.'

2.2.4 The social model of disability under scrutiny

Despite the popularity and widespread adoption of the principles of the social model, Shakespeare and Watson argue that the social model has shortcomings (2002, p.4); they suggest that the social model has become a 'sacred cow, an ideology which could not easily be challenged' (2002, p.5). They also suggest that the simplicity of the model lends itself to the assessment of policies and the attitudes and conduct of organisations; the 'strong' version of the social model, or one that 'view[s] the world in black and white' is one that activists use in public discourse but do not hold to in their private life (2002, p.6). Morris suggests that 'there is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created' (Morris, 1991, p.10) and Vasey argues 'If a person's physical pain is the reason they are unhappy then there is nothing the disability movement can do about it' (Vasey, 1992, p.43).

The social model of disability therefore is subject to an increasing level of scrutiny; however, there are also those who defend the social model; Oliver for example states that 'we must not assume that models in general and the social model of disability in particular can do everything; that it can explain

disability in totality. It is not a social theory of disability and it cannot do the work of social theory' (1996, p.13). Oliver uses a quote by Hevey who states that his first encounter with the social model was instrumental in changing his view of his own disability; 'I realised that my disability was not, in fact, the epilepsy, but the toxic drugs with their denied side-effects; the medical regime with its blaming of the victim' (1992, pp.1-2).

2.2.5 'Fixing' the social model

Despite the largely positive influence of the social model, it is obvious that there are still issues with its effect. Consequently, to address this issue, and to address the concerns of many critics of the social model, scholars have looked at how it might be improved in order to have a more positive influence on the lived experiences of disabled people. During the course of these considerations, there have been various attempts to provide and develop a conceptual schema to define the heterogeneous relationships between illness, impairment, disability and handicap (Oliver, 1996, p.2) which are believed to be the areas of the model that require improvement. My own experience as a disabled person has shown me that there are still many people who confuse disability and impairment and some university staff I have encountered have similar views to the lecturers in Riddell and Weedon's study who have doubts as to whether some disabled people can ever be 'fit to practice' (Riddell and Weedon, 2014, p.19). Some members of the university staff I encountered informed me that 'there is a limit to what can be done to accommodate certain disabilities'. Despite the negative attitude on display here, the relevant part of this statement for the social model is the use of the word 'disability' instead of impairment. This may perhaps just be a legacy of common language use, but I believe it exemplifies the shortcomings of the social model in changing such interpretations.

In the 1980s and 1990s established schemata were challenged and new definitions of impairment and disability were proposed and many of these alternative models were proposed by disabled activists and disabled people; works such as the article *Defining Impairment within the Social Model of Disability* (Thomas et al., 1997, pp.1-3) which appeared in the *Greater Manchester Coalition of Disabled People*,

and *Defining Disability and Impairment* (Northern Officer Group, n.d.) were published. In the main, these alternatives are proposed with a view to addressing what is perceived to be the omission of ‘the experiences of the impaired body’ (Shakespeare and Watson, 1996, p.8). What has been termed a ‘social model of impairment’ (Oliver, 1996, p.10) is discussed by Oliver who suggests that such a model is inevitable but also voices reservations as to its benefits (Oliver, 1996, p.16). However, Shakespeare and Watson argue that ‘this is an area that is far too important to be left in the hands of medical sociologists and their like. We are not arguing that the body is real or essential, but that what we need is an understanding of the experience of disabled people in terms of the body, rather than the disembodied Cartesian subject’ (1996, p.7). Shakespeare and Watson suggest that instead of trying to adjust or alter the social model of disability to compensate for its shortfalls, it should be put aside and a whole new model should be developed (2002, pp.9-10).

2.2.6 The affirmative model of disability

No discussion on the models of disability would be complete without a consideration of the affirmative model of disability. Contrary to the personal tragedy model, the affirmative model does not describe disability as a problem to be solved. Rather it portrays disability as a ‘positive personal and collective identity’, it is a non-tragic view of disability and impairment (Swain & French, 2000, p.569) and as such could be perceived as the antithesis of the personal tragedy model. Cameron argues that although a disabled person may not perceive their impairment as a problem, other people’s responses to impairment can make it a problem (Cameron, 2014, p.6). The gulf between most non-disabled people’s perception of disability and the actual experiences of a disabled person often leads to the misconception that disabled people cannot have a rich and fulfilled life, that they are constantly striving for normalcy, and that they cannot be ‘pleased and proud’ of the person they are (Swain & French, 2000, p.569). According to Swain and French, the social model of disability ‘has not, in itself, underpinned a non-tragedy view’ despite being at odds with the view that disability is a personal tragedy (2000, p.571). Although they acknowledge disability as ‘the oppression of people with impairments in a disabling

society’, Swain and French argue that the affirmative model is not about oppression as such, it is about the positive portrayal of disabled people and their identity. Swain and French’s argument is clarified by highlighting two main points; first, being denied access to facilities does not automatically correlate with a non-tragic viewpoint. Second, because the social model separates disability and impairment, the society that implements full civil rights and participation for disabled people might still view impairment as a personal tragedy (Swain and French, 2000, p.571). The affirmative model of disability therefore focuses on an area of disability that is not accounted for in either the medical model or the social model. However, Grue has concerns about the way in which Swain and French explain how the affirmation model ‘encompasses’ impairment (Grue, 2015, p.205). Grue agrees that ‘Swain and French are quite clear in presenting their reasons why being a part of a disability movement may be a basis for positive identity – these reasons include solidarity and shared experience as a way to reject identity threats’ (2015, p.205) but argues that although the experience of impairment may involve positive features, she has difficulty with the notion that the experience of impairment is valorised because positive things happen to, or are accomplished by, people with impairments (2015, p.205). Grue’s argument is that positive things can be achieved by non-impaired people and that many forms of impairment by their nature make achievement almost impossible; only those disabled people who are fit will be able to take part in the Paralympic Games (2015, p.205). Like the social model of disability therefore, the affirmative model is not without its detractors. This constant scrutiny however means that these models will be continually monitored to ascertain their effectiveness and appropriateness.

2.2.7 The role of language in shaping the concept of disability

Language plays a crucial role in social relationships and the language that people use reflects people’s attitudes and can affect how they deal with a given set of circumstances (Clark and Marsh, 2002, p.1) and Peters claims that ‘Worldwide, people with disabilities experience invasion of their disability identity through the practices of labelling and hegemonic language usage detrimental to their images’ (Peters, 1999, p.103). Language therefore is an important factor in the lives of everyone, but the use

of language has particular significance for disabled people given the way societies perceive and conceptualise disability and impairment through the use of language (Clark and Marsh, 2002, p.1; Barnes, 1992, p.19). Terminology is a particularly contentious subject in relation to disability and is exemplified by the debate concerning the best method of describing disabled people. The term 'disabled people' has been adopted by advocates of the social model of disability in order to acknowledge the fact that disability arises from social oppression, rather than from factors pertaining to the individual, such as impairment (Shakespeare and Watson 2001, p.4). However, in North America the term 'people with disabilities' has been adopted because 'the North American approach has mainly developed the notion of people with disabilities as a minority group, within the tradition of US political thought' (Shakespeare and Watson, 2001, p.4). There is also the view that the 'person-first' form of this term is more appropriate as it places the individual before their disability and avoids accentuation of disability over the person (Gernsbacher, 2017, p.859). However, supporters of the social model argue that using terms such as 'people with disabilities' suggests that the disabling effect arises from within the individual rather than from society (Clark and Marsh, 2002, p.2).

Another controversial term that is the word 'handicap' or 'handicapped'. Although its use is still widespread in the USA, this term is deemed offensive and has been rejected by disabled people because as Barnes puts it "'handicap" denotes the limitations on daily living which result from disability [and] these meanings individualise and medicalise the problems associated with living with impairment. Their whole focus is on the individual and their perceived inadequacy - restrictive environments and disabling barriers are effectively ignored' (1992, part 3, section 1). The origins of the word are subject to opinions, but two main theories dominate. The first and most widely known is that the word is derived from the handicapping system applied in betting circles (Clark and Marsh, 2002; Crowley and Crowley 1999, issue 66). In this case the disabled person is perceived to be at a disadvantage to non-disabled people. The second theory is that the word has evolved from the term 'cap-in-hand' which Barnes contends has allusions to begging (Barnes, 1992, p.20).

The term 'cripple' is also one that has been deemed derogatory in modern society. Clark and Marsh (2002, p.4) inform us that the origins of this word are also in doubt but suffice it to say that it is now a term of derogation and can cause offense to disabled people. However, the term 'cripple' has been reclaimed by some disabled people as an 'insider' term for disability culture (Wright State University, Crip Theory, paragraph 1). The word has been altered to 'crip' to distinguish it from its original form but as shown in Chapter 6, PhD participant Donna used the original word 'cripple' for effect, to shock and draw attention to the patronising attitude of a charity she referred to.

In addition to the perennial discussion on how to refer to disabled people, the use of other terms related to disability can be problematic for those with impairments. Terms such as 'special needs' as termed by MacDonald et al., in their book 'Musical Identities' (2002, p.163) appear regularly in academic writings and, although deemed acceptable by some, the use of these phrases is regarded by some disabled people as unhelpful (Sancho, 2003, p.90). In a report undertaken by the British Broadcasting Corporation (BBC), the Broadcasting Standards Commission (BSC) and the Independent Television Commission (ITC), Sancho cites a comment by one disabled person 'I can't stand the term 'special needs' because it's so patronising and it gives the public a really bad impression' (2003, p.90). Interestingly MacDonald et al. wrote their chapter 'Music for Individuals with Special Needs' in 2002 and only one year later the report from the BBC, BSC and ITC was published outlining the discomfort disabled people have with the term 'special needs' suggesting that unease was already palpable when the book was published. Additionally, it could be argued that because such publications and other influential academic works play a significant and influential role in the education of young people, they will inevitably influence and perpetuate the use or otherwise of terms such as 'special needs' and obscure any negative connotations associated with them. I believe the word 'special' singles out an individual and effectively separates them from the rest of their society and the word 'need' is also inappropriate as, in my view, it can too readily be associated with deficiency and inadequacy, I would

also argue that 'specific requirements' is perhaps a more accurate replacement for this phrase if indeed a replacement is appropriate. It could be argued that in general, there is an overuse of negative terms in relation to all aspects of disability and using these terms to describe the changes experienced by disabled people or their specific requirements reinforces the negative perception of disability as described by the tragedy model of disability (Swain & French, 2000, pp. 569–582).

In addition to the influence discourse has on an individual's sense of self, it also affects disabled people in the form of public perception and attitude (Clark & Marsh, 2002, p.1). It is suggested that discourse not only affects the way in which we understand ourselves but also the way in which we understand each other. For example, the word 'disabled' is often linked with the established view that disabled people are 'passive' and non-disabled people are 'active' (Brisenden, 1986, p.3). This tendency for humans to categorise and label each other, along with the effects of discourse on the shaping of our self-perception has a significant impact on the lives of disabled people; Clark and Marsh argue that 'The language that people use reflects what they think and can influence how they deal with situations. If they behave as if the problem is with the individual, they will take a different approach than if they regard the problem as being with the attitudes, systems and practices that create disabling barriers' (2002, p.1).

One of the major areas of discussion in relation to the various models of disability, the medical and social models especially, is the issue of defining 'disability' and 'impairment' and the inclusion or otherwise of these concepts in the social model. As shown in Figure 2.1, the definition of disability supplied by the Oxford Dictionary reflects how the concept is commonly understood, as a 'physical or mental condition' (Oxford Dictionary, 2013, definition 1). This supposition that it is the individual's impairment that limits their activities resonates strongly with the medical model. The fact that it is an entry in a leading online dictionary seems to support the premise that the medical model continues to play a major role in shaping current attitudes towards the concepts of disability and disabled people. Additionally, from the information in Figure 2.1 it can be seen that the definition of disability presented

in the Equality Act (UK Government, 2010, Ch. 1, section 6) describes disability as a physical or mental impairment, effectively coalescing disability and impairment.

	Definition of disability	Definition of impairment
Oxford Dictionary	a physical or mental condition that limits a person's movements, senses, or activities	the state or fact of being impaired, especially in a specified faculty
Equality Act 2010	A physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities	none available
Thomas et.al. (1997, p.2)	the disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and thus excludes them from mainstream activity	a characteristic, feature or attribute within an individual which is long term and may, or may not, be the result of disease, genetics or injury
Northern Officer Group (NOG) (1999, p.1)	the loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers	an injury, illness, or congenital condition that causes or is likely to cause a loss or difference of physiological or psychological function
World Health Organisation (2017, paragraph 1)	Disabilities is an umbrella term, covering impairments, activity limitations, and participation restrictions [...] It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives	An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action

Fig. 2.1: Definition of disability and impairment

Further evidence of the ambiguousness of this definition is that whilst the Equality Act defines disability as an impairment which has a substantial and long-term adverse effect, it does not define impairment. This raises the question: Is the defining of impairment considered unnecessary in this instance or is the meaning of the word regarded as unambiguous? It is apparent therefore that neither

disability nor impairment are clearly defined, and the confusion is no doubt compounded by the indeterminate use of the word 'disability' in contemporary society.

Terms such as 'handicapped' and 'the disabled' have been repudiated by disabled people because it is believed that they individualise and medicalise the issues linked to living with impairment (Barnes, 1992, p.20). Barnes argues that these terms focus on 'the individual and their perceived inadequacy - restrictive environments and disabling barriers are effectively ignored. They ensure that disabled people are held responsible for any difficulties they encounter during the course of their daily lives'. (Barnes, 1992, p.20).

From a personal perspective, I believe a better descriptor for 'disability' 'disabled' and 'disablement' should be developed. However, until this is achieved, my use of these words in this thesis are in line with the definitions given by Thomas et al. (1997, p.2) and the World Health Organisation (2017, paragraph 1). That is, the barriers caused by a society which does not take impairment into account. Regarding the word 'impairment', again I feel a more accurate descriptor should be found but in the absence of a better alternative 'impairment' is used in this thesis with the definition by Thomas et. al. I am not comfortable with the definition provided by The World Health Organisation as the use of the word 'problem' in relation to impairment has negative overtones as in 'trouble' or 'predicament'. To my mind this points to the 'problem' lying with the individual as opposed to the way the environment is constructed around them. I believe a combination of Thomas et al.'s definition and the World Health Organisation's definitions would represent my understanding of impairment, that it is 'a permanent or long-term characteristic of an individual that can result in a limitation in specific functions'.

2.2.8 The impact and specificity of impairments

The challenges that disabled people face can be different, despite the similar nature of the individual's impairment; Shakespeare and Watson argue that 'it is clear that different impairments impinge in different ways [...] for example, visible impairments trigger social responses while invisible

impairments may not' and go on to suggest that the recognising of the fact that different major groups of impairment have different implications and impacts is important (2002, p.12). However, exponents of the social model argue that it is the way our society is constructed that impedes disabled people (UPIAS, 1975, p.4; Oliver, 2013, p.1025) implying that disabled people belong to one homogenous group (Shakespeare, 1996, p.95). Shakespeare argues however that although disabled people have commonalities such as their social experiences (1996, p.95), there are 'differences of degree' (1996, p.96). It is clear that in addition to the difficulties related to the labels of disability and impairment, there are tensions over how impairment itself is defined and understood in relation to the barriers disabled people face. These tensions include differences in opinion over whether everyone is impaired to some extent (Shakespeare, 1996, p.96). This brings up the question of normality which is another topic that invokes contention in the field of disability studies (Sancho, 2003, p.22; Swain and French, 2000, p.573 Sutherland, 1981, p.5). However, the controversy surrounding both the suggestion that everyone is impaired, and the difficulties related to the topic of normality are beyond the scope of my PhD project.

Section 2.2 has provided an overview of the models of disability and the tensions related to these models in the field of disability studies. It has also provided an overview of language use in relation to disability and impairment. Reviewing the most pertinent literature on these topics has informed my investigation into the lived experiences of disabled music and my approach to research question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** by providing an insight into the difficulties that exist in defining impairment and by illustrating the fluid nature of the language that is used to describe disability, impairment, and disabled people.

2.3 Disability and musical performance

In addition to the understanding of the concepts of disability and impairment, other factors impact on disabled musicians as they engage in music making. One disabled musician's experiences can be used to demonstrate the combination of the psychological and the physical challenges disabled musicians can be faced with as they work to maintain their involvement in musical performance; this is the account of Rick Allen who is one of the few musicians who has described his difficulties publicly (Saccone, 2011, pp.1-7). Already an established and successful rock star, Allen was involved in a road traffic incident during which his left arm was severed. He described his experiences before, during and after his accident and these descriptions detail how he dealt with the trauma of losing his arm, the implications for his musical identity, and his decision to continue as a drummer. Allen says that his primary goal during his recuperation was to get back to drumming. He used his time in hospital to explore new ways of playing drums to accommodate his changed physicality which involved developing technical adaptations to his drum kit and working out techniques with his feet to compensate for the loss of his arm. Allen also mentions that at no point did he think 'this could be the end of my career' and that his fellow band members said, 'we don't see any reason why you can't play again' (Saccone, 2011, p.2). It seems therefore that Allen and the rest of Def Leppard had a positive attitude towards the situation and, although he admits to feeling frustrated and emotional, Allen believes his playing may actually have improved as a result of the more premeditated and analytical approach he feels is necessary to compensate for the changes in his drumming style. Allen's story encapsulates the ethos of the affirmative model. Through his positive approach and self-belief, he has retained his status as a highly respected musician and managed to keep his levels of self-esteem high enough to hold on to his identity in music. Allen appears to have had no desire to change profession or give up playing drums; 'not being able to play again never crossed my mind. I was never going to be a brain surgeon or anything, so I figured that playing drums was the only thing I could do [...] I don't think I ever doubted that I could do it' (Saccone, 2011, p.2) so Allen was compelled to change

the way he played drums (forced growth) with more use of his feet (redesigning the planned life) so by learning to play drums in a new way, he retained his planned life.

However, Allen's experience raises the question of whether the participants in my PhD project had similar experiences; Did they feel confident in their ability to be a successful musician? Did the people around also believe in their ability? Were they actively encouraged to become a disabled musician like Rick Allen? The answers to these questions would be of benefit to our understanding of the lives of disabled musicians but these factors did not emerge from the data in my PhD project as themes. However, this area of interest may be considered in a subsequent study into the lived experiences of disabled musicians.

A factor that must be considered in any change to style or method of playing by disabled musicians however is the fact that impairment has increased significance in the music world due to the physical nature of interaction between performer and instrument (Lubet, 2010, p.16). I suggest that, because impairment in the music world is regarded as having a greater impact on the functionality of an individual, the threshold that marks the division between what is regarded as 'normal' and 'impaired' is lower than the threshold for many other social activities. Many one-handed pianists would not be regarded as having an impairment other than the fact that they have musician's focal dystonia, a neurological condition that affects a muscle or group of muscles in a specific part of the body such as the hands or fingers which is usually the most part of the body for musicians. Focal dystonia causes involuntary contractions in the muscles and abnormal postures such as fingers curling towards the palm or extending involuntarily. This can obviously have a significant impact on a musician's ability to play their favoured instrument and musicians such as pianists, pipers and woodwind players are particularly at risk. However, as Lubet explains, for musicians such as Robert Schumann who had musician's focal dystonia 'his injury today largely would be regarded as a minor impairment by extra musical standards' (2010, p.15). Therefore, impairment in the music world can have a different complexion to impairment in other walks of life and pose greater problems for musicians who wish

the focus of attention in their music careers to be on their performances rather than their impairment. This heightened sensitivity surrounding the impact of impairment in the music world can compel a disabled musician to disguise or hide their impairment which is the topic of the following section.

2.3.1 Passing: a psychological concern for disabled musicians who perform in public

The account of Rick Allen's transformation from musician to disabled musician does not elucidate some of the psychological difficulties that disabled musicians can encounter when performing. One factor that can surface in the lives of many disabled people is Goffman's idea of 'passing' whereby the individual in question will attempt to disguise or mask their impairment (1963, p.57). Passing is discussed in Section 2.2.2 of this thesis in relation to the personal tragedy model of disability but as indicated in that section, passing is of particular relevance to people who are regularly in the public eye, performing musicians being a typical example. A good example of passing in the context of musical performance is exemplified in the writings of Stefan Honisch, a disabled pianist who describes his desire to appear 'normal' when performing. Honisch admits that he would often walk out on stage rather than use his wheelchair, or if he did use his wheelchair, he would transfer to the piano bench then have his wheelchair removed from public view (Honisch, 2009). Honisch now says 'presently, [...] I try to achieve "able-bodiedness" through my playing rather than through attempting to hide the fact that I use a wheelchair' (2009, p.5). For me this raises the question, why would Honisch feel the need to achieve 'able-bodiedness'?

Honisch's desire to achieve able-bodiedness may be due to a desire to distance himself from the 'disabled' identity which is invariably accompanied by social stigma, which is a strong feeling of disapproval that people in a society have about something (Cambridge Dictionary, 2018, 'Stigma'), and avoidance.

One of the major elements that contribute to the prevalence of avoidance due to stigma is non-disabled people's perception of disability. Goffman cites Carling who states;

'We all seem to be inclined to identify people with characteristics which are of importance to us, or which we think must be of general importance. If you asked a person who the late Franklin Roosevelt was, he would probably answer that Roosevelt was the 32nd president of the United States, not that he was a man suffering from polio, although many persons, of course, would have mentioned his polio as supplementary information, considering it an interesting fact that he managed to fight his way to the White House in spite of his handicap. The cripple, however, would probably think of Mr Roosevelt's polio when he heard his name mentioned' (Carling in Goffman, 1963, p.33).

Controversial language aside, this statement demonstrates the common belief among non-disabled people that disabled people constantly have disability and impairment at the forefront of their minds; that they recognise themselves and other people by their impairment or lack thereof. This statement was made in 1963 and as such must be taken in this context; however, these erroneous perceptions of disabled people still exists (Staniland, 2009, pp.1-104; Sancho, 2003, p.6; Wadsley, 2011, pp.1-3; Esmail et al., 2010, p.1154). In more recent research it was found that 'individuals with disabilities are commonly viewed as asexual due to a predominant heteronormative idea of sex and what is considered natural' (Esmail et al., 2010, p.1148). Moreover, it is still common for non-disabled people to think that disabled people have lower capabilities than non-disabled people (Staniland, 2009, pp. 26-27). The way disabled people are often perceived undoubtedly has an impact on an individual's tendency to 'pass as normal' but passing is only possible for those who can hide or draw attention away from their impairment. Honisch felt that removing his wheelchair from the stage did this, during the performance there would be no reminder of his impairment and the overall picture presented to the audience would be of a musician playing piano, with no visual cues that would draw attention to his impairment. Therefore, Honisch was able, up to a point, to divert attention away from his impairment when performing. However, passing as 'normal' is only possible if the individual can perform without the use of aids. Honisch could have his aid, his wheelchair, removed from sight while he performed, but some disabled people are reliant on physical aids that cannot be easily disguised or concealed, in these cases passing is not an option.

2.3.2 Considering the development of new interfaces and musical instrument adaptations

The topic of assistive technology is discussed by Sheldon who argues that ‘it is created by the same oppressive society that turns those with impairments into disabled people’ (2003, p.155). Although Sheldon considers assistive technology in terms of computers and the internet and the complex relationship that exists between technology and disabled people, she does not look at any of the methods employed by disabled people to engage with music. Therefore, this section looks at the production of music through assistive technology. Sheldon argues that there a tension exists between the benefits of technology and the possibility of oppression that it can also create (2003, p.155). Exclusion from parts of mainstream society is cited as one aspect of the emergence of some recent technological developments as not all disabled people are able to access the internet freely and the accessibility of computer-based applications has not kept pace with other innovations (Sheldon, 2003, p.158). However, for some disabled musicians the advent of new technologies has enabled access to music making and as such has had a positive impact on their lives.

Disabled musicians face not only the challenges that are generated through the psychological aspect of performing, but also frequently have to address challenges that occur as a result of physical limitations created by their impairments. For example, a traditional acoustic instrument such as a piano may present the musician with specific problems that can be difficult to overcome. For a musician with limited leg movement or strength, pushing the pedals might prove difficult or impossible. However, efforts have been made to negate these issues in various ways and to varying degrees of success, and one particularly innovative example is the pedal actuator invented by the Medical Engineering Resource Unit (MERU). MERU is an organisation formed to design and make disability products for young disabled people; they design and build various products to assist disabled people with physical tasks such as the ‘Instrument Holder’ which can help people with physical impairments hold a range of musical instruments and a pedal adaptation which enables remote activation of the pedals on a piano (Medical Engineering Resource Unit, 2014, n.p.). In addition to adaptations to existing musical

instruments, new technologies are being employed in new ways to enable disabled people access to music. Apple's 'iPad' in particular has been exploited to enable people with cognitive or physical disabilities to play and compose music, and new musical instruments such as the Skoog allow people to play an instrument irrespective of their levels of mobility (Skoogmusic.com, 2017, homepage). The Skoog is an electronic instrument in the shape of a cube that employs dynamic sensors to respond to the musician's touch which can be converted to a wide range of sounds using computer software.

There are other innovations that makes music more accessible such as 'Figurenotes', a practical notational system designed to assist music learners to read music developed in Finland by music educators Kaarlo Uusitalo and Markku Kaikkonen at the Resonaari School in Helsinki (Drake Music Scotland, Figurenotes, 2017, paragraph 3). Figurenotes is a system that can be useful to all beginners in music, but it has been most usefully employed to assist those with learning difficulties. It employs the use of coloured symbols to denote pitch, duration and gives the same musical information as conventional notation so facilitates easy progression to conventional notation. Music software such as Sibelius (Avid.com, 2017, homepage) and Notion (PreSonus, 2017, homepage) also contribute to the expansion of music making opportunities enabling more musicians with physical or cognitive impairments to engage in music making. These applications can be operated through a variety of interfaces such as computer keyboard, mouse, touch screen, or the relatively new human/computer interface Brainfingers which 'transforms brain and body electrical potentials from the forehead into hands-free computer controls which can be customised to each individual's needs' (Brainfingers.com, 2014, homepage). Although these technological innovations do not enable passing, they do enable people with specific impairments to engage in music making and help towards negating some of the difficult challenges they face.

The discussion in this section has provided a background against which research question 2: How do disabled musicians meet the challenges that arise when impairment impedes their ability to play their favoured instrument could be set. It has presented an overview of the most relevant literature on the

interfacing of human and musical instrument along with some of the techniques employed by disabled musicians to deal with social perceptions of the musical ability of disabled people. It has also discussed the choices disabled musicians are faced with when they experience difficulties in playing a musical instrument due to limitations dictated by an impairment.

2.4 Disability and social identity

Reasonable adjustments are a reaction to the inequalities that disabled people encounter as they venture out into the world, something that requires interaction with other individuals and organisations. A major consequence of interaction is the need to ‘place’ oneself in relation to others, to establish an identity. Defining identity is complex and can have a different meaning depending on the discipline and context (Shakespeare, 1996, p.94). Shakespeare suggests that when considering the subject of identity in relation to disabled people, ‘Parallels are drawn with the experiences of women, lesbians and gays, and black people, and post-structuralist concepts are used to problematise the issue of identity’ (1996, p.94). These parallels are being drawn more often in recent years as they are a useful way to analogise in order to provide context and better understanding of the experiences of disabled people and how they identify, or are identified as disabled people (Corbett, 2007, p.356; Morris, 1992, p.157). Consequently, in Chapter 6 of this thesis I have drawn on the issues outlined in the Stephen Lawrence Inquiry (Macpherson, 1999) which refers to attitudes that result in racism, to assist in explaining some of the discriminatory practices experienced by disabled people (Chapter 6, p.2). However, a disability identity can also be considered through means other than through looking at forms of discrimination. ‘Disabled’ is a social concept, which means that it is characterised by “categorical representational meaning systems shared by large segments of society that can provide expected characteristics for those who belong to that category as well as perceptions for their behavior and narrative history of group membership” (Deaux and Martin 2003, p.105). For the purposes of this study therefore, disability identity is explored through the concept of social identity.

2.4.1 Social Identity Theory (SIT) and group identity

Many theories have been formulated that seek to explain the phenomenon of identity but the one that has been chosen to explicate identity in relation to disability for this study is Social Identity Theory or SIT. As mentioned in the previous section, disability is a social concept SIT and works well to help clarify many of the driving forces behind the concept of disability. Social Identity Theory was developed by Henri Tajfel and assumes that we are all members of social groups and membership of such a group (in-group) results in exclusion of other individuals (out-group) (Tajfel, 1970, p.97). In SIT, interactions are categorised as either interpersonal or intergroup behaviour. The more a situation is perceived to be intergroup in nature, the more uniform attitudes and behaviour will be in the in-group towards the out-group. SIT also posits that social categorisations influence the behaviour of individuals in that group members will try to achieve a positive evaluation for their in-group and is achieved through 'social comparison', highlighting the positive aspects of the in-group in a comparison with the out-group (Tajfel, 1982, p.24). This satisfies the need for building and maintaining a positive identity and bolsters self-esteem. For disabled people SIT is particularly relevant as they are often regarded as 'other' (Shakespeare, pp.218, 227) which fits well with the idea of being categorised as being a member of an out-group. Not being included in the in-group raises the question of normality because; 'Disabled people are defined as that group of people whose bodies do not work; or look different or act differently; or who cannot do productive work. The key elements of this analysis are performing and conforming: both raise the question of normality, because this approach assumes a certain standard from which disabled people deviate' (Shakespeare, 1996, p.95). The standard in this case is what the in-group, those not categorised as disabled, deem to be 'normal' as in people who can work, have bodies that work, and look and act the same way they do. Disabled people do not meet this standard and therefore will be subject to what Tajfel refers to as 'maximising the difference' where the people belonging to the in-group accentuate and highlight the negative attributes of the members of the out-group to 'preserve or achieve a "positive group distinctiveness" which in turn serves to protect, enhance, preserve, or achieve a positive social identity for members of the group' (Tajfel, 1982, p.24).

2.4.2 Social comparison and the concept of disability identity

A key factor involved in the formation of identity is the influence of social comparisons; the self is innately social and consequently individuals reach an understanding of their self through social interaction (Andersen et al., 2002, p.159). Therefore, the act of social interaction is an important aspect of identity formation and management; Goffman argues that ‘The routines of social intercourse in established settings allow us to deal with anticipated others without special attention or thought [...] first appearances are likely to enable us to anticipate his [...] “social identity”’ (1963, p.12). If this theory holds, it means that during social interaction others will routinely anticipate our attributes and status automatically and that this automatic assessment is made possible by building on previous experiences and interactions with others in familiar settings. Therefore, these normative expectations cause us to anticipate particular attributes on first impression (Goffman, p.12) and form an important element of social interaction for disabled people who are regularly subjected to stereotyping (Shakespeare, 1999, p.164; Barnes 1992, p.39; Sutherland, A. T., 1981, p.6) and stigmatisation (Goffman, 1963, p.19). Goffman describes a stigmatised person as someone who is perceived as having ‘an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind – in the extreme, a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted, discounted one’ (1963, pp.11-12). Therefore, to be stigmatised is to be seen as having undesirable attributes (Goffman, 1963, p.12) and stems from the concept of ‘normality’. Goffman also argues that stigma equates to ‘a failing, a shortcoming, a handicap’ (Goffman, 1963, p.12), phrases which could easily be used to describe the common conception of impairment which sees disabled people as ‘individuals who want improvements in their functional abilities’ (Hahn and Belt, 2004, p.453). This raises the question of why disabled people are regarded as ‘incongruous with our stereotype of what a given type of individual should be’ Goffman, 1963, p.13). One answer is provided by Morris who argues;

‘Our disability frightens people. They don't want to think that this is something which could happen to them. So, we become separated from common humanity, treated as

fundamentally different and alien. Having put up clear barriers between us and them, non-disabled people further hide their fear and discomfort by turning us into objects of pity, comforting themselves by their own kindness and generosity' (1991, p. 192).

Therefore, disabled people are seen as different from the majority in order to distance them from what might be regarded as 'normal'.

Looking at the way social interactions influence perceptions from the perspective of disabled people, it is argued that individuals come to understand their self as a result of the feedback they receive from significant others (Andersen et al., 2002, p.159), the link between health and identity can cause difficulty for disabled people with regard to their identity as there is also a link between health and disability (Park et al., 2003, p.76; Watson, 2001, p.44; Shakespeare, 1994, p.298). In my view, the linking of health, disability, and identity in this way must contribute to the sense of 'difference' felt between non-disabled people and disabled people; therefore the common view of health in relation to disability will inevitably influence the shaping of a disabled person's identity and ultimately result in disabled people being viewed as different from the general population or 'other' (Shakespeare, pp.218, 227).

2.4.3 Avoidance and its role in constructing disability identity

In addition to the theory that disabled people remind non-disabled people of their own mortality, the innate preconceptions and instincts humans have towards difference is believed to impact on the way disabled people are perceived. The effects of disgust engendered by the human instinct to avoid disease is a theory put forward as one of reasons why disabled people are avoided. Park et al. present what they refer to as an 'evolutionary disease-avoidance model' which describes a link between evolved disease-avoidance and the avoidance of people with physical disabilities (2003, p.67). Park et al. posit that physical differentness is tempered by a prevalent feeling of discomfort around people with visible physical disabilities and suggest that this discomfort is an evolved emotion which underlies current negative attitudes towards disabled people. Evidence has confirmed that physical proximity to physically disabled people causes non-disabled people to be uncomfortable and this results in physical

avoidance unless there are no face-saving mechanisms in place. Snyder et al. carried out a study exploring what they believe is the desire most people have to avoid physically disabled people (Snyder et al., 1979, pp.2297-2306). Their study was devised to ascertain whether given a choice, people would avoid sitting next to a physically disabled person. One conclusion from Snyder et al.'s research was that when given a face-saving option, most people will choose to avoid being in close proximity to disabled people and that participants who sat next to a physically disabled person while watch a movie described themselves as 'tense', jittery' and 'on edge' (1979, p.2303). Park et al. argue that this is the same behaviour demonstrated when a contagious disease is encountered (2003, p.4).

However, the study undertaken by Snyder et al. (1979, 2297-2306) concludes that most people will choose to avoid being in close proximity to disabled people must be tempered by the fact that not all people will feel this way, wariness of disease and sensitivity to disgust will vary from person to person, and because disgust develops early in children (Rozin & Fallon, 1987, p.34) and the things that engender disgust will vary between cultures (Kenrick et al., 2003, p.23). Park et al. suggest that cultural background had an important influence on the results of their study which examined 'the influence of both personality and contextual variables connoting disease on the automatically activated cognitions' (Park et al., 2003, p.75). Through a series of categorisation trials, participants were asked to respond to a target stimulus; the results were then analysed with the 'implicit association test' (IAT) a reaction time method that measures differential cognitive association of social categories (e.g., disabled, non-disabled) with semantic information (e.g., disease, health). In addition to the IAT procedure, participants completed a 'Perceived Vulnerability to Disease' questionnaire designed to assess individual differences and a revised version of Haidt's 'Sensitivity to Disgust' questionnaire (Haidt et al., 1994, pp.701-713). From the data gathered it was determined that along with the general conclusion that 'a heightened fear of disease [...] leads to increased prejudicial responses to people with physical disabilities', participants of European descent were inclined to more negative disease-related associations with disability than the East Asian participants. Park et al suggest this may be due to

‘differences in cultural mythologies and belief systems pertaining to the etiology of ill health’ (Park et al., 2003, p.78). It should also be noted that just as culture will influence the level of prejudices towards disabled people, so must the emotional and moral differences between individuals, regardless of their culture.

Many contagious diseases are accompanied by visible physical and/or behavioural cues and many of these cues are replicated by physical disability, so it is expected that these cues will generate the same or similar feelings of disgust and avoidance when a person with physical disabilities is encountered (Kurzban & Leary, 2001, pp.199-200). However, it is unlikely that disease avoidance processes have evolved to make distinctions between symptoms of contagions and non-contagious conditions; therefore, evolved disease-avoidance mechanisms will be responsive to a range of non-contagious disease-connoting cues such as physical disabilities and facial disfigurements (Park et al., 2003, p.68).

It can be seen that being identified as a disabled person is a complex process and elements such as fear and disgust play a part in reinforcing a disabled identity. Fear and disgust work to generate the desire to avoid people who are deemed to be different such as disabled people. However, my own experiences of being a disabled person have prompted the belief that a major factor that generates avoidance of disabled people is embarrassment or the concern that, as a non-disabled person, an individual will say or do something that will offend the disabled person with whom they are interacting causing ignominy. This in turn will result in a ‘loss of face’ which means a drop in an individual’s reputation or how they are regarded by their society (Leong et l., 2017, p.396) for the non-disabled person; this is a scenario that I encounter daily but prior to my PhD project appeared not to have been researched to any degree. Consequently, it presents an opportunity to fill a gap in disability studies literature and is a topic discussed, albeit indirectly, in Chapter 5 where the issues of the ‘spread effect’ are considered. However, a full examination of embarrassment arising from social interactions is beyond the scope of this thesis.

2.4.4 The spread effect or ‘does he take sugar’

One of the most common perceptions that face disabled people as they interact with others is the phenomenon known in the USA as ‘the spread effect’ (Wright, 1960, pp.1-408). The spread effect is the label given to the belief that a person who has one impairment will automatically have other impairments, that the impairment has an effect on other senses or functions (Dembo et al. 1975, p.39). The phrase ‘spread effect’ was first coined by Beatrice Wright in 1960 and has been adopted and discussed in the disability studies field in the USA regularly since; as such, the label ‘the spread effect’ is well known in disability studies in the USA (Keany and Glueckauf, 1999, pp.139-152; Shontz, 1984, pp.77-84; Dion and Walster, 1972, pp.285-290; Wright, 1960, pp.1-408) but less so in the UK. As an attitude or perception however, it is a feature that is well known to disabled people in the UK but more commonly under the guise of ‘does he take sugar’, a name applied to this phenomenon following the broadcasts of a radio programme with the same name (Roger and Marsden, 2013, p.48). Rogers and Marsden describe the phenomenon as ‘the sentiment of talking about someone who is disabled in the third person, while in their presence, regardless of whether that person can speak for him- or herself’ (2013, p.48) which is an appropriate description of how this scenario often manifests. However, Rogers and Marsden go on to suggest that this is a kind of ‘overlooking’ (2013, p.48), which implies that the disabled individual is being ignored. Wright’s interpretation of the spread effect is at odds with Rogers and Marsden’s suggestion as she argues that the spread effect is a perception of an impairment spreading into other aspects of the disabled person’s life, that is, ‘the subject expects the lot of the person with a disability to be worse than the apparent reality’ (Wright, 1960, p.72). This description does not allude to the disabled person being ignored since the person making the assumption will have to consider the situation of the disabled person and make a judgement on their cognitive and physical capabilities. Section 5.2 in Chapter 5 of this thesis explores the issues surrounding the spread effect through the experiences of both the PhD project participants and my own experiences as a wheelchair user.

2.4.5 Bullying and subtle forms of oppression

In addition to features such as the avoidance of disabled people and the spread effect, one of the most disturbing manifestations that can be attributed to the in-group and out-group ‘maximising the difference’ element of Tajfel’s Social Identity Theory is the oppression or bullying of people perceived to be members of the ‘out-group’. Although bullying is a phenomenon that can be found in most forms of human interaction, disabled people are more likely to experience ‘subtle forms of oppression, including imbalanced personal relationships, social exclusion, restricted autonomy and a higher tolerance for maltreatment within segregated settings’ (Hollomotz, 2012, p.477). Hollomotz argues that experiences of oppression and violence, both manifestations of bullying, occur on a continuum, and that taking such a broad approach accounts for subtle and everyday instances of oppression and intrusion (Hollomotz, 2012, p.487). In other words, disabled people can experience oppression and bullying in subtle forms such as a derogatory comment or exclusion, or in extreme forms such as physical violence. These are elements of social interaction that Corker and Davis found in their research (2003, pp.75-90) but the data in my PhD project shows that for disabled adults, much of the bullying they experience takes the subtler form with exclusion being one of the most common forms of bullying. However, life as a disabled person means exposure to systematic oppression and disempowerment (Hollomotz, 2012, p.487) and as such will have a cumulative effect throughout the life of a disabled person.

Section 2.4 has introduced theories and discussions that help to contextualise the findings in my PhD project that relate to research question 3: **How does interpersonal interaction impact on the lived experiences of disabled musicians?** This was achieved by providing an insight into the dynamics of social relationships through a critique of various works by commentators including Tajfel (1970, pp.96-10, Corker and Davis (2003, pp.75-90), Goffman (1963, pp.1-173) and Hollomotz (2012, pp.477-493) who present different aspects of social and self-identity and how they are shaped and maintained.

2.5 How a disability identity is shaped and maintained by perceptions

In addition to features like low expectations and avoidance, attitudes towards disabled people are also coloured by negativity (Ostapczuk & Musch, 2011, pp. 399-411). Wendy Magee presents the idea that individuals need to 'transcend the body' in order to come to terms with their losses (Magee, 2002, p.180), a view that is challenged in section 4.1.4 of Chapter 4; 'Understanding the realities of impairment', where data collected from participants, excerpts from online blogs, and my own experiences as a person who has experienced the journey from being regarded as a non-disabled person to being regarded as a disabled person are used to argue against Magee's assertions.

2.5.1 Supercrips; the portrayal of disabled people as 'superhuman'

Magee's theory of transcending the impact of impairment is an example of how being identified as a disabled person means being the subject of certain preconceptions and attitudes. However, in addition to being regarded as inferior, objects of pity, or people who need to be cured, disabled people can be represented as people who are 'overcoming their limitations' and 'triumphing against the odds' (Shakespeare, 2016, p.1138; Grue, 2015, pp.204-218). Despite the positive reception of the 2012 Paralympics, some commentators have expressed concerns about the way disabled people are promoted as 'superhumans' (Shakespeare, 2016, p. 1138). It could also be argued that events such as these do not have a lasting effect on the attitudes of the general public; the results of a recent poll undertaken for the UK charity Scope states that five years on from the 2012 Paralympics in London, 'A quarter (28%) of disabled people did not feel the Paralympics delivered a positive legacy for disabled people' (2017, paragraph 1). The 2012 London Paralympics were widely covered by the media which could be construed as a positive factor for disabled people. However, Barnes and the British Council of Organisations of Disabled People assert that although 'neutral' terminology is used overtly in most media broadcasts, terminology such as 'plucky', 'brave', and 'courageous' are also used regularly resulting in tacit patronisation and sentimentality (Barnes & British Council of Organisations of Disabled People, 1992, p.8). It seems therefore that perceptions of disabled people tend to be

polarised towards either end of the spectrum of understanding of what it is to be a disabled person with poor representation of the middle of the spectrum. Shakespeare argues that in relation to disabled people 'strong messages of physical difference and personal deficit are reinforced' (1996, p.104). I would suggest that the messages of 'physical difference' is commensurate with the supercrip label where physical difference is celebrated and personal deficit could be equated with the pity and tragic end of the spectrum. The difficulty that the lack of representation of disabled people from the middle of the 'perception of disability spectrum' presents is the adverse effect this can have on the self-perceptions of disabled people. As Morris argues 'The messages we receive are very strong and clear and we have little access to different values which may place a more positive value on our bodies, ourselves and our lives. Our self-image is thus dominated by the non-disabled world's reaction to us' (1991, p.28). If disabled people's self-image is developed through the non-disabled world's reaction to them, it is reasonable to assume that they will have a negative perception of themselves, and this will lead to a reciprocal process that is self-perpetuating. Because of the tendencies to represent disabled people as either superhuman or tragic, disabled people will be prone to internalise these perceptions of themselves, as Shakespeare argues, 'disabled people are socialised to think of ourselves as inferior' (1996, p.104), so it is reasonable to suppose that seeing how disabled athletes are regarded will be internalised and generate an inferiority complex. It can be argued therefore that as we need to be able to see ourselves from the perspective of our society in order to develop our self-consciousness and self-reflective awareness (O'Neill, 2002, p.80); this presents particular difficulties for disabled people. If a society and its members do not have an accurate understanding of what it means to be disabled, the disabled person will build their sense of self on misconceptions, biased attitudes and negative perceptions of that society. Therefore, the negative perceptions and attitudes experienced by disabled people are important influences on their self-esteem. For an aspiring musician with a disability, these issues must have an impact on their self-belief and confidence. I would argue that a disabled person who aspires to be a successful musician might have a tendency to analogise what it takes to be a disabled musician with 'superhuman' athletes who compete in the Paralympics and this

might trigger feelings of inadequacy that will prevent them from attempting to initiate a career in music.

2.5.2 Self-perception

In addition to the impact on identity by attitudes and perceptions such as superhuman or tragic, there are other factors that need to be taken into account when considering the self-image of disabled people; changes to an individual's physical or cognitive capabilities can also influence how disabled people see themselves. Research has shown that a change in identity can occur during and after the acquisition of a chronic illness (Gibson et al., 2005, p.502; Charmaz, 1983, p.107). Although these authors refer to chronic illness, disability and chronic illness are often referred to in tandem as the effects and consequences are analogous (Wendell, 2001, p.17); therefore, I feel that research in this area is pertinent to this research project. Charmaz describes the 'loss of self' that can result from 'a crumbling away of [...] former self-images without simultaneous development of equally valued new ones' (Charmaz, 1983, p.168). Charmaz goes on to describe this loss of self by detailing the causes of the feelings of loss such as depletion of productive function, stigma and a restricted existence (Charmaz, 1983, p.168). Gibson et al. expand on the work of Charmaz by categorising the major themes that transpire from the respondents' in their study, these fall into two groups; 'loss' and 'response to loss' (Gibson et al., 2005, pp.507-508). The 'loss' group themes are loss of a stable familiar personality and the loss of self-positioning. The 'response to loss' group includes; emotional suppression to meet others' expectations, redesigning the planned life, forced growth, struggling with support, discovering the spiritual self, and identity reconsolidation (Gibson et al., 2005, p.508). Themes in the 'loss' group illustrate aspects such as loss of self-esteem and a weakened sense of self or 'a loss of self-positioning or definition in relation to the external environment' (Gibson et al., 2005, p.509). From a musician's viewpoint, possibly the most difficult losses to deal with are those related to work or profession. Gibson et al.'s study shows that people whose disability cannot be accommodated at work may lose their livelihood and feel they have lost their ability to contribute (2005, p.503). Therefore, an overlap is

evident between disruption of musical identity (loss of status as a musician) and social status (lack of contribution to society). In the response to loss group, the themes which stand out from a musician's perspective are 'redesigning the planned life' and 'forced growth' (Gibson et al., 2005, p.508).

Section 2.5 has expanded the discussion on disability and social identity in Section 2.4 by focusing on how a disability identity is shaped and maintained through the perceptions and attitudes of others and disabled individuals themselves. Since the self is developed and maintained through social relations (Charmaz, 1983, p.170), Section 2.5 also relates to research question 3: **How does interpersonal interaction impact on the lived experiences of disabled musicians?** Research question 3 is the sole focus of Chapter 5 in this thesis since topics related to interpersonal interaction formed a large proportion of the interviews with the participants in my PhD project.

2.6 Experiencing the education system as a disabled student

It is clear that concepts such as the models of disability have made an impact on the perception of disability. Hevey's comment in Section 2.2.4 exemplifies the way in which the social model has changed the perception of disability from the perspective of the individual, but the social model has also influenced the practices and attitudes of institutions. In Chapter 6 the two final research questions are addressed: Question 4: **'How do disabled musicians experience institutional discrimination?'** and Question 5: **'How effective are reasonable adjustments at combating institutional discrimination?'** My PhD project shows that disabled people experience major obstacles during their time in music education and that these obstacles have a significant impact on their journey to becoming a musician. Beauchamp-Pryor states that 'Disabled students are accessing higher education in increasing numbers, but this I argue does not necessarily mean that their experiences reflect equality and inclusion' (2007, p.ii) and Barnes et al. argue that 'There are signs of a slow but steady increase in the proportion of disabled learners, and the role of public policy has been one of the crucial influences here' (2009, p.6). Barnes et al. report that in general, there is some form of support service in institutions and the existence of some form of disability equality scheme (2009, p.vii). However,

evidence from my PhD project shows that despite these measures to tackle inequality and exclusion, and the fact that the numbers of disabled people attending education facilities are on the increase, experience at institutions is frequently negative for disabled students. These negative experiences occur despite significant funds being awarded to higher education institutions (Barnes et al. 2009, p.19). In addition to ‘bricks and mortar’ education facilities there are also institutions that provide qualifications in music via coursework and examinations that can be provided by private tutors, including the Associated Board of Royal Schools of Music (ABRSM) and Trinity College. The data in my PhD project shows that these institutions also create barriers to music through their policies and practices.

Given the negative experiences of disabled musicians at both education facilities and qualification providers like the ABRSM that are reported in my PhD project, I decided it prudent to discuss how education and other institutions work to deal with inclusion and equality issues. This has led to a consideration of ‘reasonable adjustments’ which are discussed at length in Chapter 6.

2.6.1 Reasonable adjustments and The Equality Act (2010)

In 1995 the Disability Discrimination Act (DDA) instigated the implementation of ‘reasonable adjustments’ which have been carried through to the Equality Act (2010, Chapter 15, p.63) which replaces the Disability Discrimination Act (1995). Reasonable adjustments are intended to ensure a ‘level playing field’ for disabled people when they interact with various institutions and are the tools that schools, colleges and universities use when trying to ensure disabled students do not experience discrimination during their studentship. However, research has shown that the implementation of reasonable adjustments can be haphazard and can vary depending on the attitude of the individual tasked to carry them out (Riddell and Weedon, 2014, p.1-24). Therefore, the views of staff members can influence how rigorously or otherwise reasonable adjustments are implemented and the ‘level playing field’ that institutions are required to provide for disabled students can be difficult to achieve. The negative influence of staff members in the implementation of reasonable adjustments is shown in

the research carried out by Riddell and Weedon which revealed that ‘university lecturers themselves were sometimes deficient in their knowledge of disability issues and the values which they were modelling for their students’ (Riddell and Weedon, 2014, p.16).

2.6.2 Interpretation of The Equality Act

In addition to the rigour with which reasonable adjustments are implemented, interpretation of the law poses an issue for disabled people. The Equality Act states:

Duty to make adjustments

Where this Act imposes a duty to make reasonable adjustments on a person, this section, sections 21 and 22 and the applicable Schedule apply; and for those purposes, a person on whom the duty is imposed is referred to as A.

The duty comprises the following three requirements.

The first requirement is a requirement, where a provision, criterion or practice of A’s puts a disabled person at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, to take such steps as it is reasonable to have to take to **avoid the disadvantage**.

The second requirement is a requirement, where a physical feature puts a disabled person at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, to take such steps as it is reasonable to have to take to **avoid the disadvantage**.

The third requirement is a requirement, where a disabled person would, but for the provision of an auxiliary aid, be put at a substantial disadvantage in relation to a relevant matter in comparison with persons who are not disabled, **to take such steps as it is reasonable to have to take to provide the auxiliary aid**.

(The Equality Act (2010) section 20, p.10)

The University of Edinburgh has chosen to interpret the duty to make reasonable adjustments as follows:

The Equality Act doesn’t state that we have to anticipate the needs of every prospective student, but the University is required to think about and take reasonable and proportionate steps to overcome barriers that may impede people with different kinds of disabilities.

(The University of Edinburgh, (2017), Student Disability Service, ‘Duty to make Reasonable Adjustments’)

These interpretations are interesting. as the comment; ‘The Equality Act doesn’t state that we have to anticipate the needs of every prospective student’ seems to imply that the university, while acknowledging its duty to anticipate the barriers their students might encounter, has inserted a ‘get out clause’ into its policy. Interestingly, the University of Strathclyde does not include such a caveat in their explanation of reasonable adjustments;

The University also has a duty to **anticipate reasonable adjustments** i.e. to plan and take proactive steps to address the barriers that impede disabled people and, where feasible, to put adjustments in place in advance. Anticipatory adjustments should be made for students with all disabilities and not just for the categories of disability which students in your department have.

(University of Strathclyde, (2017), Information for Staff, Legislation and Reasonable Adjustments)

This topic is considered in Chapter 6 where issues such as the implementation of reasonable adjustments and interpretation of The Equality Act (2010) are discussed in more depth through examples drawn from PhD project participants and my own experiences as a music student.

Section 2.6 has introduced some of the issues that can arise in relation to music education and disabled people; the aim being the contextualisation of the data presented in Chapter 6 of this thesis, which considers the experiences of disabled people as the journey through the music education system. In doing so, Section 2.6 relates to research question 4: **How do disabled musicians experience institutional discrimination?** and research question 5: **How effective are reasonable adjustments at combating institutional discrimination?** During the process of discussing the topics related to these research questions, Section 2.6 has revealed some of the tensions that exist between the intentions of reasonable adjustments and the actual experiences of disabled people as they journey through the music education system.

2.7 Project aims and research questions

This chapter has provided a background and element of context to help position the findings revealed in Chapters 4, 5, and 6 in relation to extant theories that relate to disability and impairment. It has shown that language has an important role to play in the way disabled people are perceived and how they perceive themselves. A survey of existing literature has highlighted the tensions that exist in relation to the use of particular descriptors such as ‘disabled people’ and the person-first ‘people with disabilities’ term due to the argument over whether the person-first form is more suitable because it accentuates the individual over disability, or whether ‘disabled person’ is more applicable as it emphasises the fact that people can be disabled by society. Terms like ‘special needs’ are also in question due to their negative connotations and subsequent impact on the perceptions of disability and disabled people. Another aspect of language used in relation to disability is the definition of specific words. The definitions of ‘disability’ and ‘impairment’ pose particular problems for disability scholars, these issues have been highlighted by the inception of the social model of disability and the concept it presents. A leading feature in the models of disability is the issue of social identity and the shaping of identity through social interaction and the concept of normalcy. Disabled people are often categorised as a group of people who are different from the rest of the people in a particular society and as such have been ascribed a specific identity that marks them out to be ‘other’. This ‘otherness’ is posited by some to be the result of an innate form of disease-avoidance and by others to be a response to being reminded of one’s own mortality (Shakespeare, pp.218, 227).

According to a UK study ‘nearly four in ten people think of disabled people as less productive than non-disabled people all or some of the time’ (Staniland, 2009, p.27). Given this fact, along with concepts such as being ‘other’ (Shakespeare, pp.218, 227) and having less value in society, disabled musicians are particularly susceptible to the impact of the devalued or low status attributed to disabled people and there is an increased likelihood that they will be subjected to a devalued status and low

expectations. Consequently, to establish or maintain a career in music, disabled musicians will be compelled to find ways of mitigating the effects of this devaluation.

Issues such as the devalued status of disabled people and the way in which disability is understood is at the core of the social and affirmative models of disability and, although the medical model still plays a major role in the way disability is understood, the social model has overtaken it as the most common way to understand disability related issues with the view that disability is a phenomenon that is socially constructed.

Another factor for consideration is how the understanding of disability can take different forms. These ways of understanding disability lie within a 'perception of disability spectrum', a spectrum which has at one end the common perception that disabled people are deficient individuals who are to be pitied, and at the other end the view that disabled people can be superhuman, people who have against the odds overcome their disadvantages.

How disability is perceived also affects the way disabled people perceive themselves. The views and attitudes of others can be internalised and by doing so affect the self-perception of the individual. If a disabled person is perceived to be different, they will feel different. This in turn generates a compulsion to 'pass as normal' in some disabled people, a phenomenon that is of particular relevance to disabled musicians who are regularly being assessed and judged because of their propensity to perform in public.

Related to the act of performing is the physical aspect of being a disabled musician. Adaptations to enable disabled people to engage with music are becoming more commonplace with many innovative solutions coming from the world of electronics. However, increasing the ability of disabled people to perform in public with the aid of technology brings us round again to how disabled people are perceived, how attitudes towards disabled people manifest, and how these perceptions and attitudes

impact on the lived experiences of disabled people who engage, or attempt to engage in music making. These topics are covered in the investigations and outcomes in the findings chapters, Chapters 4, 5 and 6 which seek to answer the research questions asked in this PhD project.

Chapter 4 addresses two research questions. The first, question 1 **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** is addressed by considering examples from the PhD participant interviews and my own experiences that illustrate common misconceptions regarding impairment. Chapter 4 also examines the impact misconceptions can have on disabled people's interaction with the music world. Following the analysis of data in relation to question 1, Chapter 4 then focuses on research question 2 **How do disabled musicians meet the challenges that arise when impairment impedes their ability to play their favoured instrument?** by examining the intersection of impairment and music making, both from the perspective of disabled musicians and from the people with whom they interact.

In Chapter 5, research question 3 is considered which asks **How do individual attitudes and perceptions of disabled people manifest and how do they impact on the lives of disabled musicians?** Analysis of the experiences of the participants in this PhD project as they interact with individuals, along with my own experiences in this regard are the main sources used to elucidate the points raised by this question.

As many of the issues recounted by PhD participants and myself occurred in an educational setting such as college or university, Chapter 6 begins with an examination of institutional discrimination and seeks to answer research question 4 **How do disabled musicians experience institutional discrimination?** The efficacy of reasonable adjustments that are provided to help enable disabled people access to services and facilities is an important factor when considering the lived experiences of disabled musicians; consequently, Chapter 6 seeks to answer questions 5 **How effective are reasonable adjustments at combating institutional discrimination?** These questions emerged as a

direct result of the analysis of the data gathered from the interviews with PhD participants and from my own experiences as a PhD student while undertaking this PhD project. In answering these questions, the aim of this PhD project is to explore the lived experiences of disabled musicians with a view to identifying the challenges and barriers they face in the music world. However, before considering the data, these research questions and the findings in Chapters 4, 5 and 6, an explanation of the research method and analytical framework used to bring these findings to light is presented in Chapter 3.

CHAPTER 3: METHODOLOGY

3.1 Introduction

This chapter presents an overview of the methods and approach used to gather and analyse data for this PhD project. Section 3.2 presents a brief outline of my theoretical approach to the research and an overview of the rationale for using a qualitative study drawing on semi-structured interviews and autoethnographic data to collect and analyse the data. Section 3.3 discusses the rationale for including an autoethnographic element to my PhD project and section 3.4 provides a brief description of the process of incorporating the autoethnographic element into my thesis. Section 3.5 outlines the data collection process, from the initial contact with candidates to the interviews with the chosen participants. It explains the issues encountered during correspondence with the candidates and covers the reasons why some candidates were deemed unsuitable and others recruited. Section 3.5 also discusses the methods used to record the interviews and the process of transcribing these recordings in preparation for the data analysis stage. The section concludes with a chart explaining the coding system used to document the speech, sounds and visual cues that occurred during the interviews.

Section 3.6 of this chapter explains the analytical framework used to guide the analysis process and begins with Section 3.6.1, a brief consideration of the two main types of data analysis, quantitative data analysis and qualitative data analysis. This is followed by Section 3.6.2 which discusses thematic analysis since this is the method used in this PhD project. Section 3.6 also discusses the thematic analysis framework set out by Braun and Clarke (2006, pp. 77-101) which formed the foundation for the method of analysis used in my project and the chapter concludes with Sections 3.7 and 3.8 which consider the ethical and reflexive elements of my project.

3.2 Theoretical considerations

I would argue that the interpretation of all experience cannot be accomplished without considering historical and social contexts. Consequently, the methods used to generate data in this PhD project emanate from a social constructionist standpoint. Social constructionism dictates that a critical stance is taken toward our assumed ways of understanding ourselves and our environment (Burr, 2003, p.3). It encourages us to be critical of the belief that the nature of our world is easily understood through our observations and to question the view that common knowledge is based on impartial observation of the world. Therefore, social constructionism disagrees with what are referred to as positivism and empiricism, epistemological positions that are typical of sciences such as physics and biology. Positivism and empiricism involve the belief that the attributes of the world can be disclosed through observation and that what exists is what we perceive to exist. Conversely, social constructionism instructs us that social phenomena are not ‘simple unchanging events that we can measure but events that need to be understood in a specific way within particular social and historical conditions’ (Langdrige, 2004, p.253). Coming to this research from a social constructionism standpoint and given that the purpose of the research is to investigate lived experiences, the choice of research methods in this PhD project naturally points to a qualitative approach. Denzin and Lincoln (2011, p.8) suggest that qualitative researchers emphasise the socially constructed nature of reality and the relationship between the researcher and what is studied; they also argue that qualitative research methods look to answer how social experience is created and given meaning. This chimes with the aims of my PhD project and I deemed it the most appropriate approach for this PhD project given the aims are to understand human actions and their consequences for disabled people.

3.3 Why add an autoethnographic element?

Although my experiences as a disabled musician and PhD student did not always chime with those of the participants, I experienced numerous incidents and attitudes during the course of this PhD project that corresponded with the stories recounted in the interviews. Among the reasons why I decided to

add the autoethnographic element was my increasing difficulty in separating the two aspects of my experience as a PhD student, the research element, and the experiential element. These factors were in play from the beginning of the PhD project as, being a disabled person researching the experiences of other disabled people, the PhD project was always likely to bring up issues that chimed with my experiences as a disabled person. However, I did not anticipate the severity and extent to which the negative experiences I encountered as a disabled student would impact on my ability to complete my PhD project. Consequently, I decided to include these negative experiences in this PhD thesis and this allowed me to continue the PhD project; otherwise I would have realised my intention to withdraw from the PhD process. This inclusion of my own experiences as a PhD student and musician is identified as the autoethnographic element in this PhD thesis.

Autoethnography is a method of research that applies the researcher's personal experiences as ethnographic data and the term autoethnography is applied to both a method of research and the text that is generated by the researcher (May, 2011, p.2). The term is a development and combination of the Greek words for self, 'auto', culture 'ethno', and 'graphy', a term used to describe the research process. Autoethnography commonly involves the consideration of the researcher's personal experiences to help understand elements of social reality and is a comparatively new research method.

Autoethnography can be divided into two general forms, the first being where the researcher researches their 'home' society, culture, or group. However, the term autoethnography has more recently been used to describe research where the researcher's personal experiences and emotions are used as data to be analysed in connection with the broader social context (May, 2011, p.2). It is argued that the use of personal narratives such as those found in autoethnographic research are prejudiced but autoethnographers counter this by maintaining that all knowledge originates from a particular viewpoint, that unbiased knowledge is not possible and taking into account subjective experience is valuable (May, 2011, p.2). Having explained that autoethnography is a combination of autobiography and ethnography, Ellis et al. write, 'Most often, autobiographers write about "epiphanies"—

remembered moments perceived to have significantly impacted the trajectory of a person's life' (2011, section 2). Remembering moments that have had a significant impact on my life is the method I used to gather data for the autoethnographic element of this project because, as Bochner argues 'epiphanies reveal ways a person could negotiate "intense situations" and "effects that linger—recollections, memories, images, feelings—long after a crucial incident is supposedly finished"' (1984, p.595). I concur with this standpoint along with the views of Ellis et al. who state that autoethnography is the documentation of epiphanies that stem from 'being part of a culture and/or by possessing a particular identity (Ellis et al., 2011, section 2), in my case the identity is that of a disabled person who is a musician and student of music. I believe the autoethnographic element of this PhD project is just as important as the data gathered from the interview element because it adds what Ellis et al. (2011, section 2) describe as 'aesthetic and evocative thick descriptions of personal and interpersonal experience' to the data in my project. As explained in chapter 1 of this thesis, my experiences as a PhD student became more and more relevant to this PhD project because they chimed with the experiences of the PhD project participants. This resulted in some adjustment to many aspects of the project such as the analytical framework and the thesis layout, and it also played a crucial role in the outcome of the project.

In addition to all of the reasons outlined above for including an autoethnographic element to my PhD project is the therapeutic value of writing about my experiences while undertaking the project. For Ellis et al. writing is a way of knowing (Ellis et al, section 4.2) and writing personal stories can be therapeutic and for Ellis (2000, pp.400-401) autoethnographies are about the notion of being 'Other', a notion that is discussed in this thesis and one particularly relevant to disabled people. Ellis also argues that autoethnographies involve critical engagement and deal with social problems (2000, p.401); I argue that the examination of the social problems discussed in my PhD project benefits from the contribution made by my personal narrative. However, the overriding justification for my decision to include an autoethnographic element to my PhD project is the fact that without it this thesis would not

exist. As mentioned in Chapter 1, I reached a point during my PhD programme where I felt no longer able to continue due to the stress and emotional strain I was experiencing. During the time I was considering my decision to withdraw from the programme, I spoke with friends who referred to the cathartic value of writing about negative experiences. I decided to try to write about my experiences in short bursts initially to determine whether that cathartic value would enable me to resume and duly discovered that I was able to start writing my thesis again if I explored the experiences of my PhD project participants with my own. This motivation however does not diminish the importance of the other reasons I have cited for adding the autoethnographic element; it just represents the initial catalyst for my decision.

3.4 How the autoethnographic element was incorporated

In addition, a method of incorporating the data into the thesis had to be worked out so that the autoethnographic data complimented, supported or contrasted with the data gathered from the PhD project participants. For clarity and simplicity, I decided to incorporate the data gathered from my own experiences as a PhD student into the thesis in a similar form to the data gathered from the PhD project participants i.e., as single-spaced text with a single line border. This helps to indicate that it is a resource like the PhD project participant's interview extracts. However, to help distinguish it from the interview extracts it is headed 'reflective comment'. In addition to these reflective comments are extracts from my PhD journal, these are presented in the same format but headed 'PhD journal extract'.

The autoethnographic element of my project was analysed using the same thematic analysis method employed to analyse the interview transcript data. The PhD journal texts, emails and other sources were colour coded to identify themes and omissions then the Braun and Clarke (2006, pp. 77-101)'s six phase process applied. However, another layer was added to this process; once the data had been coded, it was read through to look for themes that correspond with the themes identified in the interviews with project participants. The themes from the participant interview data were then analysed to look for any correspondent themes in the autoethnographic element; thus, this phase was reciprocal

in nature. This cross-referencing between the two elements was carried out until I felt the analysis had reached a point where the main themes of the data as a whole were identified. This added phase helped to confirm the identification of emergent themes in both sets of data and added a layer of analysis that strengthened the validity of the themes. The reflective comments in the thesis are equivalent to the main body of text, the main difference being they are differentiated from the main text and formatted to show they reflect my personal experiences.

The autoethnographic element is used in the analysis to expand or help clarify the topic under discussion by adding context or perspective to the comments of PhD participants or by being the focal point of the topic which is then contextualised by examples from the PhD participants and other sources. Once all of the themes were identified, quotes, examples and extracts were chosen in the same way as they were chosen from the participant interviews. In other words, the autoethnographic data was selected to illustrate the topic at hand. For example, in Chapter 4, I will discuss PhD participant Matt's difficulties in adapting to changes in his physical abilities, and this was a theme that emerged in several of the interviews with the PhD project participants. Therefore, to provide extra context and illustrate how similar problems can have a different impact on each individual, I compared Matt's difficulties and the solutions available to him with my own. Although the challenges Matt faces are similar to mine, I do not have the option to change to a smaller version of my preferred instrument and despite the fact that there are electronic and bellows pipes, these instruments are not permitted in Highland piping competitions and do not provide a comparable experience when playing them in the way that moving between different saxophones can.

A consequence of adding data from my own experiences later in the PhD project was that major revisions to most of the chapters had to be made; this was done during the normal drafting of the chapters and although it made the drafting process more complex and arduous, I feel the inclusion of my own experiences made a significant improvement to the depth and range of the data. The autoethnographic element of the PhD project was useful in clarifying and contextualising much of the

data gathered from the PhD participant interviews and this was reciprocated in the examples provided in the autoethnographic element.

For the autoethnographic element, the data were collected predominantly from my PhD journal which was updated on a regular basis throughout the PhD project. The initial intention was to keep a record of my experiences as a PhD student whether they were good or bad, but the entries soon became almost exclusively negative with time due to the frequency of the barriers and attitudes I encountered and my increasing frustration and anger. Other sources of data for the autoethnographic element existed such as conversations with my wife who was my support assistant on campus and who also experienced the issues I encountered in the university. Following these conversations, I would compile notes and add these to my PhD journal for future reference.

Another source of data was my university email account as some of the negative incidents were discussed through this medium. Therefore, a folder was added to my account to be used exclusively for email conversations where the topic was an issue that I was experiencing. The majority of these emails were to my PhD supervisors, the Estates Department, and other administrators at the university.

The reflective comments and PhD journal extracts in this thesis were predominantly inserted to expand or help clarify the topic under discussion; they also give an insight into the significant difficulties that I encountered while working on this PhD project since this research does not stand isolated from the issues that it explores. Barriers and challenges have been encountered during the course of this PhD project that are similar to those of the research participants; therefore, the addition of the autoethnographic element provides an important layer to the research.

Sources of bias can be a concern when undertaking a qualitative research project and these may include the assumptions, perspective and familiarity of the researcher. For example, the interviewer may be familiar with the participant's community or share a common history. Conversely, they may be

unfamiliar with the subtleties of the participant's culture or have no experience of the participant's individual circumstances; both perspectives have their merits and shortcomings. Other sources of bias are: the gender or age of the interviewee and interviewer, and the presence of an interpreter can impact on communication as meanings can become lost in translation. However, in some situations a familiarity with the research subject can be advantageous. As the interviewer in this study, my close association with the world of disabled people proved to be more of an asset than a disadvantage as 'insider knowledge' provided me with the ability to customise questions to yield more focused and insightful questions as the interviews progressed. From this viewpoint, my closeness to the research subject can be likened to Heidegger's existential phenomenology which describes our 'inextricable link to the world in which we live and its impact on what it means to be human' (cited in Shaw, 2010, p.235). As Langdrige points out, bracketing can be very difficult to achieve (Langdrige, 2004, p.278) and, in this study, it seems reasonable to assume that bracketing would be even more difficult due to the numerous commonalities, close links and vested interest I have with the research subject. As described in Chapter 1, the experiences I had during the PhD project proved too intimately linked with the experiences of the PhD project participant's experiences and the data that was emerging from the analysis to enable any form of bracketing; in fact, I concluded that my own closeness to the topics being considered would enhance, clarify, and give added context to the points being made in the thesis.

3.5 Data collection

3.5.1 Participant Recruitment

My experiences in the music world have led me to question why I encountered so few disabled musicians. As a musician and wheelchair user, I wanted to understand why I was in such a minority and that my focus would be on people like myself. With that in mind I set out to find people who have a mobility impairment and engage in music making who would be willing to participate in this PhD project. My initial concern, given the fact that I had encountered no musicians with a mobility impairment throughout my career, was that I would find few or no people who fitted my initial recruitment criteria and who would help me to answer the research questions in my PhD project. This proved to be the case as, although my calls for participants were answered by eighteen people, only six fitted the criteria exactly, that being a person who;

- had a mobility impairment and engaged in some form of music making
- had experience of music performance or composition
- was willing to discuss issues that arise in relation to impairment and playing a musical instrument or singing
- was willing to reflect on the way they are perceived as musicians and how those perceptions impact on their lives
- had attended or have interacted with a music education establishment such as a college or music qualification body

I did not think six participants made a large enough sample to fully explore the issues at hand. There is conflicting advice on acceptable sample sizes for a qualitative research project: for example, Bernard (2000, p.178) suggests that most ethnographic studies should be based on interviews with thirty-sixty participants, while Kuzel recommends six to eight interviews for a homogeneous sample and twelve to twenty data sources “when looking for disconfirming evidence or trying to achieve maximum variation” (1992, p.41). Kvale however states that the number of interviews in common studies is approximately 15 plus or minus 10 because if the number of participants were too small, it may be difficult to generalize. Conversely, too many participants can make the process of collecting and analysing the data too time consuming (2007, p.43). Therefore, taking into account the difficulties in recruiting participants and the information I found in extant literature, I decided to include people with sensory impairments such as sight and hearing impairments during my search for participants I had

been made aware of some individuals with sensory impairments who were interested in becoming participants. This decision was made easier by the fact that I was experiencing issues with a progressive sight impairment myself.

Participants were sought through various sources such as disability forums, charities, personal contacts, musician's websites, musician's union, and arts organisations. Music therapists were considered as an avenue through which participants could be sought but it transpired that most music therapist's clients are people with learning disabilities and as such did not fit the requirements for this study. Once the responses to my calls for participants began to subside I examined the information provided by each of the respondents to ascertain their suitability as a PhD participant. As previously mentioned, my list of prospective participants levelled at 18 people who seemed suitable for this PhD project; however, 7 of these prospective participants were either judged to be unsuitable for a variety of reasons including their availability or issues with communication. One candidate lived in Australia and was not confident in their use of video conferencing applications such as Skype or FaceTime. In addition, some respondents withdrew voluntarily during the assessment stage for different reasons. This left a total of 11 participants who took part in the PhD project, 8 of whom were recruited from organisations that facilitate music engagement for people with impairments. These are all organisations with charitable status that specialise in facilitating access to training, adapted instruments, and performing opportunities for all levels of musical proficiency. The remaining 3 participants were recruited via an online disability research network.

3.5.2 Participant details

The table in figure 3.1 outlines relevant details of the 11 participants selected to take part in my PhD project. All names shown are pseudonyms to protect the identity of the individuals but the remaining information is factual;

Participant pseudonym	Age at time of interview	Instruments	Impairments	Music qualifications	Music education established attended	Notes
Abbie	20	Clarsach, Piano	V, GR, M (WU)	BA (Hon)	Music school, University	Attended different university for honours
Adam	17	Percussion	P, C	Standard grade	Mainstream Secondary School	
Carol	28	Viola, violin, recorder, piano, bassoon, flute	H, M (WU)	BA (Hon)	University	Attended various universities
Don	65	Voice, guitar, keyboard	Derm, M	Higher	College, Conservatoire	Did not finish degree course
Donna	40	Voice, guitar	M (WU)	N/A	Self-taught	
Emily	45	Voice, violin	P	N/A	Private tutor	
Martin	20	Percussion, guitar	H	Standard grade	Secondary school	Attended mainstream secondary then school for deaf people
Matt	75	Saxophone, clarinet, keyboard, cornet	M (WU)	Diploma	College	
Robert	19	Guitar, percussion, voice	M (WU)	Standard grade	College	Did not finish college course

Rose	27	Electronic instruments	CP, M (WU)	BA (Hon)	University	
Suzie	34	Voice, keyboard, piano	V	BA (Hon)	University	

Figure 3.1: Table of participants

Due to the shortage and specific requirements of the type of interview participant required for this research project, the interview process had to be considered and planned very carefully. A considerable proportion of the participants have multiple impairments, or their individual impairments give rise to symptoms that can inhibit speech, cognition and stamina. Consequently, many participants originally deemed suitable for the interview process were deselected, and choices and compromises had to be made regarding the remaining participants to ensure that interviewees were not stressed because of the interview process. Issues that arose during the recruitment phase were mostly to do with communication. Some participants speech was difficult to understand necessitating the presence of their personal assistant or relative to interpret their responses. Other participants required extra time to process the information and formulate their responses due to slower cognitive functioning such as perception, language processing, memory and attention span. These circumstances necessitated a flexible approach to the interviewing process and the main considerations in this regard were: the duration of the interview, the number of interviews with each participant, and the time span between interviews.

Following an initial assessment of the data gathered from the eleven interviews, one interview with each participant was deemed sufficient, especially when the limitations and health considerations of the participants and myself were considered. In addition to the aforementioned accommodations, participant number four, Rose, was forwarded a copy of the interview questions shown in Figure 3.1 two weeks prior to the interview in order to afford her sufficient time to consider and formulate her responses.

3.5.3 The interview process

My PhD project could be described as an attempt to understand human actions, which in this case are centred on behaviour towards and perceptions of disabled musicians along with the impact of these factors, was achieved through semi-structured interviews. Brewer argues that ‘The methods used must therefore permit access to people’s social meanings and activities and involve close association and familiarity with the social setting’ (Brewer, 2000, p.312) and Kvale suggests that ‘The semi-structured life-world interview seeks to obtain descriptions of the life-world of the interviewee with respect to interpreting the meaning of the described phenomenon’ (2007, p.2). For my PhD project therefore, the semi-structured life-world interviews Kvale describes were deemed the most appropriate method of accessing the disabled musician’s social meanings and activities through a close association and familiarity with the social setting that Brewer (2000, p.312) refers to.

Langdrige (2004, p.51) suggests that there are advantages and disadvantages to collecting data through interviews; for example, some individuals may be adversely influenced by the sex, ethnicity or culture of the interviewer. Furthermore, people can sometimes feel the need to present themselves in the best possible light, especially to those they perceive to be in a position of power. However, these interpersonal variables can be mitigated with the use of strategies, such as avoiding academic terms or developing a rapport with the interviewee. Langdrige also provides guidance for successful interviewing and lists three key techniques to help interviewees feel comfortable. These are:

- use of appropriate language
- neutrality
- confidentiality

If the participant feels at ease they are more likely to talk about the more intimate aspects of their lives. This was particularly important for the participants in this PhD project since the conversations usually centred on aspects of their impairments and their physical and mental well-being. I believe that being a disabled person was a bonus in this respect as most of the participants said that they felt that I would

understand what they were talking about and were able to say more about their issues than if talking to a non-disabled person. However, the impairments of the participants cover a wide range so there were times when I felt that I was not totally 'in tune' with the difficulties the participant was referring to, even although they may have felt this to be the case. For instance, Adam spoke at length about the bullying he was subjected to at school, but bullying is not a subject I have first-hand experience of, so I could not empathise with his feelings in the same way as I could with the participants who are wheelchair users when they spoke of their frustrations and anger in relation to attitudes and misconceptions.

A disadvantage that is often associated with semi-structured interviews is the possibility of veering off-topic, but this can often lead to unexpected and even richer data than was anticipated at the outset of the interview (Langdrige, 2004, p.50; Kvale, 2007, p.8). This was a common occurrence during the PhD project interviews but in the majority of cases these off-topic wanderings yielded excellent data that was still relevant to the focus of the PhD project. These off-topic discussions were the main reason why some of the interviews exceeded the anticipated time of one hour per interview as, even if the off-topic segment took some time, the PhD participant said they wanted to continue with the interview until the rest of the semi-structured questions had been discussed. The participants all seemed to have a strong desire to make the data as complete and rich as possible. Only on one occasion did a participant talk about something that did not relate directly to the research; Robert spoke for about ten minutes on the reasons why he decided to buy a new car. However, even that related to the PhD topic in that it provided some context for the importance he places on appropriate means of transport for someone who has his type of impairment. Therefore, although veering off-topic can be construed as a disadvantage, it can also be an advantage.

Among the strengths of gathering data through a qualitative approach is the closeness to the source of the data and the ability of the researcher to capture the individual's point of view (Denzin and Lincoln, 2011, p.7). This also applies to the semi-structured interview process as in this PhD project the

interviews generated over 70 thousand words of text that was suitable for analysis. This was due in part to the format of the interviews; as mentioned previously, the semi-structured format was chosen for the PhD project interviews as it offers a flexible method of data collection, if the participant veered off topic, there was scope to allow this. Although there were instances where the topic was not relevant to the PhD project, they were infrequent and outweighed by the instances where respondents provided data that was not anticipated but was useful. For example, PhD participant Adam was not asked to talk about bullying, but he spoke at length about the bullying he experienced at school and this prompted me to look again at the preceding interviews for any references to bullying by other participants. This revealed several instances where participants spoke either openly or more discretely about bullying and was consequently identified as a key theme and allocated a whole section in Chapter 6 of this thesis.

Despite the fact that the interviews in this PhD project were relaxed and flexible, semi-structured interviews still require that a schedule of a number of questions are asked during the interview in a predetermined order (Langdrige, 2004, p.50; Kvale, 2007, p.8) and this script was followed in the interviews for this PhD project. Figure 3.1 shows a copy of the script used in the interviews;

1. Tell me the story of your life as a musician e.g.:
How did you become interested in music?
How did you learn music?
What role does music play in your life?
- 2. What are the positive and negative aspects of your experience as a musician e.g.:**
What things have had a positive influence on your music making?
What things have had a negative influence on your music making?
- 3. How has music making-shaped the way you see yourself?**
- 4. How do you think music-making has shaped the way that other people see you?**
- 5. How has your relationship with music evolved over the years?**
- 6. How do you see your role in music now?**

Figure 3.2: Semi structured interview questions

Kvale (2007, p.8) suggests that adherence to the script will depend on the nature of the study and, although this list of questions was taken into each interview, the majority of interviews needed only the first question to be asked to initiate a discussion that covered most of the questions that followed. I felt that given the benefits of allowing the interviewee the freedom to venture off-topic, the best approach for my PhD project would be to follow their lead as long as they were speaking about something that was related to the aim of my PhD project. As it transpired, in most cases asking the participant to ‘tell me the story of your life as a musician’ was enough to illicit a large amount of data and took up the majority of the time allotted to each interview. Some of the other questions in the schedule were asked in interviews but these instances were infrequent as it was common for the participants to talk at length and pre-empt my questions without prompting. In fact, although one hour was the allotted duration of the interviews, many exceeded this allocation by a considerable margin, the Skype interview with Donna lasted almost two hours.

The initial plan for this PhD project was to rely on the data gathered from the interviews with the eleven participants. However, as the issues I encountered as a PhD student began to impact on my research, and I realised that in addition to the interview element of my project it would be necessary to add another dimension to the PhD project through the inclusion of an autoethnographic element, as discussed in Section 3.3. This element may be understood in the terms used by Langdrige who states that another element of ethnography is ‘the immersion of the researcher in a field setting’ (2004, p.308). Although Langdrige is referring to an element of ethnography, this phenomenon readily describes the role I ultimately played in the PhD project. My role in this PhD project began as a researcher who happened to also be a disabled musician, researching his own field, the world of disabled musicians. However, this eventually evolved into the role of researcher/participant because I was experiencing issues that were comparable with the experiences being recounted by the PhD participants.

Prior to the interview process I made myself familiar with the general guidance available on conducting interviews such as that provided by Langdrige (2004, p.50) and Kvale (2007, p.8) and despite being a disabled person myself, I also felt it prudent to familiarise myself with advice on interviewing disabled people specifically. However, literature on this specific area of research was not readily available so I turned to other sources and combined the guidance I found with my own knowledge to conduct the interviews in a manner that was both ethical and mindful of the interviewee's specific circumstances. Particularly useful were Mooney's considerations on 'Qualitative Interviewing with Vulnerable Populations: Ethical Considerations When Conducting Narrative Interviews with Young People with Cancer' (2014, pp.1-18), and 'Tips for interviewing people with disabilities' on the National Center on Disability and Journalism website (National Center on Disability and Journalism, 2017).

3.5.4 Difficulties encountered during the interview process

During the recruitment process, various difficulties were encountered which impeded progress. For example, some of the individuals contacted use assistive technology such as screen readers and voice recognition software to read and send emails and texts while others are assisted by a personal assistant or relative who reads and types the text for the participant. These specific requirements had a marked effect on the timescale of the recruitment process as some prospective participant's responses were delayed because they had to wait for their personal assistant or relative to become available to write a reply. This had the effect of slowing down the recruitment process considerably and made timetabling the meetings and interviews challenging.

An initial target of 16 face to face interviews was determined as this was considered an optimal number that would provide sufficient data to allow the identification of patterns across the data, while maintaining a sample size small enough to make the reading and rereading process manageable (Braun and Clarke, 2006, p.16). However, due to the scarcity of suitable participants and the restrictions imposed by the allotted timeframe of this PhD project, it became apparent that the initial target of 16

participants was unattainable. Following several calls for participants, emails to specific individuals, and communications with music and disability related organisations, only eight disabled musicians could be found who were based within a travelling distance that was feasible within the limitations set by both the participant's and my impairments. Consequently, prospective participants who were located further afield were contacted in order to augment the total number of participants. This raised the number of participants to eleven which falls within the guidelines set by Braun and Clarke as the requisite number for a study undertaken by a UK doctoral researcher.

Recruiting participants from further afield meant that communication would have to be made using some form of technology. Following extensive research, it was determined that internet video applications such as Skype and FaceTime were the best medium for interviewing participants as this afforded several advantages over using the telephone. The main advantage was my ability to see the participant which meant that any visual cues such as hand gestures or facial expressions could be noted. However, although these applications worked reasonably well, they also had drawbacks. For example, some participants did not have Skype or FaceTime installed on any of their devices and were not able or willing to install one. Further, some participants were not familiar with the operation of these applications and it proved too difficult to provide them with appropriate instruction given their impairments and my limited knowledge. It also became apparent during the recruitment process that due to their individual impairment, some prospective participants were unable to use Skype or FaceTime. Specific issues arose in the case of blind people, deaf people, and people with speech limitations due to the limitations of the technology and the limitations resulting from their impairments. Interviewing via Skype or FaceTime also required the installation of additional software to record the interviews as this facility was not available during the period the interviews were undertaken. Subsequent research also revealed the fact that there were more recording software packages available for Skype than for FaceTime at that time, so it was decided that where possible, Skype would be used for the interviews. However, the software available for recording Skype conversations also had

drawbacks as not all were stable and reliable. Consequently, there was an initial period of trial and error to ensure that a stable, high quality recording programme was chosen.

In addition to communication difficulties when organising the interviews, another factor that had to be considered was fatigue on the part of both interviewer and interviewee. Some impairments are accompanied by excessive fatigue caused by the nature of the disability or medication; thus, it was decided therefore to carefully consider the duration and frequency of the interviews with each participant and adapted these aspects to their specific situation. This was also governed by my own issues with fatigue and ability to concentrate. These are brought about by my impairment which gives rise to chronic pain coupled with effects from pain management medication. It was decided therefore to limit each interview to a maximum of 1 hour and limit the number of interviews with each person to 2 in one week. For individuals who preferred shorter interview sessions the interview duration was reduced to 45 minutes and a follow up interview scheduled a week later.

Although most prospective participants were happy to take part in the study, one or two had reservations. One prospective participant seemed very keen to begin with but as the method of conducting the interview was discussed (in this case via Skype) she became increasingly uncomfortable with her decision to participate. It transpired that this was apparently due to her fear of being identified through the visual interface of Skype. She described herself as a 'controversial disability activist' and preferred to be interviewed by audio means only in case government officials identified her. Therefore, I decided in this instance that it would not be prudent to proceed with the interview given the participant's reservations; these circumstances would not be conducive to a relaxed and productive interview. Another participant wanted to know before agreeing to participate, how the information would be used and stored. After a brief explanation of the purpose of the study and the security of the data, he felt reassured and agreed to participate.

3.5.5 Transcription method

This section describes the various methods and equipment used during the data collection and analysis process. All the face-to-face interviews were recorded on two devices, an Olympus Digital Recorder and a LiveScribe Smart Pen and Notebook, which was also used to take notes during the interviews. The LiveScribe Pen and Notebook enabled me to review the interview more efficiently as it provided the facility to move to specific passages or sentences of the recording to coordinate the notes. All files are stored on two USB flash drives and the university DataStore facility. As both the interview recordings and the interview transcriptions contained sensitive and personal information, I ensured that all personal data was stored on devices or storage facilities that were encrypted.

Once the recordings were checked, copies were converted from mp3 format into Audacity Project Files (AUP) using Audacity Sound Editor. This specific playback software package was chosen as it had the facility to enlarge the playback position indicator, enabling me to follow and adjust the playback of the recording; this proved useful given the issues related to my sight impairment. Audacity also afforded the ability to slow the speed of the recording without altering the pitch of the voices which was particularly useful if the interviewee spoke quickly or their speech was unclear. It also provided a clear visual representation of the speech patterns of the interviewed and interviewee showing the current position in the recording and making navigation through the recordings easier. To write and edit the text, the Audacity files and Word documents were displayed on two large monitors, this viewing method provided the facility to enlarge and alter the text to suit any limitations resulting from my sight impairment.

The mp3 recordings were played back via headphones and the computer and monitors were located in my home study; this offered the facility to listen to the recordings and write the transcriptions in complete privacy.

3.5.6 Transcription process

Once all the relevant files were in place on the computer, the recording of the interview was listened to several times to enable me to become familiar with the content. Each mp3 file was opened in turn in Audacity and the transcription was typed in small sections as the recording was played back and the wave pattern of the speech was followed. This method allowed easy navigation through the recording and skip or rewind to specific points; it also meant that any parts that proved difficult to hear or understand could be played several times or slowed down using the tempo tool in Audacity. It was also possible, to some extent, to enhance speech on the recording at points where there was background noise.

Each interview was transcribed into a single Microsoft Word document containing information on the interview such as location of the interview, some relevant details of the participant and the recording method e.g. Skype or digital recorders. Any issues encountered during the interview process were also included along with a participant overview, interviewer's observations and a reflective commentary.

Interviewer text was coloured brown and interviewee text was coloured black; this helped to differentiate between the two speakers. In the case of Rose's interview her personal assistant's words were also transcribed so these were typed in green font.

3.5.7 Transcription Coding symbols

To help with the analytical process of finding and denoting themes, I developed a method of coding which was used to denote distinct types of speech, overlaps in the conversation and non-speech elements such as sighs, pauses or laughter. Figure 3.2 shows the symbols used;

Symbol	Example	Explanation
~	~Don	name change to preserve anonymity (tilde)
[quite a [while Mo: [yeah	Left brackets indicate the point at which a current speaker's talk is overlapped by another's talk.
]	and I thought] Mo: you said]	Right brackets indicate the point at which two overlapping utterances end.

#	###	Unintelligible, one symbol per syllable
#	#you're #kidding	transcribed words are uncertain
(.)	to get (.) treatment	A dot in parentheses indicates a short pause (less than 1 second).
(...)	Yes (...) yeah	Numbers in parentheses indicate longer pause (over 1 second)
_____	What's <u>up</u> ?	Underscoring indicates some form of stress via pitch and/or amplitude.
::	O:kay?	Colons indicate prolongation of the immediately-prior sound. The length of the row of colons indicates the length of the prolongation.
WORD	I've got ENOUGH TO WORRY ABOUT	Capitals, except at the beginnings of lines, indicate especially loud sounds relative to the surrounding talk.
(H)	I feel that (H)	audible inhalation
(Hx)	I feel that (Hx)	audible exhalation
(word)	Would you see (there) anything positive	Parenthesized words are possible hearings.
(())	confirm that ((continues))	analyst comment on any topic
-	talking about- uh	A hyphen after a word or part of a word indicates a cut-off or self-interruption, often done with a glottal or dental stop.
*	And then *I *remember	Words marked with an asterisk are markedly quiet or soft.
><	>we were just<	"Greater than" and "less than" carrots in this order indicate that the talk between them is rushed or compressed.
<>	>	"Less than" and "greater than" carrots in this order indicate that the talk between them is markedly slow.
↓ or ↑	↓are you↓	The up and down arrows mark sharp rises or falls in pitch or may mark a whole shift or resetting of the pitch.
#	# it was in the	Indicates a rasping or 'creaky' voice quality.
£	£ it was so	Indicates the speaker is smiling while speaking.
@	@	Marks laughter
@word	@you're @kidding	symbol marks laughter during word
(----)	It was (----) the shelf	Marks break in signal resulting in loss of sound in Skype

Figure 3.3 method of coding

Having this coding system allowed me to recall specific instances where I felt the PhD participant was communicating an emotion that was important to the analysis. For example, when participant Carol was asked if she wanted to add something that had not been covered in the interview she said; ‘I don’t want people to f- not that I don’t want people to find out, but I sort of (.) I’m worried about what people will think if you’re a deaf musician, who wants a deaf music teacher, she can’t (...). Ok, tell me more! Well it’s just the perception of the disability that it’s all consuming that you can hear nothing you know and eh that then you can’t possibly relate to music because you can’t hear it so you know, how can I play something you know, how can- how can I listen to somebody play something and have anything whatsoever to say about that’. The (.) symbol shows that Carol hesitated before saying she is worried, I interpreted this to mean she was thinking of the best way to describe her feelings and that this showed she felt it was important that I understood exactly how she felt. The symbol (...) shows that Carol paused for more than a few seconds before I asked her to expand on her comment. At the time, I did not think Carol was going to say what she believed people think about a deaf music teacher, so I prompted her to continue in order to learn more about her feelings. When doing the analysis, there was a possibility that I may have misinterpreted this as me interrupting rather than Carol just stopping mid-sentence and missed the significance of this piece of text. The underlining shows that Carol emphasised the words ‘nothing’ and ‘anything’. These are words that demonstrate Carol’s strength of feeling and may have gone unnoticed during the analysis without the symbols as prompts. Therefore, the use of symbols in the transcriptions made it easier for me to interpret the text during analysis by preserving the context of the interviews and capturing the emotional and interactive dynamics of the dialogue.

3.6 Method of analysis

3.6.1 Analysis overview

As the focus of this research project is on human experience, behaviour and emotions in a social and cultural context, I decided to use a qualitative research method as it ‘recognises the subjective

experiences of participants' and 'may produce unexpected insights about human nature' (Langdrige, 2004, p.15). My PhD project examined a specific area of interest to establish general conclusions from multiple observations of various phenomena; this method is consistent with an inductive approach which is one of the main characteristics of qualitative research methods (Langdrige, 2004, P.15). Qualitative research refers to a range of methodological approaches which aim to generate an in-depth and interpreted understanding of the social world by learning about people's social and material circumstances, their experiences, perspectives, and histories (Kemparaj and Chavan, 2013, p.1). Qualitative research is primarily exploratory research that generally follows inductive reasoning to develop a theory; it is usually used to discover trends in thought and opinions and look deeper into the problem. Common data collection methods used in a qualitative approach are unstructured or semi-structured techniques such as focus groups, individual interviews, and participation or observations, the sample size is usually small, and respondents are selected to fulfil a given quota. In inductive reasoning, the researcher begins with specific observations then attempts to detect patterns and regularities to develop hypotheses that can be explored with a view to generating conclusions or theories. While deductive reasoning usually has a narrower focus, and is concerned with testing or confirming hypotheses, inductive reasoning is a more open-ended and exploratory method of analysis (Thorne, 2000, p.68).

Quantitative researchers argue that the purpose of science is to uncover truths and to use scientific methods to establish a fuller understanding of reality (Thorne, 2000, p.68). However, most qualitative researchers agree that 'the relevant reality as far as human experience is concerned is that which takes place in subjective experience, in social context, and in historical time' (Thorne, 2000, p.68). These types of human experiences feature prominently in studies related to physical impairment and identity and as they are unique to the individual, this inductive research approach was deemed the most suitable as it would provide an efficient and rigorous method of examining accounts of the individual experiences of participants during the preliminary stages of the research project. The inductive method

begins the investigation at the individual level with people and the accounts of their unique experiences, it then moves upward through the stages of analysis towards a general statement. This provides a broad range of subject matter, some of which may not have been considered or may have been missed if a different research method had been adopted.

As described in Section 3.5, one of my chosen methods of data collection was semi-structured interviews. To ensure robustness of analysis, all of the transcripts from these interviews were submitted to both supervisors and the method of analysis and coding was discussed and challenged. My decision to employ the framework recommended by Braun and Clarke (2008, pp.77-101) and the method of coding was discussed and approved by my supervisors at that time along with the use of thematic analysis over alternative methods such as Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) and Grounded Theory. These factors were discussed and monitored by my supervisors throughout the data collection and analysis phases of my PhD project.

3.6.2 Thematic analysis

Thematic analysis is an accessible and theoretically flexible approach to analysing qualitative data. Although it sometimes referred to as a tool for use across different methods and not a method as such, Braun and Clarke argue that it warrants classification as a method in its own right (2008, p.77). Qualitative analytic methods can be divided into two categories. The first category includes methods that are either linked to or originate from, a theoretical or epistemological base. Some of these methods such as conversation analysis (CA) and interpretative phenomenological analysis (IPA) are relatively restrictive in how the method is applied, the analysis being guided by a detailed formula. Other methods in this category such as grounded theory, discourse analysis or narrative analysis have different versions that have emerged from within the same broad theoretical framework (Braun and Clarke, 2008, p.78). The second category consists of methods that can be applied across various theoretical and epistemological approaches as they are typically independent of theory and epistemology. Thematic analysis belongs in this category, and by virtue of its theoretical freedom, it

provides a flexible and useful research tool, which can potentially provide a rich and detailed, yet complex, account of data (Braun and Clarke, 2008, p.78). Furthermore, because thematic analysis is different from other analytic methods such as IPA and grounded theory in that it is not linked to any pre-existing theoretical framework, it can be utilised within a variety of different theoretical frameworks (Braun and Clarke, 2006, p.81).

Thematic analysis is a good method for identifying, analysing and reporting patterns (themes) within data, its basic function is to organise and describe data in rich detail (Braun and Clarke, 2006, P.78). However, it often continues beyond this, and interprets various other aspects of the research topic. Because thematic analysis is simple to use, it is particularly appropriate for researchers new to qualitative analysis and it provides flexibility in the choice of theoretical framework. In addition to these advantages thematic analysis can be used to produce qualitative analyses suited to informing policy development, it can generate unanticipated insights, and it allows for social as well as psychological interpretations of data (Braun and Clarke, 2006, p.97). One of the reported disadvantages of thematic analysis is the fact that it requires an existing theoretical framework to confirm analytic claims. Therefore, to address this concern, the 6-phase guide to performing thematic analysis presented by Braun and Clarke was followed as this has been specially developed for use with thematic analysis.

3.6.3 Codifying and sorting themes

Braun and Clarke suggest that ‘thematic analysis is a poorly demarcated, rarely acknowledged, yet widely used qualitative analytic method’ and that it can provide ‘an accessible and theoretically flexible approach to analysing qualitative data’ (2006, p.2). The flexible nature of thematic analysis is often seen as a benefit but unless it is used in conjunction with a solid theoretical framework this flexibility might prove detrimental. For this reason, the six-step guide set out by Braun and Clarke (2006, pp. 77-101) was used in the data analysis phase of this study as this was formulated specifically to assist with the thematic analysis method. Figure 3.3 summarises the six phases of analysis, but it is

important to note that Braun and Clarke regard this as a recursive process, the steps summarised do not necessarily have to be followed in sequence (2006, p.16). They also assert that these are guidelines, not rules, so they will need to be applied in such a way that they fit well with both the research question(s) and data.

Phase	Description
1. Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Figure 3.4: 6 phases of thematic analysis (adapted from Braun and Clarke, 2006, pp.87-93)

Some researchers argue that transcribing is ‘a key phase of data analysis within interpretative qualitative methodology’ (Bird, 2005, p.226) and, as such, is an interpretive act in itself. Additionally, Braun and Clarke argue that the time and close attention spent in transcription results in a greater depth of knowledge and familiarity with the data that would be difficult to replicate otherwise (2008, p.88). It is also the case that decisions made during transcription on elements such as punctuation can alter the meaning of data. For these reason, all of the interviews were recorded and transcribed by me. As interviewer and transcriber of all the interviews, I was in an excellent position to understand the context and nuances of the dialogue in the transcriptions. However, in order to ensure a comprehensive

familiarisation with the data the recordings were listened to several times before, during and after the transcription process and the transcripts were also read and re-read several times.

3.6.4 Generating initial codes

Phase 2 began once all the data were read and I was confident that I was fully familiar with the data. Once this was achieved initial codes were then produced from the data. Codes can be described as methods of identifying elements of the data that is of particular interest to the researcher (Braun and Clarke, 2008, p.88) and are typically topics that appeared to be particularly important to the participants. The generation of these codes was accomplished by making considered assessments of what seem to be the areas that participants felt most strongly about, that were discussed by the more than one participant, or were felt to be of relevance to the study. To do this each transcription was read in turn and any topic that appeared to generate strong feelings, was spoken about at length, or was referred to on more than one occasion was noted and searched for in the rest of the transcriptions. Although many of the codes identified were chosen because they are mentioned by several participants, others were chosen because a participant was very vociferous or emotional when talking about the subject.

During the data analysis process, the code identification process was informed constantly by the guidelines set out in the theoretical framework. All opinions, feelings and preconceptions of the researcher were monitored and assessed during the analysis process via the reflective diary in order to mitigate them as much as possible. Being a disabled musician myself, I can identify and empathise with the feelings and opinions of many, if not all of the participants when they referred to issues relating to disability and music participation.

3.6.5 Searching for and identifying themes

The anthropologist Morris Opler (1945, p198) describes the identification of themes as a crucial phase in the analysis of cultures. Opler identifies three main principles in relation to the analysis of themes.

First, themes are only discoverable through the manifestation of expressions in data. Second, some expressions of a theme are self-evident, but others are subtler, and lastly that cultural systems comprise sets of interrelated themes. Opler states that the importance of any theme is related to how often it appears and its prevalence across different cultural beliefs and practices. He also suggests that people's reaction to the contravention of a theme, and to what extent specific contexts impact on the force and variety of a theme's expression, are also indicators of a theme's significance.

Themes can originate from data (an inductive approach), and from a prior theoretical understanding of the phenomenon being studied (an a priori, or deductive approach). A priori themes come from characteristics of the phenomena being studied and from definitions found in literature reviews. They also come from local constructs and from researcher's values, theoretical orientations, and personal experiences; however, in general themes are generated from data (Ryan and Bernard, 2003, p.88).

One of the main methods used in this project to identify themes involved cutting and sorting quotes or expressions that seemed important and arranging these quotes/expressions into piles of things that match (Lincoln and Guba 1985, pp.347–351). There are many different ways of doing this. The quotes can be written on cards or sheets of paper and referenced. The quotes can then be spread out on a large surface such as a table and sorted into stacks containing similar quotes. This was the technique I used at the beginning of the analysis but because of my sight impairment I had to make the cards very large to enable me to read the text. This made the process unwieldy and awkward, so I had to devise a different way of applying this method. Consequently, I decided to colour code each quote in the transcripts using Microsoft Word (see Figure 3.4) and cut and paste them into new Word documents that had been given a title that reflected the topic of the emerging theme. This proved to be a relatively efficient method which addressed the physical problems posed by using cards.

Repetitions are another indicator of potential themes and subthemes. In the interview with PhD participant Carol it is noticeable that throughout the interview she frequently returns to the topic of her

competence as a musician and gauges her ability by comparison with other musicians. Carol referred again and again to ideas related to her level of ability and the ability of others; thus, it can therefore be concluded that for Carol these ideas are important areas of concern. To help understand how these ideas relate to each other, the interviewee's verbatim expressions, in this case Carol's, were gathered onto one document along with researcher's notes and scrutinised to identify common concepts with the view that the more the same concept occurs in the text, the greater the possibility that it is a theme.

In addition to theme identification techniques, omissions from the discourse can also indicate the presence of a potential theme. For example, during PhD participant Carol's interview, she failed to mention the fact that she was a wheelchair user, so I asked her in a later email why she did not mention being a wheelchair user suspecting that she may have been avoiding the topic. It transpired however that Carol believed that being a wheelchair user was less of an issue for her than her problems with fatigue. Therefore, omissions from texts may not be the result of avoidance, but are what Spradley (1979, pp.57–58) describes as abbreviating, omitting information that everyone knows or in this case, the speaker does not believe it to be as important an issue as one they would prefer to discuss. However, it can be difficult to determine whether the topic has been deliberately avoided or that the speaker just assumed the listener was already familiar with the topic.

So, you finished your music degree at Niles University? Yes, it's a complex route, I started in music then I did an education degree in the middle, then I did French and Chinese and then I finished it with music @@. **Well, that's quite an eclectic mix, that's good! @@.** Ok, so after you got your degree in music, eh, what did you go on to do after that? Em that's very recent that I've- finally finished that em so I've done private teaching a:nd eh and that's pretty much as far as I've got to. That's us up to date. **So, sorry to harp on about the highs and lows again but could you tell me what you think are the things that have played a part in shaping your journey through music?** Eh, it's always been this time thing you know, that everything has to be full-time yea, huge time commitments. There is not a conservatoire that offers a part-time course eh at undergraduate level, e:m and I've tried to get permission to do my teaching placement part-time and the- they gave it after eh (.) very close to court action really, a:nd eh then didn't quite sort of follow through on it actually being part-time. Then there was the government requirements which were full-time agai:n and- so that is the repeated barrier for me in- in progressing is that you have to be capable of run- and particularly in music courses. They want to include non-music students in things like orchestra and choir and whatever, so

you can have a nine o'clock lecture and choir at eight o'clock at night ok. So, **the days are just ridiculously massive.** Em, so **that's got in my way over and over and over and over again** and getting to that point with Niles University where they said **'yea you can come and do as much or as little as- as you want to do in order to qualify. If you want to do two afternoons a week we'll work round that, and that was so important right**

Figure 3.5: interview extract with colour coding to identify emerging themes

Once all data were initially coded and collated, the focus of the analysis was turned from the codes to the wider ranging category of themes. This began with a consideration of how the initial codes could be combined to form an overarching theme by classifying them into potential themes and collating all the appropriate coded data extracts within these themes. A method of visualisation was devised whereby themes could be easily identified; this took the form of a chart listing the codes which were colour coded to make the identification process as simple as possible to accommodate my sight impairment. Figure 3.4 is an extract from an interview transcript showing how different text colours were used to help identify themes.

3.6.6 Reviewing themes

Phase 4 involved the refinement of the candidate themes once they were assembled. During this phase, some candidate themes were deemed not to be themes because there was not enough data to support them or the data are too disparate. Candidate themes were also reduced because it was possible to merge them with one or more other candidate themes. Two levels of reviewing and refining the themes were undertaken in this phase. The first level involved reading all the collated extracts for each theme and thinking about whether they form a meaningful pattern. If the candidate themes appear to form a meaningful pattern, the second level of this phase was initiated. If the candidate themes did not fit into a meaningful pattern, the theme itself was considered to establish whether it was the problem, or whether some of the data extracts within it did not fit within the theme. In this scenario, the theme was reworked and either a new theme was created, or the theme was discarded. Level two of this phase comprised of a similar process but was applied to the entire data set. In this phase, the entire data set

was reread to ascertain whether the themes ‘work’ in relation to the data set as a whole and to code any additional data that may have been missed during the earlier stages of the coding.

3.6.7 Defining and naming themes

In phase 5, the themes were further refined to the point where they could be used in the analysis. Each theme was considered in relation to how it fitted into the general picture that the analysis of the data shows in relation to the research questions, and to minimise any overlap between themes. It was at this point that the names of the themes were established for the final analysis. In this PhD project, four overarching themes were identified which correlate to the following research questions:

- 1. ‘How is impairment commonly understood by others and how do these perceptions impact on disabled musicians?’**
- 2. ‘How do individual attitudes and perceptions of disabled people manifest and how do they impact on the lives of disabled musicians?’**
- 3. What is institutional discrimination and how does it impact on the lived experiences of disabled musicians?**
- 4. How effective are reasonable adjustments at combating institutional discrimination?**

3.6.8 Producing the report

Phase 6 was done after a set of fully worked-out themes was established and includes the final analysis and write-up of the PhD project. During this phase, examples that capture the essence of the point being made were chosen to illustrate the themes that emerged. Extracts from the PhD project interviews and a PhD journal that was written during the course of the project were chosen along with reflective comments to help illustrate the story being told about the data, and the analytic narrative was constructed to give a clear and concise description of the data and make an argument in relation to each of the research questions.

3.7 Ethics

3.7.1 Ethical consideration related to PhD project participants

Prior to the commencement of this PhD project, I completed the initial self-assessment ethical checklist as required by the College of Humanities and Social Sciences. This was completed under the guidance of the principal supervisor of my project at that time and as no major issues were evident, ethical approval was granted by the Reid School of Music. In any type of research there are many ethical factors that must be taken into consideration before conducting the study and The Economic and Social Research Council (ESRC) lists six key principals that it recommends are addressed;

1. Research should be designed, reviewed and undertaken to ensure integrity, quality and transparency.
2. Research staff and participants must normally be informed fully about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks, if any, are involved. Some variation is allowed in very specific research contexts for which detailed guidance is provided in Section 2.
3. The confidentiality of information supplied by research participants and the anonymity of respondents must be respected.
4. Research participants must take part voluntarily, free from any coercion.
5. Harm to research participants and researchers must be avoided in all instances.
6. The independence of research must be clear, and any conflicts of interest or partiality must be explicit.

(ESRC Framework for Research Ethics (FRE) 2010, p.2)

During the course of this PhD project, these principals were followed as far as possible with particular attention paid to the safety and anonymity of the participants. This was achieved by allotting a pseudonym to each participant and changing names, locations and any references that may identify the participant or other parties in the thesis. Figure 3.6 is screenshot of the email sent to prospective participants which outlines the purpose of the PhD project and gives an indication of the ethical procedure;

PhD research project

In this research project I hope to address the overarching question 'why are there so few disabled musicians?' I'm a musician and a wheelchair user and have personal experience of the issues faced by disabled musicians but I'd like to try to understand these issues from the perspective of other disabled musicians in order to try to understand what the main barriers to music participation are and how they might be addressed.

In order to focus my research I've decided to concentrate on musicians who have a physical impairment such as those who are wheelchair users, people with a sight or hearing impairment, amputees etc. However participants don't have to be professional musicians or perform at a high level, all skill levels are relevant to the study.

The participants will be interviewed either in person or via Skype or FaceTime. Interviews should last approximately 1 hour and will be recorded (audio only) but will be as relaxed as possible, it won't be a question and answer session, more a chat about the lived experiences of the interviewee.

Participants identity will be protected and all information will be handled ethically and with sensitivity under the guidelines of the College of Humanities and Social Sciences (University of Edinburgh) Code of Research Ethics.

If you would like more information regarding the project please feel free to contact me at the email address given below,

Regards, George

--

George Low, PhD researcher
Institute for Music in Human and Social Development
Room 6.10, Dugald Stewart Building
3 Charles Street
Edinburgh
Tel: 07473128935
Email: george.low@ed.ac.uk

Figure 3.6: email to participants

Any personal details of the PhD project participants have been stored on the University of Edinburgh's secure DataStore facility and an encrypted USB storage device. Once the PhD project is finalised this information will be deleted apart from contact details.

After consent was given by the Reid School of Music, each participant candidate was sent an email inviting them to take part in the project. Included in these emails the prospective participants were reminded of the purpose of the project, the ethical procedure, and each individual was asked how they would like to proceed. For example, they were asked whether they had any specific issues they would like to discuss before taking part, if there was any topic they did not want to discuss, and if they were happy to discuss their impairment and its effects. The uniqueness of each candidate and their particular circumstances meant that these emails had to be tailored to suit the individual circumstances of the candidate. Each candidate was informed that they were not obliged to discuss anything during their interviews and if they felt uncomfortable in any way they could terminate the interview at any time

without explanation. The candidates were also informed that they could withdraw any data relating to them from the project at any point during or after the interview. All candidates were at this stage informed that their discourse may be used verbatim, but they would be anonymised and would only be referred to using pseudonyms; they were also informed on how the data would be used in the future.

Immediately prior to and following the interviews, I recounted this information to each participant and told them that the information they had given, the notes taken, and the recordings made could all be deleted at any point should they wish. All participants stated that they wished to proceed and were happy for all of their data to be used in the project.

Contact details of both of my supervisors were supplied to each participant in the event that they required further information on the project. None of the participants contacted the supervisors at any point or requested any further information. However, some participants requested the outcome of the project to be passed to them so upon completion, an electronic copy of the thesis will be emailed to those participants; feedback to all participants will also be provided by email.

3.7.2 Ethical considerations related to individuals discussed in Research Journal extracts

The autoethnographic component of my PhD project presented significant difficulties regarding the anonymity of individuals mentioned in my Research Journal and my own life experiences. From the moment I decided to incorporate elements from my own experiences as a disabled student and musician, I was determined to show how the attitudes and behaviour of specific individuals impacted on my time at university. An important aspect of the discussion on the university members of staff, and their role in my journey through my PhD project, is the seniority of the staff involved; many of these staff members held very senior positions in the university, both in the academic and the administration side of university management. As such, these individuals were among the few people who could influence policy and practices that impacted on my life as a disabled student. I felt that

pointing out the seniority and influence of these individuals added to the power of my argument and excluding this information would reduce the significance of their role in the eyes of the reader.

In earlier drafts I revealed the job title of particular individuals to emphasis their role in my story; however, upon reflection I have decided to alter this thesis so that these individuals cannot be identified through their job title and the time they were employed in that role. This is not only to protect the individuals involved, but also to ensure I do not contravene any laws regarding defamation. My PhD thesis is subject to Scots law where defamation, also known elsewhere as libel or slander, is described as ‘the delict (i.e. wrongdoing) of defamation occurs when a person makes a communication that contains a damaging and untrue imputation against the reputation of another person’ (Scottish Government, 2011, p.11).

Towards the end of my time as a PhD student, I decided to take out an official complaint against the University of Edinburgh. Whilst my complaint was partially upheld, I believe it is in the best interest of all parties concerned to adhere to ethical principles such as anonymity; therefore, in the interest of avoiding unnecessary litigation or ‘naming and shaming’ anyone, I decided to anonymise those involved as much as possible while retaining as much of the impact of their actions as possible.

In addition to the university staff members discussed in my thesis I also refer to judges and tutors in the world of competitive piping. As with the university staff I have anonymised these individuals and avoided including any information that might lead to identification. The information provided, as in that provided in relation to university staff, is all true; again, however, I have avoided the possibility of defamation, even though in this case the tutor referred to is now deceased as is the senior judge he was conversing with on the phone. In Scotland, it is not possible to bring a defamation action on behalf of a deceased person (Scottish Government, 2011, p.8), but I felt it would be appropriate to avoid damaging the reputation of the individuals involved given their high status in the piping community and to avoid distressing any surviving relatives. In addition to the aforementioned measures to

anonymise individuals in the piping world, it must also be stated that I had many piping tutors during my career as a competing piper, all of whom are deceased. My time as a competing piper was from the 1967 until 2002, and the majority of people who were piping tutors at that time are now deceased; this adds to the anonymity of all of the individuals referred to in this thesis.

3.8 Reflexivity

As a disabled person writing on disability objectivity was something that was not possible while working on this PhD project. Given the nature of the data collection methods and the fact that my personal experiences as a PhD student are an integral part of this PhD project, I believe it is important that my own views and prejudices are transparent throughout this thesis. As a disabled person, I encounter constant reminders of the discrimination and prejudice experienced by disabled people. Interaction with others usually results in comments on my impairment, or some reference to disability such as 'what happened to you?' or 'it must be hard for you'. In this PhD project, I had a dual role as both researcher and instrument of research, I was both observer and participant at the same time. Therefore, I brought with me what the PhD project participant Suzie refers to as 'baggage' to the research field.

The baggage I refer to is the product of both my own personal experiences of daily life as a disabled person and experiences gained from interaction with other disabled and non-disabled people. I am subject to discrimination and prejudice and seen and experienced the inequalities that disabled people face. This does not mean that my experiences are exactly the same as those of the PhD participants, or that I have a special insight that a non-disabled person is not able to access. That assertion would suggest that for this type of research disability is a prerequisite which is not the case. My experiences as a disabled person are unique to me despite the things I may have in common with other wheelchair users. For example, I am a white, Scottish male with impairments that were acquired between the ages of thirty and fifty and a background in public service and traditional music; PhD participant Donna is a formerly female transsexual with a background in disability activism, and we have very little in

common in our life experiences apart from being labelled as disabled people. However, it must also be pointed out that being a disabled person did impact on this project and the interplay between the participants and myself as the researcher, especially during the interviews as some of the PhD participants mentioned that they felt more comfortable speaking to someone who has a degree of empathy with their particular circumstances. Additionally, were it not for the fact that I am a disabled person, I do not believe I would have been inspired to engage in this research to begin with.

However, as argued by Watson (2001, p.94) 'there is also a downside to researching what some may see as shared social experiences'. For example, I did encounter situations where the PhD participant assumed that I knew certain facts and at some points even said things like 'people like us' or 'you'll know what I'm talking about'. While I am familiar with many of the problems the participants describe in their interviews, I also found that some of the participants did not fully explain some issues or situations because they assumed I was already familiar with them. However, all of these interpretations and considerations of the relationship between the participants, the PhD project, and myself was, and still is, being used reflexively.

3.9 Conclusion

This chapter has presented the methods adopted to gather and analyse the data used as the focus of this PhD project. The experiences of the PhD project participants have yielded a wealth of data that in isolation could and may provide material for future research projects and this is also the case for my own experiences as a PhD student. However, although analysing the full wealth of the data gathered is beyond scope of this PhD project, the breadth of the data has allowed me to carefully select extracts and examples that illustrate the challenges disabled musicians and music students face. The initial decision to use thematic analysis as the method of choice made incorporating the autoethnographic element less difficult than would have been the case if another method had been chosen. For example, Interpretative Phenomenological Analysis recommends the bracketing of the researcher's

preconceptions and perspectives from the research and that would not have been possible with the inclusion of the autoethnographic element of the PhD project.

The next chapter marks the start of the analysis and findings component of this thesis which comprises three chapters that present the data and analysis that addresses the five research questions:

Question 1: How is impairment understood and how does this understanding impact on disabled people as they engage in music making?

Question 2: How do disabled musicians meet the challenges that arise when impairment impedes their ability to play their favoured instrument?

Question 3: How does interpersonal interaction impact on the lived experiences of disabled musicians?

Question 4: How do disabled musicians experience institutional discrimination?

Question 5: How effective are reasonable adjustments at combating institutional discrimination?

CHAPTER 4: ‘YOU CAN’T PUT A NYLON STRING CLASSICAL GUITAR IN FRONT OF A ROCK BAND AND EXPECT TO BE HEARD’: THE CHALLENGES OF HARMONISING MUSIC AND IMPAIRMENT

4.1 Perceptions of impairment and their impact on disabled musicians

4.1.1 Introduction

This chapter focuses on two key aspects that influence the lives of disabled musicians; how disabled people come to be regarded in respect to musical aptitude, and the devices disabled musicians employ to meet the challenges of playing a musical instrument. As such this chapter differs from the following two data chapters which focus on the interpersonal aspect of life as a disabled musician, and the experiences disabled people have as they work towards a music qualification via music education institutions.

Challenges for disabled people come in different forms, but two main areas of concern are referred to by participants during the PhD project interviews; the attitudes and perceptions of others regarding their impairments and the physical implications their impairments had on their ability to play, sing or compose. In Chapter 2 of this thesis, the affirmation model of disability was explored and the negative way in which disabled people and impairments are often perceived is highlighted as a major challenge for disabled people (Cameron, 2014, p.6). Therefore, this chapter focuses on impairment from two perspectives; the way impairment and its effects are perceived by others, and the way impairment actually affects the lived experiences of disabled musicians in reality. During the project interviews, participants regularly refer to situations where attitudes towards, or perceptions of their impairments, cause them concern or actively impede their ability to engage in music making. Consequently, this chapter considers two research questions, the first of which, question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** is answered in Section 4.1. Through examples drawn from the PhD project interviews and

my own experiences as a disabled musician, I consider how the PhD project participants and I feel we are regarded, and how we believe our impairments impact on the way others see us from a musical standpoint. This consideration builds on the work of Swain and French (2000, pp. 569–582) and Cameron (2014, pp.4-10) who conceptualised and developed the affirmation model of disability.

The second area of concern for the PhD project participants, and an issue I have encountered over many years, is the challenge of finding ways to deal with the technical problems that occur at the meeting point between musical instrument and physical impairment. The confluence of impairment and instrument is an area that many of the participants in my PhD project refer to and in doing so tend to focus on the physical aspect. There are some references to the emotional issues that can be a factor in the process of maintaining or adapting ways of playing an instrument with particular physical limitations such as frustration and disappointment, However, these references did not amount to a significant theme. Therefore, despite the difficulties in categorising and defining impairment, I decided to centre this area of my PhD project around physical difficulties the participants recount which in turn results in a focus on individual impairments. Therefore, the second research question addressed in this chapter, question 2: **How do disabled musicians meet the challenges that arise when impairment impedes their ability to play their favoured instrument?** is considered in Section 4.2. Given that playing musical instruments require the interfacing of human and instrument by necessity, and that this process is complex given that it requires both physical and cognitive responsibilities (Fitts, 1954, p.262; Overholt, 2009, p.224), it is not surprising that many participants refer specifically to their impairments and the difficulties they can experience in continuing to engage in music making. Therefore, Section 4.2 discusses the challenges disabled musicians face in relation to their impairment and the ability to continue playing their favoured instrument. Examples include the views of two participants who raised concerns about their ability to continue playing their chosen instruments and other examples of the adaptations made by disabled musicians. The discussion in

section 4.2 is also reinforced by my own thoughts and experiences on the issues that arose as I attempted to maintain my ability to continue playing Highland Bagpipes.

For clarity and focus, I use the term ‘impairment’ as a signifier for the specific physical occurrence that results in the limitation of function; for example; wheelchair users have a mobility impairment, deaf people have a hearing impairment, and blind people have a vision impairment.

4.1.2 How impairment is commonly perceived

4.1.2.1 Introduction

Before discussing issues related to impairment, the concepts of disability and impairment must first be considered to find out how impairments are commonly understood and to provide context while discussing physical and sensory impairments. The UPIAS (Union of the Physically Impaired Against Segregation) definition of disability is, ‘something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society’ (UPIAS, 1975). Therefore, disability and impairment are perceived as two distinct phenomena; impairment is the deviance from what is commonly regarded as ‘normal’ that differentiates people with impairments from those regarded as being unimpaired and disability is the collective barriers such as discrimination and prejudice that people with impairments encounter. Carol Thomas suggests that disability is a product of the social relationships between individuals who are considered as having impairment and those who are defined as ‘normal’ and can be described as ‘the active and purposive social exclusion and disadvantaging of people with impairment’ (Thomas and Corker, 2002, p.18). Although there appears to be agreement in general terms on the definition of disability, different views and interpretations of impairment exist. For example, Thomas states that impairment ‘should be theorized as a biosocial phenomenon’ (Thomas and Corker, 2002, p.24); therefore, Thomas focuses on the interaction of biological aspects and social relationships. However, Corker questions whether impairment is rooted in language since it had been ‘labelled within medical discourse and these labels, and the ideologies on which they are built, frequently determine how people have learnt to respond to your impairment -

or disable you - in the social context' (Thomas and Corker, 2002, p.26). Therefore, as concepts, impairment and disability are inherently difficult to define. However, as stated in Chapter 2, the definition of impairment I use in this thesis is derived from those of Thomas et. al and The World Health Organisation and is 'a permanent or long-term characteristic of an individual that can result in a limitation in specific functions'

4.1.2.2 The specificity of impairments

Different impairments have differing individual and social implications (Shakespeare and Watson, 2002, p.12), which often result in challenges that are specific to each person. For example, Sally French, who has a visual impairment, describes an incident where she says to her mother 'The wind gets in my way'. French explains, 'The wind makes a noise which obscures the small auditory cues which, though rarely appreciated until they are absent, are so helpful when walking about' (French, 1999, p.21). French also explains that 'as a visually disabled child, I constantly looked at the ground [...] The ground is where most of the danger lies; by looking down I have the greatest likelihood of seeing objects or steps in my path. True I sometimes get slapped in the face by an overgrown hedge, but ground objects are far more common, and my distance vision is so restricted that looking down is much more functional than looking up' (French, 1999, p.22). By contrast, participant 'Suzie' who also has a visual impairment, describes challenges she remembers as a child:

George- You mentioned barriers Suzie, could you talk a bit more about that?

Suzie- Well, as a kid it was all about practical things to an extent, well as a young child you know from sort of 4 to 11 or whatever there were two things going concurrently and I think with dis- with disability from my point of view they've both kind of been- been issues but in different ways and I think the social one has been more prominent for me

George- right.

Suzie- Em, so the practical issues it was things like, you know how do I access stuff, how do I read, how do I get the information, how do I get the feedback that I need e::m, in any- in any situation. So, whether it's how do I get access to the written feedback on the board, how do I

get access to the- the writing on the paper, how do I get access to what they're doing in a science experiment, so I really could conceptualise what they're actually explaining.

Suzie; piano, voice

Humans have a propensity to categorise each other, to ascribe group membership and to judge each other on the basis of these categorisations (Tajfel, 1970, p.97). However, the contrast between Sally French and PhD participant Suzie's concerns relating to their visual impairment shows that people with impairments can experience different challenges due to their differing circumstances, their goals and aspirations, and their psychological makeup. This difference is apparent even if the individuals are classified as having the same impairment. An example of this can be seen when comparing the data collected from interviews with PhD project participants Carol and Martin who both have a hearing impairment. In Section of this thesis 4.1.2.5 Carol shows deep concern about how she is perceived as a deaf music teacher but Martin does not refer to his impairment's impact on how he is perceived as a musician at any point during his interview. It is apparent therefore that Carol's concern about the impact her impairment has on her perceived musicianship is not mirrored by Martin despite having the same impairment. Another example of how disabled people may appear to have a similar impairment but their circumstances are different can be seen when comparing my own situation with that of PhD project participant Rose. Both Rose and I use a wheelchair to get around but that is where the similarities end, Rose has a speech impairment and limited use of her arms whereas I do not. We also differ in that Rose can stand and walk for short distances while I cannot. These are significant differences but as discussed in Section 5.2 of this thesis, there can often be the misconception that all people who use wheelchairs cannot walk. Consequently, inappropriate attitudes and adjustments can occur because they are based on these symptoms alone with no account taken for each individual set of circumstances. This 'one shoe fits all' approach is particularly important for disabled people who engage in activities that require adjustments to be implemented such as music education or performance. In Section 4.2.5 of this chapter I discuss issues relating to assistive technology and include an example from my interview with PhD participant Suzie. This short extract from that

example shows how an inflexible approach to adjustments can impede access to music education for disabled musicians;

Suzie- When you learn braille, your authority classifies you then in a different way because you're classed as educationally partially sighted before that, and then when you learn braille you're classified as educationally blind so everybo- everything changes

Suzie; piano, voice

Suzie did not have access to Braille until she was in her teens, this meant that for Suzie learning music theory would be delayed until that time. Therefore, research question 1 **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** can be answered by stating that the inflexible way in which impairments are often categorised can result in disabled musicians encountering barriers to music performance and education. However, this inflexibility is just one factor that has an impact on the lives of disabled musicians; the following discussions examine other ways in which access to music and music education can be impeded.

4.1.2.3 Supercrip or dependant: The polarisation of perceptions

The way impairment is commonly perceived can have a wide range of effects on disabled people. According to Corker, in the Western world the socio-cultural environment 'views disability as deviance, damage, dependence - the so-called 'sick role' - and perpetuates labels and stereotypes which stigmatize, disempower, deskill and marginalize disabled people' (1998, p.221). Swain and French argue that 'despite some variation, the tragedy view of disability is widespread across cultures [...] and remains so entrenched in society today that it has become an ideology' (2008, p.4). A major factor attributed to the perpetuation of these entrenched ideologies is the way impairment is often represented in the media. French argues that personal tragedy underlies representations of disability in numerous ways for different dramatic purposes, such as being bitter and twisted (for example, the character Potter in *It's a Wonderful Life*) or pathetic (for example, Tiny Tim in *A Christmas Carol*)' (2004, p.34) and Shakespeare comments that 'the main problems with mainstream representations of disabled people are that such characters are usually objectified and distanced from the audience. Their

particular impairment is made the most important thing about the person. The character usually slips into one of three major stereotypes: the tragic but brave invalid (for example, Tiny Tim); the sinister cripple (for example, Dr No); the “supercrip”, who has triumphed over tragedy (for example, Helen Keller)’ (1999, p.164). Stigmatisation, which is described in detail in Section 2.4.2, and disempowerment, are experienced by disabled people in their daily lives, and the ideology of disability that Swain and French speak of, (Swain and French, 2000, pp. 569–582) are also encountered in the music world (Lubet, 2010, pp.1-208) and can have a significant impact on their ability to develop and maintain their status as a musician or music teacher. In fact, as referred to in Chapter 2, Lubet suggests that for a musician an impairment can have a greater impact on how the individual is regarded by their peers, ‘Schumann’s injury would almost certainly not qualify him as a person with a disability (PWD) under the ADA of 1990 (Americans with Disabilities Act home page n.d.) which requires that a condition impede “major life activities,” a classification that in practice refers not to any particular individual's activities but to those of an imagined norm. This norm would most certainly be neither a concert pianist nor anyone with—or needing—remarkable manual skills of any kind.’ (2010, p.16). Therefore, for musicians the threshold between being classed as ‘normal’ and ‘disabled’ is lower than the threshold for the rest of society. Although low expectations are a factor in most disabled people’s lives, many participants make comments throughout my PhD project interviews about working harder than others to gain the same recognition for their achievements as others. There are also many references to how they are constantly reminded of how they are regarded by others as having ‘less than normative structure or function’ (Scully, 2002, p.56).

Consequently, the data in my PhD project show that because disabled people are already regarded with low expectations, and disabled musicians fall into a category below this level of expectation, they have a greater gap to traverse than non-disabled musicians when it comes to proving their ability. Additionally, the evidence gathered in my PhD project shows that once a disabled person becomes successful in music, there is a tendency for them to be regarded in a way that corresponds with the

‘supercrip’ stereotype. As will be discussed later in this chapter, Abbie refers to comments such as ‘she’s amazing’ when asked how she feels others perceive her and Robert uses almost the same wording when he says ‘oh you’re an inspiration and you’re amazing’ when he describes what others say about him.

Reflective comment

During the period when I was competing while using crutches I heard similar comments as I walked onto stage or was approached by audience members after a performance. People would say things like ‘I don’t know how you do it despite all your problems’ or ‘I couldn’t do what you do’. These comments are in sharp contrast to comments I receive when not performing which are usually more negative such as ‘you’re young to be in a wheelchair’ or ‘that’s terrible, what happened to you?’

Suzie comments on a similar scenario whereby she is seen and feels different once she gets on stage;

Suzie- it’s really strange though because when I’m not playing music people see me in a completely different way right. But they s- well they seem to mm... they see me- and I think I see myself in a different way, I think that’s the key. But when- I think it is about other people and how they see me, but I think what happens is when I get in a certain environment my brain has learned that in that environment I’m in control uh huh. And therefore, I would act differently and therefore other people would see me in a different way.

Suzie; piano, voice

These examples show that disabled people are viewed differently when they become performing musicians. When not in their performer guise they are identified as the ‘brave but tragic invalid’ (Shakespeare, 1999, p.164) but as they fulfil their role as a music performer they become imbued with the ‘supercrip’ stereotype that Shakespeare describes (1999, p.164). This helps to address research question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** This data from my PhD project shows how perceptions can change depending on the role of the disabled person in question, how impairment is commonly regarded with respect to musicians, and how that understanding impacts on the lives of disabled musicians. However, there are other factors that emerge from the data in my PhD project that shape the way in which disabled musicians are regarded. Section 4.1 continues to examine the way

impairments is understood with an exploration of the misinterpretation of the way impairments impact on disabled musicians.

4.1.2.4 'I would struggle to read this too': understanding the impact of impairments

Low expectations of disabled people form a common theme throughout the eleven interviews with the participants and this leads to the question; what factors drive these negative perceptions and how are they perpetuated? There are many factors that are believed to drive attitudes towards disabled people but one issue that participants refer to regularly in the PhD project interviews is how others do not understand what it means to have their impairment or impairments.

In the main, non-disabled people can accept that wheelchair-users require level access to buildings and as such are disabled by barriers in the built environment (Swain and French, 2000, p.570). However, it is more difficult for non-disabled people to understand what constitutes a barrier if they are not familiar with it or it is less obvious. For example, Carol, in her follow up email to me addresses this issue by explaining the difference in attitude she experiences when asking for adjustments related to physical access as opposed to asking for adjustments or accommodation for her chronic fatigue;

Carol- I've always found that the more the adaptation is physical, the better people can cope. Especially if that adaptation involves the musician themselves having equipment which makes the "problem" go away. But if it involves them having to alter attitudes, curricular content, habits, it is much harder.

Carol; violist, violinist, recorder player, pianist, bassoonist, flautist

It appears therefore that if a person's physical limitation resulting from an impairment is not fully understood, there is a corresponding impact on the attitude towards that person. This difficulty can also be compounded if the impairment is believed to be understood based on common experiences as Carol later explains;

Carol- the other aspect is that people feel they know where you are coming from, and that they too have experienced the same thing. They have been tired, they have been unwilling to get out of bed, they have felt sore, they think it is the same and they think you should be able to push through and rest later because that is how their bodies work.

Carol; violist, violinist, recorder player, pianist, bassoonist, flautist

Having more than one physical impairment, namely being a wheelchair user and having a hearing impairment, has given Carol an insight and unique perspective into the way perceptions related to specific impairments can have on the lives of disabled people.

Reflective comment

This insight is something I share with Carol as I have a progressive sight impairment and I am also a wheelchair user. Like Carol, I am aware of the general understanding that non-disabled people have of wheelchair users. In fact, I agree with Carol that because most people do not use wheelchairs and have little experience of the lived experiences of wheelchair users, they err on the cautious side when making assumptions and observations as they do not feel they have license to empathise with wheelchair users.

A comment Carol makes gives good insight into how she feels wheelchair users are perceived and why this perception exists;

Carol- they don't feel they understand being a wheelchair user and they don't feel entitled to tell you how to live, how to cope, what to do.

Carol; violist, violinist, recorder player, pianist, bassoonist, flautist

Carol's comment refers to a way of life that many people feel they cannot relate to and consequently will not attempt to empathise with the experiences of the disabled person. However, there are impairments that some non-disabled people feel they do understand or have some experience of are and tend to display a certain amount of misplaced empathy.

Reflective comment

A specific example of misplaced empathy I can relate from my own experience happened during a meeting I had to explain the problems that I was experiencing reading and writing on my computer; the member of staff and I sat at my office desk with some of my notes displayed on my computer screen. I explained the difficulties I was experiencing due to my progressive sight impairment and said to the individual; 'when I look at the text on this screen all I can see is a mass of jumbled letters, they all merge into one so I need to increase the line spacing which means I can only see a small portion of the page at a time' The response to this comment was, 'hm, I would struggle to read this too without my glasses too, ha ha'.

During this period, I was struggling to come to terms with a sight impairment that was progressing at a faster rate than was anticipated and was looking for advice and support. This issue was reported to the people responsible for my pastoral support on several occasions

throughout the first three years of my PhD. However, any references to my progressive sight impairment were met with very little response apart from one occasion where I was informed that I could be given a three-month extension on the deadline for submission of my thesis. Although helpful in the long run, this covered only one aspect of my concern as I hoped that I would be given different strategies or technology to assist with my issue; instead I felt the people in question were avoiding my requests. The impact of what I perceived as avoidance on my emotional state was considerable, I was both embarrassed and angered by the dismissive reference to the other individual's own sight impairment and as was the case in many of these situations, I did not respond to the comment made about glasses and decided to attempt to resolve my issue myself by asking my school for a larger computer monitor which was duly supplied. As with the experiences recounted by many of the participants in my PhD project, what might seem to be an innocent, inconsequential comment had a major impact on my confidence and state of mind. Like Carol's issues caused by fatigue, my sight impairment was being confused with a more common impairment that has a lower impact on the individual's life experiences. The person in question was referring to their own experience of age related vision changes (presbyopia), a process that happens naturally in people as they age and does not signify any sort of disease (National Eye Institute, 2010).

The member of staff's experience of the symptoms of presbyopia referred to in this reflective comment was informing their understanding of my sight impairment which was and continues to be a major barrier to reading and writing and a source of concern for me. The main point missed by the individual in question was that their sight impairment is easily corrected with spectacles or contact lenses, so they have the option of being able to use aids to read and write whereas my sight condition cannot be corrected. Therefore, like Carol's challenges with fatigue, my sight impairment is often misunderstood due to misplaced empathy and as can be seen, may result in emotional and confidence issues on the part of the person with the impairment.

In 'Can You See the Rainbow' (2004, pp.81-86), Sally French describes how as a child her sight impairment caused tension and the compulsion in her to go down an 'path of denial' to avoid being described as 'playing up' or a malingerer (2004, p.86). My sight impairment is also regularly misinterpreted but, in my case, this is more in line with the interpretation of the member of staff described in the aforementioned reflective comment where its impact is 'played down'. In contrast to French's account of her experience of impairment, I do not feel the need to hide it in the way that Goffman describes when he refers to 'passing' (1963, p.57).

Attempting to understand an impairment through one's own experience is only one possible explanation for the negative attitudes encountered by disabled people. An important alternative interpretation of the attitudes of others towards issues caused by specific impairments is described by French as she argues that disabled people are often the cause of discomfort and embarrassment in others and that 'disbelief remains a common response of non-disabled people when we attempt to convey the reality of our impairments' (French, 2004, p.84). In other words, the non-disabled person will effectively deny or play down the impact of the disabled person's impairment because they feel awkward talking about impairment. French recalls an example where she was not able to see what was happening during lectures and made a request for help. Her request was met with the response 'all students panic about statistics and that everything would work out fine in the end' (French, 2004, p.84). This supports the argument that, when encountering a person with an impairment they do not fully understand, some individuals will either play down its impact, or try to equate it with experiences they are familiar with. There is also a distinct possibility that the impairment will be denied completely.

My PhD project shows therefore that being identified as 'disabled' often comes with a plethora of misconceptions and attitudes that are not usually applied to non-disabled people. As argued in Chapter 2 of this thesis, 'disabled' can be characterised as 'categorical representational meaning systems shared by large segments of society that can provide expected characteristics for those who belong to that category as well as perceptions for their behavior and narrative history of group membership' (Deaux and Martin 2003, p.105). Carol's comment that people do not feel they can comment on using a wheelchair but do feel they understand issues related to fatigue shows that not only do the expected characteristics referred to by Deaux and Martin impact on the way disabled people are categorised, but that there is also a tendency for individuals to interpret specific impairments through one's own experiences. These interpretations are usually wrong due to the lack of understanding of the impairment in question. Therefore, if a disabled person has an impairment that an individual can equate to something they have experience or knowledge of, irrespective of the severity of the symptoms, they

will tend to feel they understand the impact it has on the disabled person. The comment by the staff member about my sight impairment is a good example of this. However, as Carol argues, if an impairment does not equate to something an individual has experience or knowledge of, they will not attempt to empathise or make summary judgements on the impact it has on the life of a disabled person. This is a significant finding, not least because it does not appear to be the subject of empirical research to date. However, further consideration of this finding is beyond the scope of my PhD project and may be a worthwhile topic for a future research project.

Misconceptions and misunderstandings of impairments are not confined to interpersonal interaction and interaction with institutions, they can also be found in research and academic writings. Wendy Magee presents the idea that individuals need to 'transcend the body' in order to come to terms with their losses (Magee, 2002, p.180). However, the data gathered in my PhD project contradicts this view; in fact, most participants refer to facing the challenges resulting from their impairments as opposed to transcending their body and overcoming their impairment. Emily says:

Emily- I just worked so hard at it because I really wanted to be able to do it.

Emily; pianist, singer

This theme is evident in many of the interviews as participants refer to the ways in which they work or push through the challenges they face because of their impairments. For example, when Don was asked how he felt music shaped him as a person he replied;

Don- it's given me an understanding of e:h (.) if, if you keep going and e:h you know you enjoy it and, and you work eh, then that shapes you in terms of eh (.) knowing what can be done. A lot of mental health eh, where they are at the moment is to say 'accept, accept, accept' you know

George- mm.

Don- well you do, you accept, but, but I wouldn't want either any physical or mental ill health to stop me from making music.

Don; guitarist, singer, composer

Don's comment echoes that of many of the participants who assert that with the right support disabled people can achieve many of their goals, not by rising above their pain, discomfort or limitations but by working through them or finding strategies that will enable them to succeed. Additional support is given to Don's comment by Suzie's observation;

Suzie- you just push and push and push, and you just work until you're at the standard that you need to be right, but it's @exhausting @@. So, yea but- but I wouldn't not do it though, do you know what I mean? Like you just wouldn't.

Suzie; pianist, singer

Reflective comment

My own experiences as a disabled person support these assertions. From a personal perspective, coming to terms with the limitations caused by my impairments was not achieved through what Magee describes as transcendence, but instead involves what I would regard as the ability to accept, understand, and work through or with the limitations set by my impairments. The way in which I eventually came to accept my status as a disabled person was to embrace and understand my physical changes as opposed to transcending any feelings of loss. Research in this area is almost non-existent but one of the benefits of access to what is commonly referred to as the 'disabled community' is that issues such as these are discussed on a regular basis by disabled people. In conversation with others I have encountered many more disabled people who have described the acceptance of their limitations in very similar ways to my own experience rather than through 'transcending their physicality'.

To illustrate this point further I will relate a story of a more personal nature that I believe exemplifies the pervasive idea that disabled people must overcome their disability. This example shows the issues raised by this misconception from two perspectives; first; the way in which the medical model still informed the medical profession in the 1990's, and how the views and notions of a society can have a detrimental impact on the lived experiences of a disabled person through that individual's internalisation of these views and beliefs.

During the early years of my transition from a non-disabled person to a disabled person, I was constantly faced with practitioners such as physiotherapists and surgeons telling me that they could make me 'normal' again. I attended numerous hospitals, clinics, physiotherapists and chiropractors who all made vigorous attempts to reverse the progress of my impairment. During this period, I was extremely unhappy and found it difficult to face the world. I was reluctant to engage in social activities and found myself constantly preoccupied by thoughts of what life would be like if I could be rid of my pain and lack of mobility. Eventually I was referred to a surgeon who reviewed my medical history and said, 'I think you need to think about your situation in a different way. It's highly unlikely that your condition can be improved far less cured, it would be like trying to put toothpaste back in the tube'. This comment stayed with me for several weeks. I slowly realised that the surgeon was making good sense and that I was

vainly clinging to the hope that I would someday be ‘normal’ again. Consequently, I decided to act on the surgeon’s advice and seek help with pain management and eventually went for counselling with a clinical psychologist. The professionals I was now receiving support from now began the slow process of rebuilding my identity, I was now becoming a disabled person as opposed to a non-disabled person who had temporarily become disabled. The result, after many pain management and cognitive behavioural therapy sessions, was a full transformation from an extremely unhappy introvert into a contented and motivated disabled person. Knowing and accepting my status as a disabled person and resisting the socially imposed burden of the notion that I must strive for a cure, or fight against being different, released me from the oppression that was both external and internal.

My experience of coming to terms with my disability did not include Magee’s views on ‘transcendence’ (Magee, 2002, p.180). On the contrary, the way in which I eventually came to accept my status as a disabled person was to embrace my physical changes as opposed to transcending any feelings of loss. Research in this area is almost non-existent but I have the benefit of being a member of a community that discusses these aspects of disability on a regular basis. Through the disability community I have encountered more disabled people who have addressed their transitional issues in the same way as I have rather than through ‘transcending their physicality’. Examples of this attitude can be found in many blogs and disability magazines; Raul Krauthausen speaks of his acceptance; ‘I’ve gotten better at accepting myself how I am. This has made life a whole lot easier.’ (Krauthausen, 2014, paragraph 2) and White notes that ‘after coming to grips with the physical, and learning to see my wheelchair as my chariot, my real journey to wholeness began’ (White, 2014, paragraph 2). These comments show that there is a view among disabled people that, in contradiction to Magee’s ‘transcension’ idea, the most effective way to come to terms with permanent physical changes is to accept, absorb and adapt.

These findings support the assertion that Magee's views exemplify on how misconceptions and poor understanding of the lived experiences of disabled people can permeate all aspects of our society. The findings also help to answer the first part of the research question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** through examples showing that, if an individual can equate an impairment with a health issue they

have some experience or knowledge of, they tend to believe they can empathise with or make judgemental comments on how that the effects of that impairment manifest. There is also the emergence of evidence that disabled musicians are subject to the belief that they will not perform at the same level as non-disabled musicians. Suzie's and Emily's comments that they feel they have to 'push and push and push' and 'work so hard' show that there is a tendency for disabled musicians to try to exceed what is expected of a non-disabled person in order to counter low expectations. I feel that this tendency to 'over-perform' is evidence of Shakespeare's argument that 'disabled people are socialised to think of ourselves as inferior' (1996, p.10) and Morris's view that 'The messages we receive are very strong and clear and we have little access to different values which may place a more positive value on our bodies, ourselves and our lives. Our self-image is thus dominated by the non-disabled world's reaction to us' (1991, p.28).

4.1.2.5 Who wants a deaf music teacher? How impairments are perceived to impact on musical ability.

There are many interpretations of what it means to have a specific impairment and some of these interpretations are beneficial to disabled people, for example knowing that a wheelchair user will need a ramp to enter a building. However, being a disabled person also means being subject to interpretations that can be construed as prejudiced. Such misconceptions can be found in the way impairment impacts on the ability to be a successful musician or music teacher. In addition to making several references to her skill levels, Carol voices concerns about how she might be perceived in relation to being deaf and being a music teacher by saying she is worried how she will be viewed by others;

Carol- Em (...) I think there's an angle with my hearing that is something that I used to always struggle with sometimes that I sort of feel like I- I don't want people to f- not that I don't want people to find out but I sort of (.) I'm worried about what people will think if you're a deaf musician, who wants a deaf music teacher, she can't (...).

George- Ok, tell me more!

Carol- Well it's just the perception of the disability that it's all consuming that you can hear nothing you know and eh that then you can't possibly relate to music because you can't hear it so you know, how can I play something you know, how can- how can I listen to somebody play something and have anything whatsoever to say about that

Carol; viola, violin, recorder, piano, bassoon, flute

It is clear therefore that Carol frequently thinks about how she might be perceived in relation to her status as a musician, a concern that extends to how her impairments might be perceived to impact on her ability to claim that status as she also feels there is a perception that being deaf means that she will not have the required skills or abilities to do the job satisfactorily. As stated in the introduction to this section, the perception that deaf people will not be able to be a competent music tutor is maintained at least in part by media portrayals where the disabled individual's impairment is characterised as 'the most important thing about the person' (Shakespeare, 1999, p.164). It is my contention that the tendency to focus on the impairment of an individual is a factor that, like low expectations, heightens the level of self-doubt in disabled musicians which in turn will intensify their motivation to prove their worth as a musician.

Carol was not asked specifically about her hearing or how it relates to her life as a musician; therefore, it appears issues relating to her hearing are important to her and something Carol wants to discuss, something she feels concerned about and something she feels impacts on how she is perceived. In Carol's view, there is a belief that having a hearing impairment precludes an individual's ability to be a music teacher. However, Carol explains later in the interview how her hearing impairment manifests:

Carol- I can hear relatively normally in the very low frequencies and then it drops to a big loss in the mid frequencies, em, then it goes back to normal thresholds in high frequencies, but I get transposition

George- ok.

Carol- so, if you play me very high frequencies I hear them at a lower frequency, and then there's things that I can (.) my ear responds but I can't actually hear them.

Carol; viola, violin, recorder, piano, bassoon, flute

Therefore, despite experiencing music in a different way from most others, Carol demonstrates that she can and does have the ability to interact with music in a meaningful way. Whittaker explains that ‘Over the years I’ve been asked on countless occasions how I ‘hear’ and understand music, been told that I’m wasting my time,’ (Whittaker, 2012, p.2) and as Hartmann puts it, ‘Deaf people appreciate music ... albeit differently. People assume that hearing music is the only way to enjoy music. It's not. Music is far more than just sound. It creates vibrations, has lyrics, and evokes feelings. Deaf people can experience those things on an equal footing’ (2014, n.p.). These comments illustrate the difficulty many hearing people have in understanding the concept that individuals who have a hearing impairment can enjoy and play music and along with Carol’s concerns helps to answer research question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** They also show the difficulties people with hearing impairments have in persuading others, including employers, education facilities and qualification regulators, that they too can play an important role in the music world. In a more general sense they underline what Shakespeare refers to as the difficulties we face ‘if we seek to identify disabled people on the basis that they experience particular physical deficits not shared by the majority population’ (1996, p.96). For Carol, being identified as someone with a hearing impairment creates attitudinal barriers that she faces as she works towards becoming a successful music teacher. Even given the success of Evelyn Glennie who ‘lost most of her hearing at eight years old’ and is ‘the first person in history to successfully create and sustain a full-time career as a solo percussionist’ (Glennie, 2014, n.p.), disabled people still experience attitudinal barriers that have a significant impact on their self-worth. Such attitudinal barriers can have a negative impact on the perceived value of the work of a musician.

Project participants also use performance as a method of diverting attention from their impairment. This method of diversion is referred to by Suzie who describes the how performing gives her a sense of control:

Suzie- when I get behind the piano I think because of those experiences it gives me a sense of confidence, it gives me a sense of really being in control, really in a big way, you know

George- [that's interesting]

Suzie- [like] in a way of em (.) being in charge of a group and being completely in control of what they feel and think.

Suzie; piano, voice

Suzie is using performance as a method of shaping the attitudes of others towards her; as she refers to controlling how others feel and think, it is natural to assume therefore that she is referring to shaping negative attitudes into more positive attitudes towards her as a disabled person. This strategy chimes with what Shakespeare describes as a 'form of denial [that] seeks to "overcome" impairment (1996, p.7) and, as Shakespeare argues, it is a strategy that can only result in a temporary identity. Suzie's comments seem to support Shakespeare's argument as she states that her feeling of 'being in charge' happens when she sits behind the piano. This implies that when she is not sitting behind the piano, Suzie's feeling of control is diminished or no longer exists; once Suzie come off the stage she will no longer have an identity that can be described as 'performer', she will return to feeling like she has less control and confidence and be 'the blind person' again. This finding represents one of the psychological barriers that disabled musicians can encounter and helps to answer the second research question asked in this chapter, question 2: **How do disabled musicians meet the challenges that arise when impairment impedes their ability to play their favoured instrument?**

Reflective comment

Using qualifications and performance to shape or influence the negative attitudes of others is a strategy I use constantly, both consciously and unconsciously. Immediately after I became disabled, I worked hard to show people that I could reach a high level of attainment in the piping world. Although I did reach a high level of skill, I did not attain the level in piping that I wanted to due to the increasing effects of my impairments on my ability to play and access venues. Once it became apparent that I could no longer sustain my attempt to reach my goal in piping, I switched my efforts to focus on the academic aspect of music. I undertook a Diploma in Music course at the Open University, then gained an Honours Degree in Music. As a PhD student, I am still aiming to reach high levels of achievement and so it might be argued that I

am still attempting to ‘regain a normal identity through superhuman activity and endurance’ (Shakespeare, 1996). In the third year of my PhD I became very close to giving up the PhD due to the many issues and challenges I face as a disabled student; this has shown me that I am fighting against what Shakespeare describes as ‘external disempowering agendas’ (1996). Prior to becoming a PhD student, I studied at home for my Honours Degree and so was somewhat shielded from the challenges of access and attitudes I have come to experience as a full-time student on-campus.

Another participant who uses performance as a method of demonstrating her level of skill in music is Rose. From discussions in the interview, it was evident that Rose feels it is important that her audience understand the levels of skill required for her to perform. Here she describes the reaction of others when they discover these levels of skill:

Rose- you get a lot of people coming up to you after performances, I guess just interested in how you’re doing it and realising how much is involved. It’s not just hitting a button it’s- they realise you’re reading a score as well and things like that so yea

George- mm. How do you think people react then when they find out what you’re doing?

Rose- They’re usually surprised, most people when they first see me see the chair, unless they know me. So, when they realise that I can read music and stuff they see me as a person then.

Rose; digital software, composer

Therefore, in addition to gaining a qualification, the ability to demonstrate or substantiate a high level of musical skill is used as a method of addressing the low expectations of others and reinforcing the status of the musician. However, demonstrating the levels of skill she has developed to perform can prove difficult for Rose as she uses complex digital software to compose and make music. The nature of the technology makes it difficult for the audience to see how she operates it when she performs. Rose uses a specially adapted switch which acts as an interface between her slight hand movements and the computer; therefore, the movements are subtle and not immediately obvious to an audience. Consequently, meeting audience members after a performance is important for Rose as it allows her to explain and demonstrate the level of skill required to operate the technology and in turn helps mitigate the low expectations and misconceptions of others and validates Rose’s status as a serious musician. The account describes a barrier faced by Rose; the perception that she is not able to apply a

high level of skill to playing her instrument. It also presents a method employed by Rose to overcome this barrier, describing to people after the performance how she uses her instrument and the skill involved in performing. As such, Rose's conversations with her audiences show that Rose is concerned about the way her impairment is understood by others and shows how she reacts to this concern by explaining her level of skill to her audience. Therefore, in common with the other strategies outlined above such as gaining high level qualifications and using performance to divert attention from their impairment, Rose's example helps to answer research question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** The data in Section 4.1 therefore shows that disabled musicians feel they must and commonly do employ various strategies to resist being viewed as less able and these strategies are usually centred around exceeding the level of achievement or qualification expected of a comparable non-disabled musician.

The findings in Section 4.1 also help to answer the first part of research question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** by showing that the participants in my PhD project feel there is a perception that disabled people will not have the skills necessary to become a successful musician; that their impairments will prevent them from reaching the same level of proficiency as a non-disabled person. This lower expectation of disabled musicians is also an assertion made by Lubet (2010, p.16), and the findings in my PhD project show that this perception is still prevalent and has a significant impact on the confidence of disabled musicians. The data also show that misconceptions can manifest as denial of impairment, or misplaced empathy if the individual feels they have experience or knowledge of a specific impairment. These interpretations of impairment act as barriers to engagement with music from the perspective of performers, teachers and students of music by eroding their confidence and self-belief. However, analysis of the data from my PhD project shows that attitudinal barriers are not the only challenges disabled musicians face; the physical implications of impairment are also a concern

for the participants in my PhD project. To explore this theme, the focus of this chapter now turns to impairment from the perspective of the disabled musicians themselves and looks at the reality of engaging in music making as a person with a physical impairment.

4.2 The actual experience of having an impairment and playing a musical instrument

4.2.1 Introduction

Section 4.1 considered how the lives of disabled musicians are affected by perceptions of impairment. However, in addition to attitudinal barriers such as low expectations, disabled musicians encounter significant barriers that are more obvious as they engage in music making and one that emerged as a major theme in my PhD project is the impact impairment has on disabled musician's ability to play their favoured musical instrument. Finding solutions to problems that result from physical limitations can be difficult and, in some cases, insurmountable. Therefore Section 4.2 seeks to address research question 2: **How do disabled musicians meet the challenges that arise when impairment impedes their ability to play their favoured instrument?**

To illustrate some of the issues surrounding the intersection of impairment and instrument, I draw on data from the interviews with PhD project participants Don and Matt, my own experience, and a magazine interview with Rick Allen (Saccone, 2011, pp.1-8), all of whom experienced major changes in their ability to play their preferred instrument. A brief discussion on the playing technique of Django Reinhardt (Wininger and Williams, 2015, pp. 238–243; Cramer, 2013, n.p.) is also included to add extra depth and perspective to the subject. Although the discussion that follows is based on examples that involve changes in, or the onset of an impairment, all of the data is relevant to the main focus of the discussion which is the issues surrounding physical adaptations in relation to musical instruments and impairment.

Don and Matt are two of the participants who were interviewed for my PhD project. Don has a skin disease which makes playing a steel stung guitar painful and Matt, who is a wheelchair user, has difficulty in finding a way to play saxophone comfortably. Both Don and Matt refer to specific issues that arose at the point where changes in their abilities occurred, for example, when they first acquired an impairment or when they experienced an increase in the severity of the symptoms resulting from an impairment. Don and Matt have both experienced similar emotional difficulties to the ones I experienced when my impairment eventually prevented me from playing Highland Bagpipes. Both Don and Matt give emotive accounts of the difficulties they faced during the period when their ability to play became more limited and the emotional element of these accounts chime with my own as I was going through this period in my life, therefore I believe it is an important factor to consider. What follows is an exploration of these emotional difficulties through the experiences of participants Don and Matt, Rick Allen, and my own experiences.

4.3.2 Matt's difficulties in adapting to changes in his physical abilities

Matt is a disabled musician who became a wheelchair user in his seventies. Matt is primarily a saxophonist playing saxophones in various keys, clarinet and cornet. Saxophones come in different sizes depending on the key of the instrument with the most common played being the alto and tenor (Thomas, 2017, paragraph 7) and Matt spoke about the difficulties he experiences when playing his tenor saxophone:

Matt- I'm in the wheelchair now (I) can't sort of (.) hang the tenor between your knees or over the edge because your knees muffle the- the lower notes yea

George- yea.

Matt- your thighs #. You can't do it. I've tried doing it taking the arm off uh huh and doing it that way, em, I've never played with the instrument to one side so that added (difficulties) but the wheel of the wheelchair pushes it and it bangs against it when you're playing yea

George- yea

Matt- so, you can't do that

Matt; saxophone, keyboard, cornet

Matt also discussed the difficulty he has since developing an essential tremor:

Matt- em, worse than that is that em I've developed now what they call an essential tremor, right?

George- right.

Matt- so em, clarinet is impossible now because # particularly the left hand and to get over the break I can't, I can't manipulate it my fingers wouldn't do- won't work. Em, the clarinet is out, flute is out, which I used to play. I used to teach a lot of flute as well

Matt; saxophone, keyboard, cornet

The difficulties Matt faces in playing his instruments have a profound effect on his engagement with music and his ability to maintain his status as a musician as evidenced by the emphasis he places on 'you can't do it', which is one short sentence, a tool many writers use to increase emphasis (Reference.com, 2016). Matt also paraphrases this later in the passage.

Reflective comment

Matt's experience is like my own in that he has lost the ability to play his instrument in the usual way, i.e. in a standing position. This loss of ability is due predominantly to the size and shape of the instrument but is also due to other contributory factors such as breathing problems and essential tremor. Blowing is an obvious and essential element of playing a wind instrument and like me, Matt has developed Chronic Obstructive Pulmonary Disease or COPD, a disease which affects his breathing, and in my case, it is Coughing Variant Asthma that has affected my lung capacity and ability to blow. For most wind instrument players, a breathing problem will have a major impact on their ability to play their chosen instrument; Matt finds it difficult to blow certain saxophones and so is restricted to the ones he can manage more easily.

However, there is no alternative for Highland pipers. The instrument requires a large and constant supply of air to sound properly, something I am no longer able to manage. Therefore, not having the ability to stand or walk is not the only reason I cannot play the Highland Bagpipe and is a major factor in my decision to choose to play the Border Pipes and Scottish Smallpipes. These pipes are both bellows blown and do not require the player's breath. Unfortunately, Matt does not have the option of a saxophone or clarinet that does not require the player to blow.

At the time of the interview Matt had only recently reached the point where he became a full-time wheelchair user and was beginning to experience essential tremors, a condition which manifests as an uncontrollable trembling of part of the body (NHS Choices, N.D.). Matt's essential tremor is exacerbated by having to play in a sitting position and this combination has limited the instruments Matt can play to his satisfaction. Like me, Matt's involvement with music began at an early age so it would be reasonable to assume that the emotiveness of his account is due to reasons commensurate with mine; the grief over the loss of a valued ability, and the threatened change to musical status.

4.2.2 Don's method of finding suitable adjustments to manage the changes in his physical abilities

Matt does not refer to changes in playing technique because it is not possible to play his preferred instrument. However, despite the impact of a physical impairment, it is sometimes possible to make changes and adaptations that allow an individual with a new or changed impairment to keep playing their preferred instrument.

Musical performance is naturally governed by both physical and cognitive limitations (Overholt, 2009, p.225) and any changes in a musician's limitations will impact on their musical expression which Overholt suggests are vital elements of human life (2009, p. 225). In order to circumvent any loss of capability, my PhD project shows that disabled musicians will seek acceptable alternatives and find ways to fill the gap in their musical vocabulary. This type of alteration in style and function can result in significant changes in the music produced as will be evidenced in the following discussion. These changes in style are often driven by specific circumstances such as the relationship between the musician's impairment and the instrument they play, and the availability of alternatives. This was the

case for participant Don whose skin condition worsened through time meaning he could no longer play a steel strung guitar.

Don describes the impact his skin condition has on his ability to play guitar:

Don- when you're playing a guitar eh, and your finger picking (...) you've actually got to have the nails to do it eh, (...) but with the em:m, (.) starting again, the knowledge was there of where to put my fingers, but I could not do quite the same things as I had been able to do before. (H) so, basically that was really, it was e:h (.) work, you know. I just thought if I wanna play this again I'm gonna have to work. I sort of re-learned, I learned how to use the thumb pick and I use a finger pick on three ((holds up third finger)) just the two and eh I've, I've developed a style.

Don; guitar, voice, composer

These forced changes to Don's technique and playing style would also have a major impact on how he saw his role in music. Don had previously said that playing his steel strung guitar was injurious and, as a player with a high level of skill, Don found the reduction in ability to play his instrument in the configuration he was accustomed to difficult to deal with and is evidenced by the way in which Don explains how being unable to play steel strings affected him:

Don- my skin was really bad, and I had stopped playing [...] it was injurious to play a, a steel strung guitar. So, I went along to ~Woodside Arts [...] and dabbled around with keyboards [...] I had a nylon strung acoustic guitar a:nd you can't put a nylon string classical guitar in front of a rock band and expect to be heard

George- [yea]

Don- [you know], but eh, they did a bit of homework and came up with the Yamaha Silent Guitar* which I think you must have seen?

George- Yea I saw that

Don- yea it's fantastic, that got me playing again properly

Don; guitar, voice, composer



**Figure 4.1; Yamaha Silent Guitar™*

* Yamaha Silent Guitar (Figure 4.1) is an electro-acoustic guitar that has very little volume. It is designed to be used either with headphones for practice or with a PA system or acoustic amplifier for performances and through digital sampling it can simulate the sound of a real acoustic guitar. (Silent Guitar™, N.D.)

It is notable that Don says he ‘dabbled around with keyboards’ and ‘got me playing again properly’. This shows that Don feels the adjustments he had made before getting the Yamaha Silent Guitar did not allow him to achieve the standards of musicianship he felt were needed to confirm his identity as an established musician. Therefore, finding a way to perform to what he felt was his full capacity as a musician was very important to Don and is confirmed by his later comment;

Don- the guitar itself, it’s allowed me (.) to get, you know I mean I (.) it’s just letting me be as, as eh musical as I want to be, it’s made a massive difference

Don; guitar, voice, composer

The Yamaha Silent Guitar which Don maintains enables him to play ‘properly’ on nylon strings does not however allow him to play in a style he feels fitting for one music genre;

Don- it’s quite delicate you know. You don’t want to be lamming power chords through an amp with that really.

Don; guitar, voice, composer

Don had previously explained that he fronts a rock band and one of the most common playing styles for rock guitarists utilises the power chord; therefore, it is obvious that there are limitations to the adaptability of the Silent Guitar and thus Don's playing style will differ from that of other rock guitarists.

4.3.3 Playing technique and a personal perspective on abilities and limitations

Another example of adapting to new limitations can be seen in the experience of the virtuoso guitarist Django Reinhardt whose left hand was damaged extensively in a fire resulting in a reduction in his ability to use his ring finger and pinkie. Reinhardt relearned to play guitar following an extensive period of recovery by using his fretting-hand thumb and first two fingers (Wininger and Williams, 2015, pp.238-243; Cramer, 2013, n.p.) and this change in playing style resulted in Reinhardt having a distinctive fluid style of playing:

It's amazing to see how he was able to travel the fretboard in such a fluid manner, despite the limitations due to his injury. You can also see how he used the injured fingers to play certain chord shapes

(Cramer, 2013, n.p.)

Reflective comment

Django Reinhardt could adapt his technique to play guitar in a way that met with his desired level of proficiency and Don found a different way to continue his journey as a musician by finding an alternative but in many ways similar instrument that enabled him to play without discomfort. However, like Matt, I was not able to find an adaptation that would allow me to continue playing my favourite instrument. Highland pipers invariably stand or march while playing, this is mainly due to the history of the instrument and the way in which it was developed. For many years, the Highland Bagpipe has been synonymous with war and its use in the military and as such has been designed to be played standing or marching (Scots Guards, 1995). The configuration of the Highland Bagpipe is such that the lower pitched notes such as 'Low-A' and 'B' are slightly quieter and sound through the bottom holes of the chanter (see fig. 1) and the closer the chanter is to the floor or ground the duller it will sound. This in turn changes the relationship between the higher and lower registers and affects the tone of the chanter making it less 'bright'.

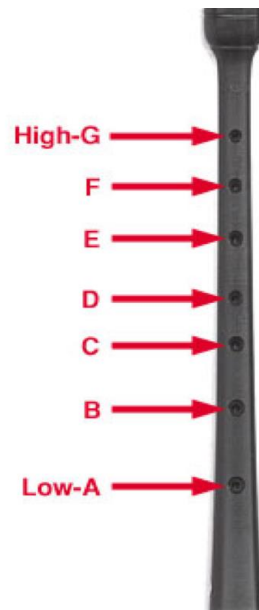


figure 4.2: photo showing finger holes on the chanter

Reflective comment (cont.)

During most of my time as a solo competitor, most players sought a bright tone as it was believed to be more pleasing to the ear and especially to the judges. However, as I could not stand I had to find a way to raise the chanter as high as possible from the ground and to adjust the tone of the chanter to make it as bright as possible. This was achieved by finding a stool that was low enough for me to sit on comfortably, but high enough to raise the chanter to almost the same level as it would be if I stood. The ‘brightening’ of the tone of the chanter was achieved by carefully filing the finger holes of the chanter; this raised the pitch of the chanter which had the effect of making it sound brighter. Therefore, like Don I could adapt an instrument enough to achieve a sound I was happy with. One caveat to this solution however arose due to my inability to walk unaided. When playing a march style tune, pipers usually march; when play a rhythmical tune such as a Strathspey, Reel or Jig the player taps her foot to help them keep accurate time. As I could neither march or tap my foot I was at a disadvantage to the other competitors and I was unable to find a solution to the problem.

These examples show that there are situations where reasonable adjustments are not feasible, where the nature of impairments rule out the circumvention of the limitations they impose. In these circumstances, the only option for a musician who wants to continue making music is to seek an alternative medium. This could be in the form of a different instrument or, as in Emily’s case, move from playing an instrument to singing. However, for some musicians, it may be possible with adaptations to continue playing a preferred instrument, but interestingly in these cases it appears the

adaptations can have an effect on the music produced by the individual. This can be either through the use of an instrument that produces sound in a different way, such as the Silent Guitar, or through changes in style caused by limitations imposed by the impairment, such as the drumming style of Rick Allen, or the fingering styles of Don and Django Reinhardt. These findings show therefore that despite technical innovations and adaptations, it is not always possible for a musician to maintain the ability to make music in exactly the same way as they did prior to the acquisition of an impairment or changes to an impairment. A decision might have to be made as to whether the musician will continue playing their preferred instrument with a different style or sound or move in another direction entirely by learning to play another instrument.

Reflective comment

During the early stages of my impairment I was able, with adaptations, to continue playing my preferred instrument; I could maintain the sound and style I had become accustomed to and continue to compete. Following this period where I managed to compete despite the effects of my impairment, I reached a point where my impairment prevented me from sitting on a stool and playing or use crutches to get around. This, coupled with the difficulties in finding adaptations that would not make me feel embarrassed or uncomfortable, meant I no longer felt able to play the Highland Bagpipe. Having been a piper from the age of six, I could not come to terms with the thought of not being able to play a musical instrument, so I sought an alternative. The closest instruments I could find to the Highland Bagpipe were the Lowland (or Border) Pipe, and the Scottish Smallpipe. The former has a very similar sound to the Highland instrument but is quieter as has been developed for indoor playing and playing with other types of instruments such as fiddle and Bodhran, a Scottish/Irish drum favoured by folk bands. The Scottish Smallpipe has a more mellow sound, is very much quieter and more suited to a small room. These instruments cannot take on the role of the Highland Bagpipe and being of a different classification are not accepted in Highland Bagpipe competitions. Like Matt, I am no longer able to play the instrument I want to, but like Emily, I have found an alternative that allows me to engage in music making, albeit in a different way. However, I was involved in the competition aspect of piping from a very early age, it was a major factor in my life not just as a musician but also as a person and so being a successful competing piper formed a large component of how I saw my status and value as a musician. Therefore, when I could no longer compete I felt my authority and potential had been severely compromised. The opportunity to reach my goal of winning a Gold Medal at the Northern Meeting had gone and with it my ability to be an influential force in the piping world.

A similar sense of loss is evident in Matt's interview where he talks about the limitations he experiences now due to his impairments:

Matt- it's a tremendous blow when you actually (.) when you- when you (..) when you can't do the things that you've- you've always had huge delight from- from doing, em particularly in music

Matt; saxophone, keyboard, cornet

Matt's emphasis on the words 'tremendous blow' goes some way towards showing the extent of the emotional affect his impairment is having on him. Matt has retired from work, so a major component of his life is his music making; I would suggest that Matt feels the same way as I did when I lost the ability to play Highland Bagpipes.

Like Matt and Don, Emily is a participant who was interviewed for my PhD project. Emily has Erb's Palsy, a birth injury that occurs when the nerves in a baby's upper arm are damaged (Birth Injuries Guide, 2016, paragraph 2). In Emily's case Erb's Palsy affects the mobility and stamina of her right arm and impacts on her piano and violin playing. Emily's story is similar to those of Don, Matt and myself where she has experienced difficulties caused by the limitations resulting from her impairment;

Emily- I haven't got much stamina in my arm so I (can't hold) the arm up to play it, it, it gets tired really quickly (H). So, when I was learning the instrument then it was quite hard work because (H) em (.) trying to get to grips with the basics really (.) uh huh. So, I think e:m (.) on the one hand there was this really high expectation (H) e:m, and I was (.) expected to perform, but on the other hand there was a limitation on what I could actually (.) whether I could deliver the goods or not

Emily: voice, piano, violin

Emily has made the decision to switch from concentrating on piano and violin to singing because she no longer feels able to fight against the pain and fatigue she experiences while playing. Although Emily still plays piano and violin, she has decided to concentrate more of her efforts on singing because she feels her impairment made playing an instrument 'hard work'. Therefore, there was a point in Emily's life where she could have given up musical performance entirely, but she chose to find a different path and maintain her status as a musician.

4.3.4 The suitability and effectiveness of assistive technologies

As discussed in Chapter 2, the use of technology is becoming an important factor in the lives of disabled people (Sheldon, 2003, 155). For some musicians who have impairments, the ability to maintain their engagement with music can be enabled by appropriate assistive technology (Drake Music Scotland, 2017, paragraph 1). Two of the participants in my PhD project, Suzie and Abbie are blind and they both discuss their use of assistive technology. However, Suzie's experience with Braille which is 'a tactile reading and writing system used by blind and visually impaired people who cannot access print materials' (Royal Blind, 2017, paragraph 1) shows the difficulties that can arise as a disabled person seeks to make use of assistive technology;

Suzie- I was using print, I was using it quite happily when I was 5 and 6 because everybody uses such massive print anyway and it's all bright colours and big print and all that kind of stuff and when I got- by the time that I got to em (.) late (.) you know when I- late primary school and we had to do lots more reading, and my eyesight was getting worse because of the strain of having to read it and stuff like that I, I definitely think that by the time that I got to age 10 I was like- I really want to learn braille now, and I'm ready to do it and (.) I'm not worried or embarrassed about the fact that I need it, it's just something that has now become obvious that it's- that I need uh huh. But it took them so long that- you know I was 14 or whatever by the time that I learnt it, em, and what that made me feel was just a little under-confident about em, assimilating all the information that I needed to assimilate because it's not just braille that you learn. When you learn braille, your authority classifies you then in a different way because you're classed as educationally partially sighted before that, and then when you learn braille you're classified as educationally blind so everybo- everything changes. They give you tactile diagrams instead of em, print ones

George- right.

Suzie- they give you em, they give you- your support changes and all that kind of stuff, you have a whole load of people responsible for producing your work, you have a different team, you have a whole team behind you. Your whole way of learning's meant to be different and they view you as completely blind but what happened to me- so I still had some vision, so I was still using it for certain things and not for other stuff, and so I got a bit confused as to when I should use my vision and when I shouldn't use my vision. But for music, actually to be honest I think what happened was that I did loads by ear so I just started learning pop songs and that became more about em, the- em, the social activity then, so I think the fact that it all became a bit, you know, confused at school meant that I then just gravitated towards learning by ear and then, you know did loads of social stuff with it instead.

Suzie; piano, voice

For Suzie therefore, it was the way in which she was classified that affected the levels of support she received at school. Being able to read Braille, according to the local authority, shifted Suzie's classification from educationally partially-sighted to educationally blind, even although Suzie's physical ability had not markedly changed. It could be argued that if Suzie had been given access to the extra support she received once she was classified as 'educationally blind', her experience as a student would have been less difficult. Suzie's example serves to highlight the fact that, for disabled people, the support they receive and access to services such as education, can depend on regulations, practices and procedures that are developed and implemented by other people and organisations.

4.4 Chapter summary

Section 4.2 has shown that in addition to the attitudinal barriers outlined in Section 4.1, musicians with a physical impairment also have to meet the challenges that arise from their physicality and the extant design of musical instruments. For musicians who have an impairment that impedes their ability to play their favoured instrument, changing playing style can be enough to allow them to continue; however, a change in playing style may not be sufficient to maintain the ability to continue playing and the musician may have to seek an alternative instrument. If, as in my case there is no instrument that can provide an equivalent experience, a new classification or genre of instrument may be learned to take the place of the instrument the musician can no longer play. The final and most radical alternative is to use modern technology to make music. PhD participant Rose has embraced the use of modern technology with great success, but this option bears consequences with regard to how the musician is perceived. Rose feels her audience do not fully appreciate the levels of skill required to make music using the electronic devices she plays due to the subtlety of the movements and the audiences difficulty in seeing how she operates the devices. I believe that Rose's level of skill is underestimated by the lack of familiarity audiences have with the use of software and computers to make music, but an examination of this topic is beyond the scope of this PhD project. It may however be a good topic to consider in future research.

For me, the difficulties presented by the parochial nature of the piping world, and what is regarded as ‘normal’, was too big a barrier to surmount and was instrumental in my decision to stop trying to find ways to play Highland Pipes. Examples in this chapter show that in some cases, physical adaptations can be made that give a disabled musician the opportunity to retain the crucial inter-play between their chosen instrument and their body, but sometimes an impairment can totally preclude the ability to play an instrument depending on the instrument and the impairment. I suggest that the factors that impact on a musician’s ability to play their chosen instrument fall into two distinct categories;

1. Embodiment: factors that are centred on the person such as their physical limitations, their motivation, and their ability to adapt to a new way of playing.
2. Socially created barriers: external factors such as conforming to established traditions, meeting expected norms, and coping with negative attitudes.

Therefore, the physical nature of an impairment and its impact on the musician’s ability to play an instrument should not be the only factors for consideration when examining the challenges faced by disabled musicians, social and psychological factors can be equally, or more important than physical factors. For example, as mentioned in section 4.1, Lubet argues that for a musician, an impairment can have a greater impact on how the individual is regarded by their peers (2016, p.16). Consequently, a musician who has an impairment is more likely to encounter lower expectations than people in other walks of life. The findings in my PhD project have shown that having an impairment, or the prospect of acquiring an impairment, can be the source of heightened tension, sensitivity or worry not only for disabled musicians who already have an impairment, but also for musicians who are not regarded as having an impairment. Therefore, a significant consequence of the lower expectations of people with impairments in the music world is the feeling that higher than average levels of skill and effort are needed to be regarded as a credible musician; it also means that a high level of resistance to negative attitudes is required to succeed as a musician with an impairment.

The data in my PhD project show that despite the resistance evident in the musicians attempts to engage in music making, seeking ways to deal with the limitations imposed by an impairment can be

very difficult, both physically and psychologically. My PhD project also revealed that the challenge of finding ways to continue playing an instrument appertain in the most part to technical problems that can either be solved, circumvented, or deemed insoluble. However, the data also show that the psychological challenges such as the impact on self-esteem, self-conception and changes in identity are more complex. Rick Allen does not speak of resistance by others to his decision to continue playing drums in Def Leppard; in fact, he was actively encouraged to do so and there is no mention of how he felt he might be perceived by his audiences and the rest of the music world (Saccone, pp.1-8). I on the other hand was not encouraged to try to find ways of continuing to play Highland Bagpipes, I felt discouraged by the attitudes towards my ability to play with an impairment when I was still able to stand so I felt extremely pessimistic about the reception I would get if I did somehow manage to find a way to continue playing Highland Bagpipes through some technological innovation. However, in addition to how other perceive efforts to meet the challenges of playing a specific instrument, the implication this might have on self-image are also a consideration. Rick Allen was comfortable enough to present himself as a drummer with one arm (Saccone, pp.1-8), I would not feel comfortable playing Highland Bagpipes while sitting in a wheelchair, even if some way could be found to do so. I believe my reservations related to sitting while playing is due in no small part to the parochial and rigid attitudes I encountered in the piping world. There is also an issue with imagery; a drummer in a group usually sits to play drums (Drums Player World, 2017, n.p.) so Allen would not look too much different to the way the public are used to seeing a drummer. However Highland Pipers are invariably seen to be standing or marching (Cannon, 1988, p.16), so a sitting Highland Piper would look very different. Therefore, the visual impact, the nature of the social environment, and my own self-image have impacted on my decision whether to attempt to maintain my status as a Highland Piper or find an acceptable alternative.

In conclusion, the data in this chapter shows that being a disabled musician involves challenges that arise from the perceptions and attitudes of others and that these factors have significant psychological

and material implications that impact on disabled musicians. These findings help to address the first research question asked in my PhD project, question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** And research question 2: **How do disabled musicians meet the challenges that arise when impairment impedes their ability to play their favoured instrument?** is answered in Section 4.2 of this chapter by showing the various strategies employed by disabled musicians to maintain their ability to engage in music making.

The following chapter, Chapter 5, considers how social and psychological factors impact on the lives of disabled musicians by considering interpersonal interaction as its main frame of reference.

CHAPTER 5: ‘ARE YOU IN THAT WHEELCHAIR OR IS IT JUST A GIMMICK?’ ASSESSING THE IMPACT OF MISCONCEPTIONS AND NEGATIVE ATTITUDES ON THE LIVED EXPERIENCES OF DISABLED MUSICIANS THROUGH INTERPERSONAL INTERACTION.

5.1 Introduction

Chapter 4 considered the challenges disabled musicians face that originate from intersection of impairment and music engagement and demonstrated that these challenges are in part created by the assumptions and attitudes of others. Chapter 5 builds on this discussion by looking more closely at interpersonal interaction which is one of the ways in which these attitudes and assumptions are communicated. In addition to the physical aspect of the challenges participants discuss in relation to engaging in music making which was discussed in Chapter 4, participants also refer at length to the role interpersonal interaction plays in perpetuating and materialising these challenges. This was identified as the most significant theme in my PhD project; therefore, unlike the other two data chapters in this thesis, Chapter 4 and Chapter 6, this chapter focuses on only one research question, question 3: **How does interpersonal interaction impact on the lived experiences of disabled musicians?** Consequently Chapter 5 concentrates on issues generated arising from interpersonal interactions through the experiences of the participants and my own journey as a disabled musician. Carol Thomas gives her interpretation of the UPIAS definition of disability as; ‘a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being’ (Thomas and Corker, 2002, p.20). With this concept of psycho-emotional well-being in mind, this chapter explores the analysis of the data from the eleven interviews with disabled musicians in conjunction with a strong auto-ethnographic element.

Section 5.2 opens the discussion on interpersonal interaction with an examination of the phenomenon known in the USA as the spread effect. Beatrice Wright first coined the phrase ‘the spread effect’ in

her book 'Physical disability: a psychological approach' (1960, pp.1-408) where she describes the phenomenon whereby physical impairment can be 'perceived as spreading to other physical aspects of the person' (Wright, 1960, p.118). This is followed in Section 5.3 by a consideration of the perception of others that disabled people represent a burden on both individuals and society with examples from the data provided by PhD project participants and my own experiences. Section 5.4 Also contains examples drawn from PhD participants and my experiences. It discusses the tendency to avoid interaction with disabled people, a phenomenon that caused me major issues while attending university. The discussion on avoidance is followed by Section 5.5 which looks at pity, a factor that arose in the interviews with PhD project participants and one which is discussed in Chapter 2 in relation to the personal tragedy model of disability. Section 5.6 follows on from the discussion on pity with a topic that is closely related, the prevalence of low expectations. This consideration expands on the discussion in Chapter 2 and considers examples from PhD participants Abbie and Rose in particular.

Another element of interpersonal interaction that is examined in this chapter is that of bullying which is discussed in Section 5.7. Many of the PhD project participants referred explicitly to bullying, but Adam's story stands out as being particularly relevant as he devoted a significant amount of time in his interview recounting his experiences and the impact they have had on him. Adam's story is contextualised with references to works by researchers such as Corker and Davis (2003, pp.75-90) and Hollomotz (2012, pp.477-493).

The range of attitudes and perceptions discussed in this chapter show the plethora of issues related to interpersonal interaction that disabled people experience. The data in my PhD project show that these attitudes and perceptions can have a detrimental impact on the lived experiences of disabled people so the next section in this chapter, Section 5.8 looks at how these factors impact on disabled people with a focus on the internalisation of negative attitudes and perceptions.

Despite the prevalence of negativity in my PhD project data, there are still some references to positive experiences. Section 5.9 examines these instances by discussing examples from the interviews with PhD project participants Suzie, Martin and Abbie as the interviews with these participants featured more elements of positivity than any other interviews. Section 5.9 is followed by a summary of Chapter 5 and a brief indication of the content of Chapter 6.

5.2 Does he take sugar? The manifestation of the spread effect

For disabled people, the impact of interpersonal interaction can have varying effects. Perhaps the effect that has the biggest impact on disabled people is the negative effect of interpersonal interaction where attempts at humour or, bullying or patronisation can cause offence or distress; however, it is my view that a lack of interpersonal interaction can also have a negative effect on disabled people. Among the factors that can have a negative impact on the lives of disabled people is described in Chapter 2 and is known in the USA as ‘the spread effect’ which is a concept that describes the assumption that one impairment will automatically be accompanied by others (Keany and Glueckauf, 1999, pp.139-152; Dion and Walster, 1972, pp.285-290; Shontz, 1984, pp.77-84; Dembo et al. 1975, p.39). For example, the following quote from Abbie’s interview demonstrates one way in which this phenomenon can manifest:

Abbie- there was one time in the ~Harp Institute in ~Eaglesfield where there was this lady, she was German, she had quite good English, she was kind of the head organiser of that night where myself and two other blind musicians were playing, and, the problem was (.) she didn’t really talk directly to me, it was almost like, talking to my mum.

Abbie; Clarsach player, pianist, singer, composer

The experience described here by Abbie suggests that the woman she was talking to was being influenced by the spread effect. The result of this negative assumption was that Abbie was left feeling angry and indignant; when asked how this encounter made her feel she replied:

Abbie- quite angry (.) and just (.) it just- it's archaic isn't it really, you know? They should be- they should know better really, nowadays.

Abbie; Clarsach player, pianist, singer, composer

This phenomenon has also been experienced by Donna who recounts an incident where she was invited to a presentation to receive an award:

Donna- I couldn't even get on the stage to accept the fucking award. Eh, and then they didn't offer me the mike to say thank you to everyone in the organisation who it really belonged to, yea? Because, because I hadn't been on stage so they just though I won't be able to fucking speak either, and that was- and that was me picking up an award.

Donna; guitarist, singer, composer

Both Abbie and Donna reacted to their encounters with the spread effect with anger and frustration. Abbie voices her frustration by saying 'they should know better really, nowadays' and Donna's exasperation is evident through her use of an expletive. These are examples of the negative impact of interpersonal interaction; however, it could be argued that these situations arise because of the lack of knowledge of the effects of impairment and Abbie's comment that 'they should know better holds particular significance. According to a study carried out in the US, frustration is a major issue for wheelchair users, particularly frustration with issues related to independence and frustration with the attitudes of other people towards disabled people (Pierce, 1998, p.120). As a full-time wheelchair user, I can empathise with the emotions experienced by Abbie and Donna, particularly with the frustration they feel during social interactions. However, in addition to the spread effect, other misconceptions are reported by participants. One common misconception is highlighted by Rose who is a wheelchair user and has Cerebral Palsy. Rose refers to a scenario that she says happens to her a lot:

PA - you also have this thing when people are shocked Ellie's mum - is that Inclusion Ellie?

Rose- yea.

PA - Ellie's mum didn't know that Rose could actually come out of her chair as well. She hadn't seen you out of your chair.

George- has that happened to you before Rose?

Rose- yea, it happens a lot. I remember at my friend's wedding I got out of the chair and the groom walked in and wondered where I'd gone @@!

PA- yea because you weren't in the wheelchair @@!

Rose- yea

Rose; Digital software player, composer

This extract from the interview with Rose and her PA illustrates the breadth of the range of misconceptions disabled people experience on a regular basis and the fact that these misconceptions can impact on the people who have these misconceptions as well as the disabled people themselves. Rose's PA describes how people are shocked when they realise that Rose can come out of her chair.

This illustrates a common misconception, that if someone uses a wheelchair they will not be able to stand or walk (Ryan, 2017, n.p).



Figure 1: A miracle in the alcohol isle

My PhD project data shows therefore that misconceptions surrounding disability can generate ignorant and discriminatory attitudes. An excellent example of these discriminatory attitudes can be found in a post on social media by the actor George Takei. Takei had seen a wheelchair user stand to gain access to goods on a high shelf in the alcohol aisle of a supermarket and decided to post a photograph with the meme; ‘There has been a miracle in the alcohol aisle’ (Levis, 2014, paragraph 1) as can be seen in figure 5.1. Following Takei’s post, disabled people quickly reacted by calling attention to the negative effect that his arbitrary categorisation of the capabilities of wheelchair users can have on the way disabled people are perceived; Takei was also sharply reminded of the effect these misconceptions can have on the attitudes they encounter (Levis, 2014, paragraph 2).

Reflective comment

It could be argued therefore that the lack of knowledge of the effects of impairment is the result of a lack of interpersonal interaction; if more people interacted with disabled people they would have a better understanding of the range effects of various impairments. A very good example of this can be found in my own experiences in undertaking this PhD project. I am a wheelchair user and cannot stand or walk, until the interview with Rose who is also a wheelchair user, I assumed the limitations caused by her impairment were similar to mine. As a result, I was surprised when Rose said she could stand and walk. Consequently, when I now see or meet other people who use a wheelchair I do not automatically assume they cannot stand or walk.

The examples in this section show how ignorance of the effects of impairment can result in a misguided perception of the capabilities of disabled people and the extent of their impairment. The spread effect is the most common phenomenon I encounter, and the data in my PhD project illustrates the level of impact it can have on other disabled people. The examples of anger and frustration experienced by PhD participants shown in this section show how insensitivity and the devalued role of disabled people contribute to the ‘battered self-esteem of persons with disabilities’ (Keany and Glueckauf, 1999, p.137).

Therefore, research question 3: **How does interpersonal interaction impact on the lived experiences of disabled musicians?** can be answered partly by the findings in this section as the comments and behaviour of individuals encountered by disabled people are often driven by the spread

effect; in turn these negative comments impact on disabled people through interpersonal interaction. The way the spread effect (Wright, 1960, pp.1-408) can impact on disabled musician is typified by the example recounting PhD participant Donna's experience. Donna was not given the opportunity to go on stage to receive her award because an individual assumed she would not be able to speak, a common assumption evidenced by Abbie's comment where she refers to someone speaking to her mother rather than to Abbie directly. Abbie says this makes her angry, a reaction I can empathise with as it happens to me regularly. These examples represent only a small sample of the ways in which the spread effect can manifest but they show that it can have a significant impact on the lived experiences of disabled people and consequently bleeds into the experiences of disabled musicians as they engage with the music world. The data shows that being subjected to the assumption that a person cannot speak because they are a wheelchair user, or are blind, impacts on the way that person feels about attending or performing at events. In the field of music therapy, it is suggested that engagement with music promotes well-being (Trondalen and Bonde, 2012, p.40); however, the data in my PhD project shows that there is a tension between this aspect of musical engagement and the social implications for disabled people. This tension is just one small factor that contributes towards the answer to the overarching question asked in the title of this thesis: **where are all the disabled musicians?**

5.3 'On the whole, disabled people are a burden' The perception that interaction with disabled people will result in extra work

In addition to such phenomena as the spread effect, the perception that disabled people will be a burden is a factor that impacts on their interaction with others (Barnes, 1992, p.15). A quick search on the internet for 'disabled people burden' resulted in several posts on forums from people who do believe disabled people are a burden on society. For example, a question near the top of the first search page on the Yahoo Answers Social Science pages asks, 'Do you think disabled people are an economic burden on the country and why?' and the majority of people who contribute to the conversation post comments such as;

'On the whole, disabled people are a burden. If we take the hardcore amoral, positive economics perspective, it's easy to see that the disabled are less productive than the abled. Two hands are better than one at making a lot of stuff.' (Yahoo Answers, N.D.)

These views posted on social media are obviously not representative of the views of society as a whole, but they do illustrate how some individuals perceive disabled people and their value to society. This perception has proved problematic for some of the participants; Suzie speaks about the relationship she had with her step-mother during a passage where she is explaining what she perceives as the main barriers she faces:

Suzie- I was bullied quite a lot at home by my step mum so that meant that- and bec- and I think she struggled with the whole blindness thing, I think it just annoyed her

George- right.

Suzie- Em, because she- obviously, you need more attention, you need more... you can't just sit and watch a film, somebody's got to describe what's going on or you need to sit close-up or - you know.

George- right.

Suzie- Em, so I think she found that whole thing really irritating so I think that I took a lot of that baggage from her and took it out into the real world

Suzie; pianist, singer

Suzie goes on to say that being treated this way by her step mother and others left her feeling inadequate and defensive:

Suzie- [I] also took it- em, took baggage from the kids as the same thing to basically mean you're not-you're not good enough, and therefore you have to work 50 times as hard, put up the shield, work really hard to do your best at something'

Suzie: pianist, singer

Tregaskis asserts that an examination of how the attitudes of non-disabled people towards disability and disabled people are formed may produce results which provide disabled people an emotional structure that will help them to 'make sense of their own personal experience of disability and oppression' (2010, p.344). Perceptions of disabled people vary depending upon the context and the

disabled person's impairment (Staniland, 2011, p.36) and a report on public perceptions of disabled people states that that 'attitudes towards disabled people have improved' since 2005, (Staniland, p.70), but my PhD project shows that disabled people are still the subject of a variety of false assumptions and hostile reactions based upon these assumptions. They can be regarded as 'visually repulsive; helpless; pathetic; dependent; too independent; plucky, brave and courageous; bitter, with chips on their shoulders; evil (the 'twisted mind in a twisted body'); mentally retarded; endowed with mystical powers; and much else' (Sutherland, 1981, p.1). As discussed in Chapter 2, the media in all its forms plays a major role in informing and perpetuating misconceptions and attitudes towards disabled people. The origins of many of the assumptions and attitudes discussed by the eleven participants in this study can be traced back to representations of disabled people in the media. Colin Barnes refers to the campaigns of carers' organisations such as The National Association of Carers that are designed to raise funds to support their members. To put forward their case many have presented the people cared for as 'a constant burden'; the success of these campaigns Barnes asserts is demonstrated by the association of the term 'carer' with self-sacrifice and martyrdom (Barnes, 1992, p.15).

As shown by Suzie's comment about her step-mother's irritation at Suzie's impairment, being perceived as a burden can impact on her emotional well-being as she carries her 'baggage' out into the real world. Attitudes like that of Suzie's step-mother emerged as a key area of concern for most of the participants and are evident through the frequency of references to the attitudes of individuals and through the way these references were recounted. For example, PhD participant Robert refers to attitudes that are related to being perceived as a burden when he describes how event organisers would not supply a ramp the stage because they felt it would be 'too much hassle':

George- So, you mentioned eh, difficulties with your entertainment brand yea, what were they?

Robert- E:m, we've got the same difficulties all the time. Em, access to venues, especially in the city

George- ok.

Robert- Most em, pubs and clubs put their entertainment downstairs in a basement area and em- because most of them are listed buildings, em, I don't have access

George- right.

Robert- Em, so (.) that's probably the main difficulty that I have. Em also, the bigger venues and like, different things em, owners and managers and that don't want to em change any of em, any of their setup for you. So, the fact of hiring a ramp to put at the end of your stage for a night, that seems like too much hassle for them so it's just, em, so you're basically just I'm- and I'm also constantly fighting with a perception

Robert; percussionist, singer, comedian

Therefore, the argument presented earlier, that interpersonal interaction can help ameliorate the misconceptions surrounding impairment, must be tempered to account for the negative experiences disabled people sometimes have during interpersonal interactions. The following section looks at another example of negativity that is evident during interpersonal interaction, avoidance.

5.4 'A wall of backs', the prevalence of avoidance in relation to disabled people

One of the major consequences of issues such as misconceptions and the spread effect, is the prevalence of avoidance of disabled people. Most disabled people experience avoidance to some degree (Hunt, 1966, p.5; Park et al., p.65; Snyder et al., 1979, p.2304) and must develop strategies to deal with this negative aspect of life as a disabled person. The word 'avoidance' may seem incongruous when talking about interpersonal interaction but avoidance can take many forms. However, for the purposes of my PhD project avoidance is divided into two categories; avoidance that manifests either directly through avoiding social interaction with an individual by evading eye contact or physically distancing oneself from them, or by not responding to requests, conversation or other means of communication such as email. The following are examples of the physical aspect of avoidance.

5.4.1 Direct avoidance

In the interview with Abbie, she recalls a specific event that also had an emotional effect on her but perhaps more significantly could have had a detrimental impact on her progress though music education. Abbie is asked to describe what she feels are the positive and negative experiences during her time at school and music college. The experiences Abbie recalls as positive are:

Abbie- being able to be in quite a lot of bands throughout my musical career em in my school days, and then going to college obviously being in the choir and the folk bands there as well so, yea, those were the real positive things really'

Abbie; Clarsach player, Pianist, singer, composer

However, as Abbie refers to one notable incident at music college that made her angry:

Abbie- the teacher was a composition teacher and (.) he was quite new at the time, and em, (.) I think he was a bit kind of daunted by having- it was quite a big class that he had and he was kind of struggling to get round everybody so having somebody that was blind and needed a bit more support was a bit em (.) of a challenge for him and, I remember he sent this really quite negative email saying that 'perhaps composition isn't for you' and basically telling me to go away.

Abbie; Clarsach player, Pianist, singer, composer

Included in Abbie's comment is reference to the teacher telling her to 'basically go away' and Abbie's recollection is an example of the avoidance disabled people experience where the person who is avoiding them does so by restricting contact or reducing the possibility of physical encounters. This incident obviously had a significant impact on Abbie as she describes it very clearly in the interview and says it made her feel angry at the time.

Reflective comment

A particularly poignant experience I had can be used to illustrate the discomfort and embarrassment people experience that results in direct physical avoidance when meeting a disabled person for the first time. I was home alone, and someone came to my front door. I am used to people reacting with surprise when I open my door as they do not expect to see a person in a wheelchair but on this occasion the reaction I observed was notable. The person who came to the door was someone I had spoken to on the phone earlier and had not disclosed the fact that I was a wheelchair user. When the door opened, the visitor was looking straight ahead, expecting to meet the gaze of someone who's eyes were at approximately the same level. When he did not see someone immediately he looked puzzled, then when I moved, he look down and saw me. It was at this point he recoiled in what I can only assume was surprise or fear; his

movement was so sudden and pronounced that I was also surprised and pushed back in my chair and we recoiled in unison. Once the visitor regained some of his composure he said, 'Oh, I didn't realise you were a cr... I didn't realise you couldn't wa...sorry, sorry'. One can assume that the missing words in his sentence were 'cripple' and 'walk'. This initial encounter made the rest of our discussion very awkward and is an incident that I can recall clearly as the actions of the visitor were so excruciatingly embarrassing, not only for him but also for me. The lesson I learned from this was to always 'warn' people if possible that they will encounter a wheelchair user; this usually alleviates their embarrassment somewhat but not entirely.

This reflective comment shows just one example of many from my own experiences that could be used to illustrate direct physical avoidance. It chimes with the studies carried out by Snyder et al. (1979, pp. 2297-2306) and Park et al. (2003, pp. 65–88) whose studies confirm their assumption that most people wish to avoid physical contact with disabled people and will generally find strategies to conceal their motives for doing so.

Reflective comment

The findings of Snyder et al.'s study are particularly striking for me as throughout the period of being a disabled person I have been aware of the tendency for people to avoid me, either by physically distancing themselves from me, or through avoiding eye contact or conversation. Avoidance is so prevalent in the lives of disabled people that it can cause a degree of difficulty and stress for the recipient.

I encountered an example of the type of avoidance disabled people experience while attending a seminar with other post-graduate students. I was first to arrive as usual as this makes it easier for me to choose a seat that has the right amount of space, is close enough to the presentation to enable me to see the screen and allows easy exit from the room without causing too much disturbance to others. The room was set out as a classroom with chairs clustered around circular tables and, as the audience filtered into the room I noticed that many were gravitating toward the back of the room which I thought was normal as few people prefer to be at the front of the room. However, as the room filled, I noticed that the table at which I was sitting effectively became an 'exclusion zone'. Once the all the audience was seated it was became noticeable that all the other tables had at least two or three people at them and I was alone at my table. This became awkward when the presenter asked the audience to collaborate on specific tasks in groups; people from another table were asked to move to my table so that I would not be left out. At this point I was almost sure that I was being avoided because I was disabled, but not 100 per cent sure. My assumption was eventually confirmed however when, during the coffee break, a 'wall of backs' appeared around the coffee stand and I had great difficulty getting near the machine. Once I managed to pour myself a coffee, I was then faced with the problem of taking my drink over to my seat. Given the fact that I felt I was being avoided, I did not feel comfortable enough to ask any of the other audience members for help as this would make them and me even more uncomfortable. My solution to this problem was to ask the speaker if she would help me and she duly obliged. Further confirmation of what I perceived to be avoidance was provided at the end of the seminar when one member of the audience

approached me and said, ‘I’m really sorry everyone avoided you like that. I didn’t know what to say to you, I wasn’t sure that you could speak until I heard you ask the presenter questions’. The memory of this incident is clearly etched in my mind and since I became a full-time wheelchair user I have become increasingly aware of the behaviour of others when attending events; avoidance being the most obvious and emotive phenomenon for me personally.

The reflective comment above describes an example of what I believe is among the most common form of direct avoidance where people avoid eye contact and either move away from me or avoid sitting or standing next to me. This type of avoidance is typified by the scenario described in Section 5.2 by PhD participant Abbie as she talks about an individual talking to her mother instead of addressing Abbie directly. These cues are usually quite overt and easy to discern but the cues related to indirect patterns of avoidance can be more difficult to recognise.

5.4.2 Indirect patterns of avoidance

Direct avoidance is perhaps the least subtle and most easily recognised form of avoidance. However, indirect avoidance can be more difficult to identify but is equally distressing for disabled people. The following examples are of indirect avoidance;

Reflective comment

As a professional competing piper, I was constantly asked to prepare and play in a different area from the rest of the competitors as I had no access to the stage. This meant playing in a different environment with different sound qualities such as too much or too little reverberation due to different floor covering or being located next to or nearer sound equipment. Preparation is a very important factor in any musical performance and being relegated to a less conducive environment can put the performer at a distinct disadvantage. Even with a working knowledge of acoustics and the effect of the environment on the tone and pitch of the bagpipe (most competition judges have years of experience of playing in competitions themselves), I was constantly disadvantaged as the competition organisers did not, or would not, ensure that they were able to accommodate people with mobility impairments. This discrimination was not recognised by the event organisers and was usually avoided by the event organisers because they did not know how to resolve the issue. ‘Just do your best George, we’ll try to make allowances’ was a regular response when I pointed out the unfairness of the situation. For me, however, this was not a satisfactory solution. At many of the venues the practice area was a very long distance from the stage and, as I was walking with the aid of crutches at the time, this meant my hands and wrists would be aching and stiff by the time I reached the stage area. It also meant that my instrument was out of tune due to the longer time it took me to travel between the areas.

In my view, bringing issues directly related to my impairments to the attention of event organisers and competition judges made them anxious and very uncomfortable. Their solution to reduce their anxiety and discomfort was to avoid seeking a solution and dismiss my requests. Therefore, by ignoring my requests they were engaging in indirect avoidance.

Like most disabled people, avoidance in all its forms has become a routine factor in my daily life. However, since becoming a full-time post-graduate student it has become more salient due to the need for close encounters with other students and staff members. One noticeable factor in this avoidance however is the tendency of people, especially those in positions of responsibility, to attempt to conceal their avoidance. For example, there was a tendency for staff members to discuss sensitive issues I was having related to access and attitudes at the university with my student support assistant when I was not present. Comments such as ‘we’re very worried about George’ and, ‘how’s he doing over there?’ were made and relayed back to me by my support assistant. These comments arose from a desire to find out how I was coping with the issues that I was experiencing as a student at the university, however the people asking the questions did not feel able to ask me in person. My support assistant also happens to be my wife which in this case may have acted to obscure the boundary between what is and is not acceptable to ask a support assistant about their client. However, I was deeply affected by these ‘remote’ comments and what I perceived to be a strategy to glean information without the possibility of an embarrassing encounter involving the person in question in case he was offended, upset or highlighted an issue that they could not resolve. I felt this was unacceptable and symptomatic of how the avoidance of disabled people manifests. The emotional effect of these incidences of what I believe to be avoidance, was compounded by what I saw as the constant avoidance of any reference to my sight impairment which is discussed in Section 2.

In addition to my own experiences of indirect patterns of avoidance, PhD participant Rose recounts in her interview the problems she encountered when she asked her school if she could do standard grade music and was told she could not. A lack of resources was cited as the reason for this decision and I would interpret this as indirect avoidance due to the school believing Rose would pose problems and added burden on the school and staff. Rose’s experience is discussed further in Section 5.6. Robert also speaks about instances where he is subject to indirect patterns of avoidance. Although he does not cite one particular example, Robert talks about how when applying for a job, some organisations will choose another candidate over a person with a physical disability who they feel will be less of a financial burden. Robert’s comments are discussed further in Section 6.1.2.5.

The ‘remote’ comments and behaviour of others described in the reflective comment above exemplify indirect patterns of avoidance towards disabled people that can be difficult to identify and address and as such can have a significant impact on the lives of disabled people.

These examples of direct and indirect patterns of avoidance help to illustrate the negative aspect of interpersonal interaction which is the subject in the research question asked in this chapter. Direct patterns of avoidance have a palpable and immediate impact on the disabled person in question, but indirect patterns of avoidance are subtler and can be difficult to identify, even for the disabled person who is being subjected to them. Like disabled people in general, disabled musicians will feel the negative impact of avoidance in their daily lives and this in turn will impact on their emotional well-being. Being a musician usually means interaction with others, either through collaboration with other musicians, performing in front of audiences, or receiving tuition from a music teacher.

Many examples can be drawn from current literature in disability studies that extoll the virtues of social interaction for disabled people, for example; Pierce, 1998, p.122; Addabbo et al. 2015, p.2609. However, the data in my PhD project shows that interpersonal interaction can also be a negative factor in the lives of disabled people; specifically, it shows that disabled musicians who perform in front of a live audience are regularly exposed to negative factors through interpersonal interaction. This exposure to negative experiences is something that disabled people themselves will avoid as shown by PhD participant Donna's comment;

Donna- I won't play anywhere inaccessible so I don't have to deal with them right, right so I- so I just won't as a matter of principle, and two, I only play gigs to- for people most of the time, or something that's relav- rel- sort of related to (disability) in some way. So, the things that I'm asked to play at are quite accessible.

Donna; guitar, voice, composer

This data helps to answer research question 3: **How does interpersonal interaction impact on the lived experiences of disabled musicians?** It also addresses the overarching question asked my PhD project: **'Where are all the Disabled Musicians?'** as the discussions on passing as described by Goffman (1963, p.57) in Chapter 2, and the findings discussed later in this thesis, show that some disabled people employ methods of hiding their impairment during social interaction to avoid the negative reactions they often experience. This shows that avoidance of interpersonal interaction is not

confined to non-disabled people but is in fact a feature that also exists in disabled people's attitudes towards social interaction. Avoidance, therefore, is a component that contributes to my theory that disabled people who either engage in music making or are considering engaging in performing or seeking music tuition, will be discouraged by the negativity they believe they will experience. The impact of discouragement therefore represents a finding that adds to the current field of disability studies that considers the aspects of disability and impairment that look at social interaction, specifically on the topic of passing (Goffman, 1963, P.57; Siebers, 2004, pp.1-22).

However, avoidance is only one aspect of the negativity that interpersonal interaction can generate, another negative element that emerged from the data is the way disabled people can be objectified and patronised.

5.5 'Oh dear, poor girl' The personal tragedy model in practice

As has been shown in the preceding sections, there are many ways in which disabled musicians can be subjected to negativity. During the interviews, many participants discuss how the attitudes of others often manifest as objectification or patronisation and the way these attitudes impact on their feelings. Although Don does not refer directly to how the attitudes of others impact on him, he does make a point that suggests he experiences objectification and how that causes him to feel aggrieved:

Don- You know you haven't got a bolt through your neck or @anything @you @know. You don't walk around with eh, sort of Edward Scissorhands.

Don; guitarist, singer, composer

Don's comment is interesting in that he appears to be pointing out that he feels that he is sometimes regarded in the same way as characters from horror or science fiction films, the 'monster' from Frankenstein and Edward Scissorhands. In other words, Don feels he is regarded as an object of curiosity, fascination or perhaps even fear; Shakespeare suggests that this type of objectification by cultural representations could be described as 'fetishism' (1997, p.222). Parallels can be drawn

therefore between Don's description of how he is made to feel by the attitudes of others, and the way disabled people are often depicted as non-human in films such as *Frankenstein* and *Edward Scissorhands* where the disabled character is a vehicle used to 'project particular emotions, or which are used to represent specific values or evils (Shakespeare, 1994, p.6). It appears therefore that Don is aware of this objectification and is demonstrating resistance to this imposed 'non-person' identity through his comment and by revealing the negative impact that these attitudes have on the way he feels. These attitudes can be difficult to deal with (Ryan, 2017, n.p.); Robert describes an instance where he was approached by an audience member;

Robert- This woman came up to me, I've never met her in my life, e:m, not even- I don't even know her name I don't know anything about her and she literally came up to where I was on my- on my decks (.) and she said to me 'are you actually in that wheelchair or is it just a gimmick?' And I- I- I- I'm not being funny like em but, I basically just laughed, I literally just laughed, I didn't know how to react, I literally just laughed, and I said, 'do you think if I was able to walk I'd be sitting here right now'

Robert; percussionist, singer, comedian

Robert says he did not know how to react which may be surprising to some since Robert has been a wheelchair user for many years and been exposed to similar comments in the past. However, I often experience similar comments and have been taken by surprise at the directness of the comment. Like me, Robert may have been taken by surprise and had difficulty in responding.

Reflective comment

Robert's comment exemplifies the dilemma I have faced many times since becoming a wheelchair user, how to react when someone crosses the line into what I regard as patronising or invasive conversation. Often comments are made in innocence, intended as a joke or as a 'filler' in an awkward silence when the non-disabled person feels they should say something to the disabled person. A good example of this is a conversation that took place in a supermarket between my wife, another shopper and myself. My wife was putting our shopping trolley into a lockable compartment provided for shoppers who wished to store the trolley while they were in the supermarket's café. A man who was passing said to my wife as he nodded towards me 'I thought you were going to put him in there as well!' My wife replied, 'why would I do that?' and he said, 'it was just a joke, no need to get upset'. However, by that time it was too late, the harm was done and I realised that he saw me as an object; he did not address me or even look at me, I was just a prop for his attempt at humour. Although I try not to let comments and

situations like this affect me, it is very difficult to let go of the feeling that some people see me as less than a person. In my view, it is this type of scenario that reinforces the negative self-image that some disabled people have. When meeting someone for the first time I often wonder if they see me, or an object in a wheelchair so I have a feeling of trepidation until the initial introductions are over. Even then, I usually spend the rest of the conversation waiting for the ‘what happened to you?’ question. These concerns can make meeting new people stressful and as a result I may give a misleading first impression of my personality to the other person.

This shows that interpersonal interaction therefore can be fraught with discomfort and emotional stress for disabled people. Being subjected to weak attempts at humour and waiting for the next flippant comment makes conversation awkward and is a regular feature. Therefore, this negative aspect of interpersonal interaction may be at least partly responsible for the inconspicuousness of disabled musicians. But for his ebullient and resolute nature, Robert might have taken the ‘wheelchair gimmick’ comment to heart and been discouraged from continuing to perform. However, Abbie’s recollection of an incident provides a more explicit example of both objectification and patronisation. In response to a question asking her to talk about any negative experiences she has as a performing musician, Abbie describes the incident and her reaction;

Abbie- I was doing a gig for em the ~Eaglesfield Hawks charity, em sort of a do-good thing and em, there was this one person who did this big long spiel after I played the keyboard about my medical things. It was almost like (.) using me as a sort of fund raising ploy

George- oh right

Abbie- and the problem was he didn’t even email me or telephone me to ask, it was ugh

George- it was just done

Abbie- yea it was just done on the spot. A wee letter was written, don’t you worry!

George- So how were you feeling when that happened Abbie?

Abbie- Disappointed cause sometimes you have such high expectations of people and then they just do something or patronise you basically.

Abbie; Clarsach player, pianist, singer

In this case, Abbie was subject to both objectification and patronisation; objectification because she was being used as a tool to promote the work of the charity, and patronisation because she was being portrayed as the unfortunate disabled person who could benefit from the good work of the charity. Abbie is astute enough to recognise both of these portrayals as she says she was ‘a fund-raising ploy’ who was being patronised. Abbie’s feelings are obvious in this example, disappointment and anger, but, in common with Robert, Abbie is a strong confident person who has the resilience to get past these challenges. Donna also refers to the methods some charities employ to elicit pity:

Donna- the organisation that I helped sort of found and (work) in a few years ago got an award, they got an award from an organisation that has like a (.) a- a- sort of charity group they like to patronise of disabled people and these are very fucking patron- have you heard of The Ingroup?

George- No.

Donna- The Ingroup Club? Well just don’t go, ok? But anyway, they run this club which is supposed to help the poor disabled un-shagibles em you know, find love and maybe a shag em, it’s just dreadful. But basically, I’ve got- I got given this activism award by the people who run that group (.) for my sex rights work. But what I would- again I just couldn’t work out whether they would’ve awarded it to the organisation that year anyway, (.) or, whether they were doing it because I happen to be disabled and they quite like patronising disabled people

Donna; guitar, voice, composer

For less determined people who do not have the fortitude and resilience of Donna, Robert and Abbie, there is a concern that they will not be able to shrug off this type of treatment and be discouraged from future performances. Therefore, the negative nature of objectification and patronisation could prove to be a key element in discouraging disabled musicians from performing and add to the cumulative effect of the elements described in the preceding sections that discuss the spread effect and avoidance.

As can be seen from previous examples in this chapter, many of the issues that disabled people encounter in their daily lives arise from how they are perceived by individuals and society. As Sutherland explains ‘one thing of which all of us [disabled people] are conscious is that we are seen to be different from other people, in ways that go far beyond the actual facts of our disabilities’ (Sutherland, 1981). Swain and French describe a ‘dominant personal tragedy model of disability’

(2000), an expanded critique of which can be found in Chapter 2. This model of disability shines through in many of the participant's discussions and is a phenomenon I experience regularly. Swain and French (year) posit that it is not possible to describe a clearly delineated divide between disabled and non-disabled people based on impairment or oppression because non-disabled people can have impairments such as short-sightedness and experience oppression due to race or gender. Additionally, disabled people can be racist or sexist and as such can be just as guilty of oppression as non-disabled people. However, Swain and French indicate that there is a divide in the perceptions of disability, specifically in relation to the experience of living as a disabled person. According to Swain and French, non-disabled people 'are much more threatened and challenged by the notion that a wheelchair-user could be pleased and proud to be the person he or she is' (2000, p.570). Abbie's comment gives an indication of how she experiences this phenomenon;

Abbie- Well I think a lot of people think wow she's amazing but em (.) there has been some experiences where (.) how to say this, (.) it's kind of like people have the sympathy vote if you like

George- oh, ok.

Abbie- it's like, because I'm blind or you know, got a bad back or something it's like oh dear, you know, poor girl, you know it's like phew (.) hello!

Abbie; Clarsach player, pianist, singer

In addition to illustrating how Abbie feels she is often regarded, this comment serves as a good example of comments made by many of the participants when asked about how they feel music making has shaped the way others see them. This question was asked initially on the premise that many of the participants would describe factors related to their identity as musicians; however, following analysis of the data it has become clear that musical identity is not a major factor of concern for any of them. In fact, the analysis shows that many of the participants were more concerned with the consequences of being identified as disabled. As musicians, they will experience the same desires as non-disabled musicians to have their status validated in order to sustain a positive self-image. However, for most people, maintaining a self-concept means 'empirical validation in daily life' (Charmaz, 1983, p.170)

and consequently this desire for validation is just as common in other walks of life such as sport, academia or employment and for non-disabled and disabled people alike. Therefore, the premise that a large percentage of the participants would comment on the difficulties they encounter when trying to maintain their musical identity has been shown to be less significant than the issues participants face due to misconceptions of their lived experiences as disabled people, not just as musicians.

Abbie's comment clearly illustrates the two most common erroneous perceptions of disabled people. The first that a disabled person who engages in an activity that might challenge them is 'overcoming their limitations' or 'triumphing against the odds' and as Shakespeare puts it is 'superhuman' (Shakespeare, 2016). The first part of Abbie's comment 'people think wow she's amazing' aptly fits with Shakespeare's 'superhuman' description. The second perception, which is ably described by the personal tragedy model of disability, is the view that disabled people are useless and deserving of pity, that they 'cannot be happy, or enjoy an adequate quality of life' (Swain and French, 2004c, p.34) and is epitomised by Abbie's comment 'oh dear, you know, poor girl'.

It is interesting that Abbie displays frustration by making the comment - 'it's like phew' - in relation to the comment 'poor girl' and a less emotional reaction the more positive 'wow, she's amazing'. This suggests that the tragic view has a greater effect on Abbie's emotions than positive perceptions. Hunt describes this attitude when he discusses the various challenging aspect of being a disabled person 'The first way in which we challenge others is by being unfortunate' (Hunt, 1966, p.2). Disabled people are often regarded as leading restricted and unhappy lives and as such cannot be content (Hunt, 1966, p.2; Swain and French, 2000, p.570) and Abbie's characterization of how she feels she is often perceived chimes with Swain and French describe as the 'personal tragedy model of disability and impairment' (2000, p.569). Hunt asserts that this attitude stems from the view that the lives of disabled people must be 'tragically upset and marred forever, we must be only half alive, only half human' and when a disabled person defies this belief they are 'assumed to have wonderful and exceptional courage' (Hunt, 1966, p. 3). Hunt and Abbie's comments are perfectly aligned, Hunt is saying that if

a disabled person demonstrates success or personal achievement, they will be regarded as having overcome great odds to achieve their success. Abbie's personal experiences bear this assertion out because she has encountered this attitude first hand, Abbie's comment 'poor girl' equates to Hunt's 'being unfortunate' and Abbie's 'wow, she's amazing' equates to Hunt's 'wonderful and exceptional courage'. I would argue that, for a disabled musician this attitude devalues any achievements they have made. I contend that if a person is perceived to be starting from a lower point of skill or competency than their peers, the level of success they achieve will be correspondingly lower. In addition, due to the extra effort that is believed to be necessary to overcome the issues related to their impairment, a disabled musician will not have the means to reach the same levels of competency as a non-disabled musician. Another exacerbating factor in this scenario is the lower threshold of impairment mentioned previously in this chapter and all of these contributory factors make success in the music world a difficult goal to achieve for disabled people. Consequently, in answering research question 3: **How does interpersonal interaction impact on the lived experiences of disabled musicians?** this section has shown that factors such as objectification and patronisation along with the attitudes outlined in the personal tragedy model of disability and impairment, have a significant impact on the lived experiences of disabled musicians by devaluing their achievements and creating a barrier to success in the music world.

5.6 'She'll never do exams' countering low expectations

Attitudes that are driven by the personal tragedy view of disabled people give rise to another factor that impacts on the lives of disabled musicians, low expectations. Research has revealed that disabled people are perceived to be less likely to achieve their goals or reach the same level of attainment as non-disabled people (Office of the Children's Commissioner, 2014, p.32). In addition to the effects of the attitudes of others on the lived experiences and emotional state of disabled people, low expectations emerged as an important topic during my project. This chimes with the findings of a report by the Office of the Children's Commissioner that examined disabled children's rights in England which

states that the children and young people felt that ‘in general people still hold unhelpful, negative stereotypes about disabled children and young people. They thought that people, service providers and professionals underestimated their ability and held limited expectations and aspirations for disabled children and young people’ (Office of the Children’s Commissioner, 2014, p.18).

As disabled people interact with the ‘real world’ they encounter the routines of social intercourse referred to by Goffman (1963, p.12). During these interactions, they are automatically entering the judgement process that accompanies social intercourse with people who have lower expectations of them and these lower expectations can have a major impact on their emotional state. Some of the PhD project participants give examples of the way they are assessed by others and how these assessments impact on them. During her interview, Abbie is asked to discuss what she regards as negative experiences during her school and college days and she referred to an attitude she encountered at her school:

Abbie- I think the one thing that was (.) well negative from the blind school side of things was someone saying ‘oh, she’ll never do exams, she’ll never get up to like standard grade level’.

Abbie; Clarsach player, pianist, singer

In response to the follow up question, ‘When people say these things how does that make you feel Abbie?’ Abbie said:

Abbie- Mm, I’m a bit of a tiger when it comes to those sorts of things. I very much fight in the face of adversity if you see what I mean, I like to show people that I can do this even though I can’t see, and I’ve got back problems you know, I can still, you know, take an exam or do a performance to the best of my ability

Abbie; Clarsach player, pianist, singer

Besides the allusion to her tenacity and fortitude, Abbie refers to adversity and this suggests she regards comments like these as injurious and antagonistic. Comments such as these are indicative of the prevalence of low expectations of disabled people and, interestingly, this comment was made by a

member of staff at a school for people with visual impairment, an institution specifically established to provide education, care and support to students with visual impairment.

The effects of low expectations such as these can also be observed in the responses of other participants. For example, Rose has cerebral palsy and consequently uses a wheelchair and her speech can be difficult to understand. When asked about the low points during her journey to become a musician, Rose explains that when she was in secondary school, she wanted to do standard grades and says:

Rose- Definitely not being able to do standard grade was one of the low points because I remember coming out of the parents' evening and crying because they wouldn't let me do the grades.

Rose, digital software player, composer

Reflective comment

Through personal experience I can attest to the prevalence of low expectations of disabled people. Among the many comments and remarks I have encountered since becoming a wheelchair user, one stands out. I had recently moved to a new area and had not spoken to any of my new neighbours but had seen them, and they had seen me, from a distance. Therefore, most of my neighbours were aware that I was a wheelchair user. I had already started my PhD and was travelling into Edinburgh three days per week to work on campus and attend seminars and meetings. One of my neighbours had noticed this regular routine and during a conversation with my wife asked, 'I see George goes out in the car regularly, does he go to a day centre?' my wife responded by saying; 'no, he is doing a PhD at the University of Edinburgh and goes in to work three days a week'. This reply was met with surprise and puzzlement, but the neighbour refrained from further comment.

These examples clearly show that disabled people can experience disablist attitudes from all quarters and in many different contexts. Suzie's reference to 'taking baggage' from people out into the world reveals the way in which negative attitudes and comments can be internalised and carried into other situations. It is apparent therefore that negative attitudes like bullying, low expectations, and being made to feel like a burden have a long-lasting impact on disabled people. However, for disabled musicians, it appears that engagement with music offers a way to help deal with the internalisation of the negativity they are subjected to. Abbie counters some of the negativity she experiences by telling

people of her achievements in music, Suzie combats the internalisation of the negativity she experiences by working ‘50 times as hard’.

‘Working hard’ emerged as a strong theme from the data in my PhD project. Whether through direct reference such as Suzie’s ‘50 times harder’ quote, or through inferences like Abbie’s ‘I like to show people I can do this’, most of the PhD participants made a point of referring to how much input they feel is required to succeed as a disabled musician. Therefore, I suggest that what might be regarded as ‘over-achieving’ is being used by disabled musicians as a method of countering low expectations and represents another significant finding in my PhD project as it has been considered to any extent in existing literature or research. In Chapters 2 and 4 I discussed the work of Lubet who argues that what might be regarded as a significant impairment in the music world can at the same time be regarded as a minor impairment in the rest of society (2010. p.15). I also argued in these chapters that the threshold that marks the point where something is regarded as an impairment is lower in the music world as a result of this increased significance of ‘minor’ impairments. I now suggest that a compulsion to ‘overachieve’ and ‘work 50 times harder’ is imbued in disabled musicians because of the lower impairment threshold I suggest exists in the music world. If there is a perception that levels of impairment are more significant, it follows that musicians who have an impairment will feel they have to try harder to compensate for their impairment. Therefore, the fact that disabled musicians feel they have to work harder than others because of the increased significance of impairment in the music world can be added to the list of findings from my PhD project that help answer research question 3:

How does interpersonal interaction impact on the lived experiences of disabled musicians?

5.7 ‘Make him feel terrible’ the impact of bullying on disabled musicians

The list of negative elements that emerge from the data that are related to interpersonal interaction and can have a negative impact on disabled musicians must also be extended to include bullying. One of this PhD project’s participants, Adam, speaks with pride about his evolving role as music tutor to

aspiring disabled musicians. One of the factors that could be responsible for his strong motivation and drive to inspire other disabled people become involved in music making is the difficulty Adam faced due to bullying at school. Bullying is a strong theme that emerged through analysis of the data and so requires consideration in detail. It chimes with the findings of Corker and Davis whose work 'Portrait of Callum: The disabling of a childhood' (2003, pp.75-90) describes how bullying was an important theme that emerged from their observations and interactions with 'Callum' [pseudonym], a fourteen-year-old deaf boy. Like the study by Corker and Davis, bullying is a notable theme that has emerged in my PhD project and is evidenced by the comments of Suzie, Martin, Adam and Robert who all refer explicitly to bullying in their interviews.

Bullying is not exclusively experienced by disabled people. In the UK, it has been estimated that over 16 000 young people aged 11–15 at state school are recorded as absent with bullying being cited as the main cause and 78 000 are recorded as absent with bullying being reported as one of the reasons for absence (Brown et al., 2011, p.17). However, it has been established that disabled children and young people in England are at greater risk of bullying and its adverse consequences than non-disabled children during critical periods in their school careers and development (Chatzitheochari et al, 2016, p.14) and that in general, disabled people encounter higher levels of violence than the population average (Chatzitheochari et al, 2016, p.13; Hollomotz, 2012, p.477). Therefore, it was expected that themes related to bullying and oppression would emerge from the data in this study. Analysis of the data has confirmed this to be the case as bullying emerged as an important theme in the interviews, especially in the interview with Adam who had suffered a protracted period of bullying at school.

For the purposes of my PhD project, bullying is defined as a systematic abuse of power and is characterised as aggressive behaviour or intentional harm-doing by peers that is carried out repeatedly and involves an imbalance of power, either actual or perceived, between the victim and the bully (Olweus, 1994, p.1173). Bullying is often used to gain social status and disabled people can be regarded as 'easy targets' (Chatzitheochari et al, 2016, p.4) allowing perpetrators to improve their

social standing. Bullying manifests in two forms; direct bullying, either physical or verbal aggression such as hitting or name calling, and indirect bullying through social exclusion or rumour spreading for example (Wolke and Lereya, 2015, p.883). Figure 5.2 gives a more detailed definition of bullying;

- | |
|--|
| <p>A. Direct bullying refers to harming others by directly abusing them. It is perpetrated by one individual or a group of people. The people who are bullied:</p> <ul style="list-style-type: none">• Are threatened, blackmailed or have their possessions stolen• Are insulted or get called names• Have tricks played on them or are subject to ridicule• Are physically abused <p>B. Relational bullying refers to damaged relationships between friends and damaged status in groups. Example of relational bullying are:</p> <ul style="list-style-type: none">• Deliberately excluding a person from gatherings• Ignoring or shunning someone or breaking off a friendship• Having lies, rumours or stories spread about them <p>C. Cyberbullying is when someone tries to upset and harm a person using electronic means (e.g., mobile phones, text messages, instant messaging, blogs, websites (e.g., Facebook, YouTube) or emails). For example, a victim of cyberbullying may;</p> <ul style="list-style-type: none">• Have their private email, instant mail or text messages forwarded to someone else or have them posted where others can see them• Have rumours spread about them online• Get threatening or aggressive emails, instant messages or text messages• Have embarrassing pictures posted online without their permission |
|--|

Figure 5.2: Definition of bullying, adapted from Wolke and Lereya, (2015, p. 880)

There are few mentions of oppression by PhD project participants who acquired impairments in adulthood. However, there are participants who refer to bullying directly in their interviews; Suzie, Adam, Robert and Martin. Most references are related to the participants' time at school, but Suzie also speaks about the oppression she was subjected to by her stepmother. This oppression is referred to in an issue Suzie spoke of in relation to being regarded as a burden in Section 5.3, however in the quote Suzie also talks about the bullying aspect of her relationship with her stepmother. Suzie reports that although she was bullied at school she was not 'massively bullied' because she has adopted what she describes as a 'loud and brash exterior'. Going on to say, 'I was impervious, supposedly impervious to their attitude' suggests that although Suzie appeared impervious to the oppression she was subjected to, she was not completely immune to their attitudes. Suzie's apparent imperviousness is not replicated by any of the other participants who spoke about oppression or bullying however. Of these participants, Adam spoke in greatest depth about the impact bullying at school had on him. Adam

has neurological damage to the right-hand side of his brain which affects both his cognitive and physical abilities; according to Adam, this was one of the main reasons his fellow students bullied him over a four-year period at school:

George- you mentioned bullying at school could you tell me a bit more about that?

Adam- well, it was- it was em heavily- it was very heavily emotional because e::h, (..) the (.) the automatic thing that people thought when I was bullied was ‘oh, hit him’. But for me- and I’ve told people I’ve told them- told my friends- they are my friends now, I’ve told them when it happened and also later on (.) physical bullying, if you ever think about it, is bad [...] because I’m disabled that-that- that was a- that was a- a- push- a push point for them, that because I have difficulties with things, and because I’m not from here, and because sometimes I can’t understand them, they took that as ‘right we’ll use that as his emotional em, standpoint’, ‘make him feel terrible’

George- right.

Adam, percussionist

Adam firmly believes that much of the bullying he experienced was initiated by the fact that he has physical and intellectual disabilities and because he comes from a different part of the world with a different culture, he also feels that those who bullied him did not understand him or his circumstances at that time and this was why they bullied him. However, research suggests that aggression is frequently used to establish and maintain status with peers through dominance relationships and that bullying is viewed as a deliberate strategy used to attain dominance (Strayer & Noel, 1986). It is widely recognised that disabled people are more vulnerable than others and are ‘subject to all manner of abuse and deprivations’ (Barnes, 2008; Oliver, 2008; Hollomotz, 2012). This makes disabled people an easy target for those who wish to elevate their social status by asserting their dominance over their peers.

Although Adam says that things have changed and he is no longer bullied, he still experiences issues that originate from the bullying such as constant reminders of these traumatic events and a feeling of conflict when he relates to the people who bullied him. Adam does not know if he should defend them because they no longer bully him and have expressed remorse in doing so;

Adam- things have changed now but I'm still constantly reminded about it at different points. And that doesn't only put me in an awkward position but, it put them in it so I- I feel as if it's- it's sort of a defence sort of thing like, even though they did something bad to me they're not doing that anymore. So, I- I defend them and they would- and they do the same for me

George- right, ok.

Adam, percussionist

It is evident from Adam's comments that the bullying he suffered has had a lasting effect on him; he appears conflicted in his feelings towards his relationship with the perpetrators despite, as Adam says, things being different. It appears Adam has successfully forged a friendship with the people who bullied him in the past, but the legacy of the bullying has left him with a conflict that not only affects his relationship currently but also his thoughts towards any future relationship with the perpetrators;

Adam- I'm in my second last year of high school so that's sort of a thing as well, like adventure groups and things it like, what happens? Do we- do we not speak any more? Do we eh, carry on being- being friends? Do we decide to go on holiday together? What do we do?

Adam; percussionist

It appears that Adam feels that he would like to preserve the relationship he has with the people who bullied him as they have become friends, which is evidenced in his later comments:

Adam- we can't just (.) leave school and not see each other because a lot of people do that, but I feel as like I don't want that to happen, because I've- they've got to know me, and I've got to know them and they- they know what puts me off. I know what them- I know what they do that- that (.) kind of annoys me or whatever. So, sort of the future of (.) eh school friendship groups kind of scares not only me but my friends. So, I feel as though- that from- from the bullying side that- that's kind of gone, with the central- with the people centrally involved with it, but, we still get reminded but we try and just leave it and think 'right, what are we gonna do?'

Adam, percussionist

It could be argued that Adam is keen to preserve these relationships as it was so traumatic and difficult for him to reach the point where he could describe these relationships as friendships. Evidence shows that disabled people are more likely than non-disabled people to be isolated and separated from one another, and from sources of collective support and strength (Shakespeare, 1996, Tregaskis, 2004);

they are also less likely to have a best friend and have difficulty with making or keeping friends (Wolke and Lereya, 2015). These facts may contribute towards Adam's desire to hold on to these hard-won friendships.

Reflective comment

This has also been a major factor in my own experiences as a disabled person. During the period up to my registration as a PhD student, I was studying for my BA degree at home via distance learning. Although this was more convenient and less stressful than attending university full-time, it also meant that I was somewhat isolated from my peers and faculty staff. Consequently, and in line with many other disabled people, I was less likely to establish new relationships and was essentially reliant on family to fill the role of friends and confidants. However, although I was isolated from other students and staff in the music department because I was not based in the music department due to the issues with access, I did manage to forge some long-term relationships with one or two of the PhD students and members of staff. This happened predominantly through attending social gatherings outside the university and through my own efforts in establishing a disability research network. The people with whom I forged these relationships have become very important in the development and maintenance of both my academic career and my social life, so I can relate to the feelings Adam has regarding his relationships with the friends he has who previously bullied him. Therefore, I would suggest that lasting friendships and relationships are a rare and important commodity for disabled people and this makes disabled individuals more inclined to place a higher value on them than non-disabled people.

The process of resolving the issues that arose directly from the bullying Adam experienced involved lots of information exchanges and a period where the perpetrators 'got to know' Adam and Adam getting to know them. As Adam explained earlier, he feels that misconceptions and a lack of understanding are among the main causes of the bullying he experienced. Therefore, the traumatic process undertaken to resolve the issues arising from the bullying, such as face to face talks and intervention by parents and senior staff at the school, have made the resulting relationships between Adam and his former bullies more valuable:

George- can I ask you, what made things change?

Adam- I think it was em, it was- there was a lot of em (.) face to face talking with the people involved, and teachers, and members of- of like senior management and things. It got to that stage where a lot of people higher up then- than our class teachers who realised something was- something was wrong. That having- having em people- have- having these people being spoken to by- by people higher up than teachers, and also the parents. Parents came in and spoke, that also- that sort of changed it and- and people understood (.) if I ever do this again, this is what happens, these are the consequences, I might lose him as a friend, and he won't take you- he won't take me back. [...]

Adam, percussionist

However, the down side of the unique way in which Adam has developed his friendships is that the thought of forging future relationships scares him, and he believes his friends feel the same way. Adam believes the relationship he has with these friends would be difficult to replace, that he would not be able to find people who understand his situation to the same degree. Despite this, Adam has succeeded in establishing a path through music education.

Adam- I was bullied for em a lot of things. A lot of things physically and emotionally because physically (.) yes, I- I'm- I'm a musician I play, I teach, I do all of these things but because say (.) I have a weakness on my right-hand side, or I've had a neu- a neu- I've had neurological- I've had neurological damage to the right-hand side of my brain that, because I have- have had that I can't be a musician. But what I've sort of got from that is, I use that as- I use my difficulties as my kind of (.) spring. I use that as this is em, he is- he is a musician, he just isn't able to do everything that his job requires him to do, the way that you expect him to. Em, and I em- so I- I've kind of adapted everything em, everything that I do musically, I've adapted and ~Artwork have taken it on. They've adapted basically from my lead of how- how I- how I should be taught. Em they've adapted it to how- eh how they teach me which basically is em, everything that they do, they've done because I've said, 'this is what I need done' yea, and this is how I need it done. Em and the- the kind of- this allows me to forget about (.) all- for 3 hours a week this allows me to forget about it and forget that I have- I have a physical and neurological difficulty

Adam, percussionist

In addition to the in-depth discussion on bullying in Adam's interview, Martin also speaks about bullying in his interview. Martin is Deaf but attended a mainstream school initially then was transferred to what Martin describes as a special needs school in his second year. This transfer seems to have had a positive impact on Martin as he says;

Martin- at the time the [mainstream] school they- they thought I was just like eh badly behaved (.) whatever. The fact is just that I found it difficult to hear what the teachers were saying and also that, because of the hearing aids, eh, it was different for mainstream school. So, they- the kids were like they eh then eh, with bullying so obviously it was stuff like that. So, I went to a main- eh special needs school which they understood what was- what was wrong.

Martin; percussionist

Like Adam, Martin believes that the bullying he was subjected to was caused by a lack of understanding of his specific circumstances. However, unlike Adam, the bullying Martin experienced did not include references to his ability to play music. Adam's language can be difficult to interpret and although the comment he makes 'because say (.) I have a weakness on my right-hand side, or I've had a neu- a neu- I've had neurological- I've had neurological damage to the right-hand side of my brain that, because I have- have had that I can't be a musician' could be misconstrued as meaning 'I can't be a musician', taking the whole text in context along with a consideration of Adam's use of language in the full interview, it is clear Adam is saying 'I was bullied for em a lot of things, they think I can't be a musician because I have a weakness on my right-hand side.' Therefore, Adam feels that he is being bullied partly because the bullies do not believe he can be a competent musician. Although Adam only refers to physical and emotional bullying, it can be assumed from his comments that he was subjected to most, if not all of the types of bullying mentioned in groups A and B in figure 5.2. That is, A. direct bullying perpetrated by one individual or a group of people who harm others by directly abusing them, and B. relational bullying such as deliberately excluding a person from gatherings, ignoring or shunning someone or breaking off a friendship, spreading lies, rumours or stories about a person. Given that Adam is a teenager at the time of the interview, it would be reasonable to assume that he also experienced some aspect of the cyberbullying referred to in group C. of figure 5.2. Another example of bullying is outlined by PhD participant Carol who speaks about the weekly peer assessments in university that one of her peers used as an opportunity to express his negative attitude;

Carol- We used to do these weekly performance classes and there was this one guy- I mean I- I- no matter what I did he put me down right. It was terrible, it was- because we all had to mark each other's performances- and he always said it was @awful @@, and it wasn't in line with everybody else's you know I'd get 12 of these sheets and he always hammered me. And everybody else was- oh they had a few comments here and there, but it was in the sort of good to very good range and he was like 'that was rubbish'

Carol; violist, violinist, recorder player, pianist, bassoonist, flautist

Carol says she believes that this person did this because;

Carol- he thought I wasn't a real student in some way

George- ok.

Carol- I don't know whether it was because I was part-time or because I came straight into the fourth year or be- because he thought they were treating me specially in some way

Carol; violist, violinist, recorder player, pianist, bassoonist, flautist

The long-term effects of bullying can be considerable, and the most common examples of bullying referred to in the PhD project interviews happened at school, college or university. Figure 5.3 is taken from research that demonstrates how victimisation in school can increase difficulties for the victim in both school and later life with anxiety, poor school performance and fewer friends being a few of the issues generated (Wolke and Lereya, 2015. p.883).



Figure 5.3: Long term effects of bullying (Wolke and Lereya, 2015, p.883)

For disabled musicians, the way bullying can manifest and impact on the individual can take different forms and create differing reactions. One account of bullying in the PhD project interviews involves the negative comments on musical ability referred to by Carol which is described on page 175, and, as such, represent a typical example of relational bullying where the perpetrator is seeking to damage the status of a group member, in this case by discrediting Carol's musical ability. Carol did not react to this instance of bullying; she says during the interview 'I never queried it in any direct way'.

A different type of bullying is described by PhD project participant Adam who experienced bullying in its physical form. In this case Adam did react to the bullying, both personally and by informing the school and his parents about the abuse he was being subjected to. The disparity between Carol and Adam's reactions to bullying is perhaps understandable since Carol was older at the time and the bullying she was subjected to was subtler. However, it is interesting that both Carol and Adam were subjected to relational bullying where there were specific attempts to damage their status as a musician.

Bullying therefore is a significant factor in the negative attitudes disabled musicians encounter. Adam's comment's show that he worries about future relationships as a direct result of the bullying he experienced. Also, both Carol and Adam's bullies targeted their musicianship which might lead to an internalisation of these criticisms and lower levels of confidence in their abilities. As with many other aspects of the negativity disabled musicians encounter, bullying can manifest in a way that is specific to disabled musicians. Carol's accounts of her experiences during peer to peer assessments show that disabled musicians can have their validity questioned subtly because of a belief that they were receiving special treatment and Adam's account shows that he experienced the same questioning of validity as Carol. Having one's competence or validity questioned is an obvious source of negativity and difficulty for any musician or student of music, however for a disabled musician who has other negative attitudes to factor into their involvement with music, bullying must be regarded as another contributor to the negative factors that impact on disabled musicians and why disabled musicians appear to be under-represented. I would suggest that there is a cumulative effect produced by the

oppression disabled people experience as part of their daily lives, and the type of bullying described by my PhD project participants and as such is a significant element of interpersonal interaction that impacts on the lives of disabled musicians. The cumulative effect of bullying in their everyday lives and the bullying they experience related to their musical competence, means disabled music students will be affected to a greater extent than their non-disabled peers by bullying.

Although Chatzitheochari et al. (2015, pp.1-19), Davis et al., (2003, pp.75-90), Hollomotz (2012, pp.477-493) and Wolke and Lereya (2015, pp.879-885) discuss the issues raised by bullying and oppressive behaviour, my PhD project builds on extant literature by revealing that bullying and related issues have a greater impact on the lived experiences of disabled music students due to long-lasting emotional effects on their confidence and perception of their value as a musician. The resultant effect of the bullying disabled music students experience can therefore be added to the negative factors that impact on the lived experiences of disabled musicians and help to answer research question 3: **How does interpersonal interaction impact on the lived experiences of disabled musicians?**

5.8 Internalising negative attitudes and low expectations

Bullying is a typical example of the type of attitudes that can influence interpersonal interactions. However, as has been discussed in the preceding sections of this chapter, there are various ways in which negative attitudes can manifest. As access to the built environment continues to improve, it is essential that a corresponding improvement is seen in attitudes towards disability and disabled people. For people with mobility impairments such as wheelchair users, increased access means a greater probability that they will interact with others. It follows therefore that this increased contact will mean more encounters with negative attitudes and, due to the possibility of internalisation of this negativity, this in turn could be detrimental to their quality of life, (Aiden and McCarthy, 2014, p.13). However, negative attitudes can also be encountered closer to home and from people who are close to us. In these situations, instead of the negativity arising at the point of interaction with others, the individual

will carry the negativity out into the world where they interact with others. This is evidenced by Suzie's comment when describing her step-mother's negative attitude towards Suzie's blindness in Section 5.3 where she says she took the 'baggage' out into the real world.

Suzie's comment shows that negative attitudes can be internalised and this in turn can result in difficulties when interacting with others. It can be surmised that the shield Suzie refers to along with her lower self-esteem and tendency towards over performance inevitably results in a feeling of 'difference' and separation or isolation which will exacerbate the tendency for people with impairments to experience exclusion from various aspects of life due to factors such as environmental barriers, limited access to education, and the negative attitudes of employers towards employing them.

Another factor for consideration when exploring internalised negative attitudes is the fact that disabled people are often believed to be 'passive and incapable people, objects of pity and of aid' (Shakespeare, 1994, p.288). These negative perceptions and low expectations can be internalised and cause a lack of confidence and reluctance to engage in social activities. In a report which contains the findings from a series of surveys commissioned by the charity 'Scope' it was found that 'people who perceive themselves as stigmatised may also internalise the negative attitudes that they encounter in a disabling society. This in turn can have an impact on people's quality of life and wellbeing. Of the disabled people who reported they had faced challenges in several areas of their lives, around a quarter (24%) said they would like to see a change for the better in their own anxiety/lack of confidence.' (Aiden and McCarthy, 2014, p.13). Examples of internalisation pervade the interviews with the eleven participants. For example, Suzie refers to a time when she was experiencing what she describes as a 'crisis of confidence' when she stayed at home and did not do anything apart from write songs by herself. Once she began to address her lack of confidence by forcing herself to engage in social and physical activities such as going to the gym and cooking, she reached a point where she realised she had been accepting of the perception that she was a victim and was not going to be that victim any

longer. It was at this point where Suzie felt able to move away from what she describes as ‘victim Suzie’ and begin to forge a successful career in music;

Suzie- I just felt like I had enough of being a victim and I wasn’t going to be a victim anymore I was gonna get a kick up the arse! So, no more victim Suzie!

Suzie; pianist, singer

Suzie reached a point where her resistance became strong enough to counter the internalisation of the negative attitudes she was facing. Abbie also displays resistance to the projected status of victim, a phenomenon that causes her to feel frustration, anger and ultimately defiance. For Abbie, a negative component of being a successful musician is the perception of others that she is a victim in the way the medical model would position her in society (Barnes, 2004, p.10) who is attempting to overcome her status as a ‘poor girl’, someone who has significant disadvantages because she is blind and has restricted growth. However, like Suzie, Abbie’s reaction to what she describes as the ‘sympathy vote’ is one of defiance:

Abbie- ‘I just remind them tactfully that em, I’ve got up to doing an Honours year you know? If I just sat on my bottom all my life I wouldn’t have got to the stage where I am now’

Abbie; Clarsach player, pianist, singer

Like many of the participants interviewed in my PhD project, Abbie and Suzie refer, or allude to, the emotional effect of the comments or actions of others. It is important to note however that the comments or incidents many of the participants refer to happened earlier in their lives; it is therefore reasonable to assume that a process of internalisation has taken place whereby the PhD participants experience long-term emotional issues as a result of the attitudes they encountered. Suzie provides a useful metaphor when she describes these long-term issues as ‘baggage’. Therefore, the internalisation of the negativity directed towards disabled musicians via interpersonal interaction is another element that can be added to the list of factors that impact on the lives of disabled musicians. The data in my PhD project show therefore that carrying that baggage as Suzie puts it is a contributory factor in discouraging disabled people from engaging in music. To internalise means to accept or absorb an

idea, opinion, belief, etc. so that it becomes part of your character; if the opinions and beliefs that have been absorbed are that the individual in question is a burden; these beliefs will actively discourage the individual from engaging in an activity that by nature encourages criticism and judgement, such as music performance or tuition. Consequently, my consideration of the internalisation of low expectations and opinions shows this to be another element that impacts on the lives of disabled musicians and in part explains why disabled musicians appear to play a less prominent role than their non-disabled counterparts in the world of music.

Up to this point in Chapter 5 the focus of the analysis has been on the negative aspects of being a disabled musician, mainly because the vast majority of experiences recounted by the participants in my PhD project, and the experiences I have had as a disabled musician and student have, in reality, been very negative. However, my PhD project shows that there are some positive factors involved in the way disabled musicians react to how they are often perceived, and some of the evidence provided equates with some of the challenges put forward in the affirmative model of disability (Swain and French, 2000, pp.569-582), the following discussion focuses on these reactions.

5.9 ‘A sense of control’ Positive experiences in the lives of disabled musicians

An important consequence of the medical and tragedy views of disability is the way in which disabled people can be made to feel disempowered (Swain and French, 2000, pp.578-579), and this premise is borne out by the data in my PhD project. Suzie, Carol and Martin all refer to control in some way with the most interesting reference being made by Suzie which is recounted in Section 4.1.2.5 where she states that she has a feeling of ‘being in control’ while performing. Suzie’s reference to a feeling of control she experiences when performing suggests she feels a lack of control at other times. This experiencing of disempowerment, a phenomenon often experienced by disabled people (Cameron, p.112) is perhaps one reason why some of the PhD project participants expressed a desire to convey a message of inspiration to other disabled people, to inspire and encourage other disabled people to keep

working towards their goals and aspirations. For example, when asked if there is anything she would like to say at the mid-point of her interview, Abbie makes a statement addressed to disabled people who are at the beginning of their journey through music education:

George- before we go on Abbie, is there anything that you'd like to mention at this point?

Abbie- I would like to just, for other people like me I would just like to say you know, keep trying and eh, find a way that works for you I think really. Cause otherwise you could be stuck for a long time really. You need to make sure you get the right support as well, the support I have now is pretty good actually.

Abbie; clarsach, piano, voice

This comment was not related to the topic of discussion at the time so was obviously something Abbie felt was important to convey. Throughout her interview, Abbie alluded to her desire to be an inspiration to other disabled people who wished to engage in music making. In this comment, Abbie appears to be attempting to draw focus away from the negative aspect of how her impairments impact on her by drawing attention to the way in which she has achieved her goals and by making an appeal to others not to give up reaching for their own goals. On the same note, Don also includes a message to others in his interview;

Don- I always feel that eh, you know if, if you can really get over to anybody without harassing them that disability is not, is not the end.

Don; guitar, voice, composer

Don referred to the investigation being undertaken in my PhD project as something that will promote awareness and it will '[take] away from the public <the right to blame people> for actually having an illness or a disability'. Don has hit upon an important aspect of disabled people's lives, the fact that blame and self-blame have a negative impact on disabled people's well-being (Vash and Crewe, 2004, p.13). The negative impact of blaming disabled people for their own situation, or as Shakespeare et al. put it - 'blaming the victim' (2017, pp.22-41) - is a major incentive for change in perceptions as outlined in Swain and French's conception of the affirmative model of disability (2000, pp. 569-582) which is described in Chapter 2 of this thesis. This shows that some of the participants wish to use

their involvement in my PhD project to convey messages to other disabled people and the general population; messages such as Abbie's to other disabled people to continue reaching for their goals, and the comments of Don who speaks about the heightening of the awareness of disability issues and the misconceptions and stigma that accompany a disability identity. This assertion is supported by another participant, Donna who as a disability activist puts over her points more forcibly;

Donna- between us as a move- as people- as a people, disabled people have been excluded and segregated. We have been afforded a lack of skill (.) because of a lack of education and the lack of inclusion that we face everywhere we go. And what I was hearing from people was, all of the skills we have got, we have to turn to the bloody pump you know? We gotta put our hands to the pump

Donna; guitar, voice, composer

Here Donna is using this research project to address the disability community, to urge other disabled people to work towards a 'positive and collective identity' (Swain & French, 2000, p.569) and is encouraging disabled people to come together to make changes in the way they are treated by the society in which they live. Donna is urging other disabled people to work towards a 'positive and collective identity'.

Reflective comment

These examples of participants trying to communicate with other disabled people and the elements of society they believe impact on their lived experiences are hardly surprising given that I also, through the medium of this thesis, am trying to alter the way in which disabled people are treated and understood. The change of focus from musical identities, to the experiences of disabled people as they journey through music education, results from my own difficulties as a disabled person and the desire to make the lived experiences of other disabled students better than my own. Therefore, I fully understand and advocate the use of this thesis by participants to encourage, motivate, and try to provide support for other disabled people.

This interest in improving the lives of other disabled students is echoed by Martin who also took time in his interview to make suggestions about how schools should be more flexible or 'think on their feet' as Martin puts it, in their attitude towards teaching disabled students. Martin has a unique way of expressing himself verbally making the meaning of his conversation sometimes difficult to follow; however, once I had spent some time with Martin I began to understand his meanings and was able to interpret his conversation well. In this case, Martin's comments have been interpreted as a suggestion

that schools adapt their teaching strategy to suit the individual student in a similar method employed by the music charity he works for:

George- is there anything you would like to add to what you've said? Anything you think you'd like to mention?

Martin- (...) No, no. To be honest the only thing I'd like to change is that, well- well I don't know if it would be possible for you to say but see like em, see what ~Lumia does- see because it's more like eh music- music- musical therapy, but em, I'd like- what I would like to say is that what I've noticed is I see like- you know every school's different, eh no sorry- yea, every school is different, and (.) what I would like if eh- if the people were like- kind of thinking on their feet a bit more like to- to help- help them because what we do is pretty much the same thing as what we do in every single school. It doesn't work as well as with that school, it doesn't very well with that school and em, it's just doing like see like some ideas that I've got for like band wise, like changing small things and that- that- small things can make a big impact, and eh, that's the way- really- really that's the way. But apart from that, no that's it.

George- that's it, ok, that's something I hadn't really thought about.

Martin- well obviously, that em, people- like kids come from like different backgrounds uh huh, and different like, parents- parents that have got like strict teaching ways or parents that are just- don't really care, don't really care. And obviously, every school's different, the teachers could be a bit more (.) like em (.) I don't- I don't want to say aggressive but they- the kids are constantly like saying like if we- if we jump out of line then obviously the teacher's going to check us. But em obviously it's different, every- every school's different and eh I do- I do do that everywhere that I go, I kind of suss out the environment before I jump in to work out what I'm going- what I'm going to do next. So that could be something you could put down maybe

George- well that's it on the machine now Martin!

Martin; percussionist

Martin's comments 'what I would like if eh- if the people were like- kind of thinking on their feet a bit more' and 'I kind of suss out the environment before I jump in to work out what I'm going to do next' suggests he feels that schools are not being flexible and adaptable in the way they teach disabled students and would benefit from adopting his methods of teaching and those of the charity he works for. However, the point being made here is that like Abbie, Donna and Don, Martin has taken the opportunity to voice his opinions through the interview and is keen to pass on his advice and knowledge to others.

Adam was also eager to talk about the knowledge and experience he has gained and how this can be used for the benefit of disabled students, albeit in a different way;

Adam- I went from coming in as a student to now it's kind of a valued- yes as a student still but I'm getting into the stages of- your teaching.

George- so you're going through that transition

Adam- yea. So, and I- and I- and I- (.) this way of teaching I enjoy because a lot of- the other tutors like they- they- mostly they're all able-bodied and e:h- and they play a variety of different instruments, but- but what I feel is that with the kids it's like I know where they're coming from. Because I think I'm the only tutor apart from ~Stuart who is eh (.) who has (.) a physical or a neurological difficulty. And from that I know exactly what- I know exactly what they're going through, and from that I can then adapt my teaching methods, eh, which have been given to ~Artwork eh, to suit that- that student. And- and I feel as though that that eh, that the kids feel they've got a student- they've got a tutor who has sort of been through what they've been through that they understand. I'm not saying that the other tutors don't but em, coming from the sense of (.) I'm in the same position as they are (.) but I'm one of their tutors.

Adam; percussionist

Adam is the youngest of the participants, at the time of interview he was seventeen and just about to sit his A levels. The music charity Adam attended was in the process of training Adam to become a tutor to the disabled musicians who attended the classes run by the charity and Adam was keen to let me know that he was no longer just a student but was also able to help other disabled people engage with music. Adam's comments show that he believes his own experiences as a disabled musician give him a special insight into the best methods for teaching music to disabled students and this theme of believing that someone who has experience of being disabled is well placed to offer advice and support to other disabled people was echoed throughout the interviews.

It appears from the comments of several of the PhD project participants that there is something of a community spirit among disabled musicians and a desire to help and encourage each other. This chimes with some elements of the in-group attributes described in Social Identity Theory (Tajfel, 1982, p.24) which is introduced in Section 2.4.1 of Chapter 2 and in which, through the establishment of uniform attitudes and behaviour, will build a positive evaluation for their group and help individuals

build and maintain their own positive identity. However, the motives of the PhD project participant's in this case appear to be less self-centred and are an expression of solidarity and support for other disabled people who wish to become musicians. This reaching out to other disabled people is evidence of a strategy to mitigate the negative impact of attitudes, comments and perceptions of others through the support of a group and as such is a method of identity management that is related to passing (Brune and Wilson, p.1) which was conceptualised by Goffman (1963, p.57) and is discussed in Section 2.3.1 of Chapter 2.

In Chapter 4 of this thesis, the account of Rick Allen's experiences as he faced the challenge of losing an arm includes reference to the members of his group Def Leppard and their support for him as he met the challenges of maintaining his status as a drummer (Saccone, pp.1-8). Also in Chapter 4, PhD participant Suzie speaks of 'being in charge of a group and being completely in control of what they feel and think' when she gets behind the piano. I have suggested that Suzie is using performance as a method of shaping the attitudes of others towards her, however it might also be posited that Suzie is creating a bridge between herself and the non-disabled people in her audience, a bridge that reduces the impact of being perceived as 'other' (Shakespeare, pp.218, 227).

In considering the positive aspects of being a disabled person in the world of music, Suzie's comments have shown that performance can and is being used to deflect the focus on the negative features of disability and impairment through performance. Performing on stage helps Suzie to control the attention of her audience and divert attention from her impairment to her skill as an entertainer. This diverting tactic is closely linked with Goffman's idea of passing (1963, p.57) and, as Wilson notes, there is often a physical and psychological cost related to (2013, p.32). However, Suzie's example of passing does the opposite as it gives her a sense of control, and for a few moments lets her experience life without a focus on her impairment. Additionally, Suzie's example also serves to show that disabled people do not always wish to embrace the affirmative model of disability and 'assert a positive identity, not only in being disabled, but also being impaired' as suggested by Swain and French (2000, p.578).

In this case Suzie is doing the opposite by deflecting attention away from her disability identity. Like many others in this PhD project, this method of deflecting attention is a finding that has not been established in existing research and presents an opportunity for further investigation.

5.10 Chapter summary

An analysis of the data in this chapter revealed that concepts such as ‘the spread effect’, ‘otherness’ and factors such as low expectations avoidance, patronisation and bullying are all ways in which attitudes and perceptions towards disabled people manifest. These factors can all be characterised as elements of one overarching theme, the poor level of understanding in relation to way disabled people really live their lives. A lack of familiarity or understanding of disability and disabled people’s circumstances can have a direct bearing on the lived experiences of disabled people. Issues such as low expectations, avoidance and objectification cause difficulties that impact on the emotions of disabled musicians and these factors play a central role in the way disabled musicians see themselves in relation to their peers and in how they believe they are seen by others. Disabled people are often seen as inspirational, Supercrips, or to use one of Abbie’s words ‘amazing’. They are also perceived as pitiful, a burden, tragic, different or ‘other’ (Shakespeare, pp.218, 227). However, there appears to be little or no middle ground in the way disabled people are regarded; these views all belong to the extremes of the spectrum of perception referred to in Chapter 2, and the findings in this chapter provide evidence that there are few perceptions of disabled people that can be categorised as belonging to the middle ground of the spectrum.

Given the profusion of negative factors that have been outlined in this chapter, it is not surprising that these factors will have a significant impact on the lives of disabled musicians. Disabled people are made to feel different, disempowered, angry and disappointed as a result of the negativity they experience, and these experiences will be no different for disabled musicians. Like non-disabled people, disabled people also have a tendency to internalise the negativity they are subjected to and as

Suzie says, 'carry it out into the real world'. Consequently, strategies are employed by disabled people to help mitigate these feelings and disabled musicians have their own ways of dealing with this negativity. Most of the participants in my PhD project have gained high level qualifications in music such as Honours Degree and Masters to demonstrate their level of musicianship and Sally speaks of having to work '50 times as hard, put up the shield, work really hard to your best at something'. Therefore, in order to achieve a status that might be achieved with fewer qualifications and less hard work, disabled musicians feel they must overachieve, to go beyond what they see as the bar that is set for non-disabled musicians. However, although the majority of findings in this chapter have been centred around negativity, some positive factors have also emerged. The use of performance to deflect focus from a person's impairment, and a sense of group identity among disabled musicians emerged from the data and can be added to the list of significant findings in relation to the impact of attitudes and perception towards disabled people.

Chapter 5 has considered how individual's perceptions and attitudes occur and how these factors affect the lives of disabled musicians. Chapter 6 investigates how as a society we are trying to reduce the negative factors that impact on the lived experiences of disabled people through reasonable adjustment, how effective these measures are, and what impact they have on disabled musicians and students of music.

CHAPTER 6: 'I'LL GET BACK TO YOU ON THAT': DISABLED MUSICIAN'S NEGATIVE EXPERIENCES IN MUSIC EDUCATION

6.1 Experiencing institutional discrimination

6.1.1 Introduction

As illustrated in Chapters 4 and 5, the attitudes and perceptions of others can directly impact on the lived experiences of disabled people in a negative way through interpersonal interaction. However, in addition to the impact of individual negative attitudes on disabled people's lives, disabled people can also be affected by the attitudes and perceptions of others indirectly, either as individuals or collectively. Chapter 5 has as its focus the impact of individual interaction on the lived experiences of the participants but in addition to the challenges they face when engaging with people individually, analysis of the findings emerging from this PhD project shows that for the PhD project participants and myself, interaction with organisations such as colleges, universities, government bodies and qualification regulators presents major challenges. Many of these challenges, if not all, are rooted in issues related to what are described as 'reasonable adjustments', provisions put in place to ensure disabled people do not experience discriminatory practices and attitudes. Therefore, Chapter 6 considers two research questions: question 4: **How do disabled musicians experience institutional discrimination?** and question 5: **How effective are reasonable adjustments at combating institutional discrimination?** Consequently, Chapter 6 is divided into two main sections, section 6.1 relates to question 4 and consists of a discussion on the issues that disabled musicians experience as they interact with institutions and organisations such as universities, colleges and qualification bodies. Following the introduction in Section 6.1.1, Section 6.1.2 looks at various aspects of institutional discrimination such as the implementation of guidelines, patronisation and disclosure of impairments. Section 6.1 is followed by Section 6.2 which relates to question 5 and begins with Section 6.2.2 which is a brief examination of the Lawrence Enquiry and relates the findings to disability issues to help provide background for a discussion on institutional discrimination and the implementation and

efficacy of reasonable adjustments. Section 6.2.3 considers the implementation of reasonable adjustments and their efficacy and is followed by Section 6.2.4 which looks at the impact of absent or inadequate reasonable adjustments then a summary of Chapter 6 in Section 6.3.

6.1.2 Institutional discrimination

6.1.2.1 ‘The days are just ridiculously massive’, institutional discrimination through the implementation of guidelines, rules and procedures

This section considers issues related to institutional discrimination and indirect discrimination, two very similar concepts that require clarification before entering the discussion. Institutional discrimination is the unequal treatment of a person or group of people by restricting access to resources such as education, housing, jobs and legal rights (Open Education Sociology Dictionary, 2017, entry: institutional discrimination). Indirect discrimination is described in Section 19 in Part 2, Chapter 2 of the Equality Act (2010) in these terms; ‘A person (A) discriminates against another (B) if A applies to B a provision, criterion or practice which is discriminatory in relation to a relevant protected characteristic of B’s’. Other sources describe indirect discrimination as an individual being treated in the same way as other people, but that treatment has a worse effect on that individual because of who they are (Citizens Advice, 2018, indirect discrimination at work - specific situations). My interpretation of these two terms therefore is; institutional discrimination is an overarching term used to describe the unequal treatment of a group or individuals by established practices of societies in general while indirect discrimination is the unequal treatment of a group or individuals that arises through the policies and practices of an institution.

The data in my PhD project shows that a significant portion of the discrimination PhD participants describe is related to the practices and procedures of institutions. Most of the issues reported by my PhD participants up to this point have been related to discrimination that arises during interpersonal interaction, that is, discriminatory practices that result from direct contact with a disabled individual. However, the findings of this PhD project show that despite Barnes et al.’s suggestion that there is an

increase in the number of disabled learners (2009, p.6), most of the participants experience some form of institutional discrimination at some point as they attended university, college or conservatoire, or take exams that are provided by a qualifications authority such as the Associated Board of Royal Schools of Music (ABRSM). A significant portion of that discrimination results from the guidelines, rules and regulations; there is, in most cases, a ‘distancing’ between the people who create and regulate rules and guidelines and the people who are subjected to those rules and guidelines, namely, the service users. An example of this distancing can be seen in the way most universities are structured as institutions and how they communicate with disabled students. University student’s usual point of contact is their tutor or supervisor but for disabled students the Student Disability Service or the administration department of their school is also an important source of support (2009, p.vi) but rarely will a student encounter a member of staff who makes up the guidelines, rules, or procedures that impact on them daily. In Chapter 4 of this thesis, I have shown that even although individuals can have impairments that are classified as being the same, these individuals can have different requirements and encounter different barriers during their time as a student (Shakespeare and Watson, 2002, p.12). However, university members of staff responsible for making up guidelines, rules and procedures in the university cannot be expected to be familiar with each student’s individual requirements, therefore they have to construct guidelines, rules and procedures in a fashion that assumes a ‘standard’ set of requirements. For example, PhD project participant Carol speaks of the issues she encountered at a university where the curriculum was not flexible enough to permit adjustments to be made that would accommodate Carol’s levels of fatigue:

Carol- There is not a conservatoire that offers a part-time course eh at undergraduate level, e:m and I've tried to get permission to do my teaching placement part-time and the- they gave it after eh (.) very close to court action really, a:nd eh then didn't quite sort of follow through on it actually being part-time. Then there was the government requirements which were full-time agai:n and- so that is the repeated barrier for me in- in progressing is that you have to be capable of run- and particularly in music courses. They want to include non-music students in things like orchestra and choir and whatever, so you can have a nine o'clock lecture and choir at eight o'clock at night

George- ok.

Carol- So the days are just ridiculously massive.

Carol; violist, violinist, recorder player, pianist, bassoonist, flautist

Carol was met with resistance by the university when she asked for more flexibility in her schedule, an issue also raised by Hannam-Swain in her journal article 'The additional labour of a disabled PhD student' (2018, pp.138-142). I suggest that this resistance to Carol's request is because the university staff have been instructed to deliver tuition over a specified timescale and to a specified number of students. In order to achieve this, they must construct a timetable that meets these obligations in the least disruptive and most efficient manner and, in my view, this is usually achieved by using the capabilities of a non-disabled student's capabilities as benchmark and construct the curriculum to suit students with these capabilities. This is a reasonable assumption since using 'normal' capabilities as a benchmark against which the capabilities of disabled people is measured is a phenomenon well known to the world of disability studies, for example; Darling, 2003, pp.881-895, Swain & French, 2000, pp. 569-582, Shakespeare, 1996, p.7 and Goffman 1963, pp.41-42. Consequently, timetables and curricula will not be set up in a way that provides access to those who have specific requirements and making discrete adjustments is the only way to enable students who have specific requirements access to courses and facilities. It is apparent therefore that the implementation of reasonable adjustments plays a crucial role in providing access to tuition for disabled students but for Carol these adjustments were ineffective. As such, Carol's example helps to answer research question 3: **How do disabled musicians experience institutional discrimination?** and research question 4: **How effective are**

reasonable adjustments at combating institutional discrimination? in that Carol experienced institutional discrimination because reasonable adjustments were either inappropriate or ineffective in this case.

Universities and colleges are not the only sources of indirect discrimination for disabled musicians and disabled music students, and indirect discrimination against disabled musicians can also be found in private practice. For example, private music tutors regularly teach students and established musicians who are aiming to gain a music qualification and these tutors are often guided, governed and restricted by the rules and regulations of qualification awarding organisations. These organisations include The Associated Board of Royal Schools of Music (ABRSM) and Trinity College London who oversee the majority of music grading qualifications in the UK. Therefore, tutors must structure their teaching in a way that enables students to achieve each grade or qualification, and this means that their practices are strongly influenced by the grading system and ultimately the awarding body. Like colleges, schools and universities, barriers to music education are also evident in the private sector of music education and these barriers can have a profound impact on disabled music students. Therefore, the autocratic implementation of rules and policies pertaining to music exams and qualifications can hinder or prevent disabled people from accessing the examination process thus obstructing their career path in music. My PhD project shows therefore that, while investigating indirect discrimination through the implementation of guidelines, rules and procedures, I have found examples that help to answer research question 4: **How do disabled musicians experience institutional discrimination?** And question 5: **How effective are reasonable adjustments at combating institutional discrimination?** by explaining how disabled musicians can experience institutional discrimination. My PhD project also shows that despite the provision of reasonable adjustments such as providing Braille, these adjustments are only effective at combating institutional discrimination if they can be tailored to compensate for the specificity of the limitations generated by individual impairments. However, in some cases reasonable adjustments are not implemented so it is difficult to say how

effective they are. For example, it took nine years for Carol to complete her degree, not because she experienced chronic fatigue, but because the teaching schedule at university was not flexible enough to allow her to rest at appropriate times and there were no adjustments in place. This chimes with the experiences of Hannam-Swain (2018, pp.138-142) who speaks about ‘the complexities of juggling the additional time-consuming events which occur when you are disabled, with PhD time, a home life and work’. I suggest that, because the universities in question did not provide a reasonable adjustment to the teaching schedule for Carol, they engaged in practices and procedures that could be construed as indirect discrimination (Equality Act, 2010, Section 19).

6.1.2.2 ‘They love running that plug and humiliating us’, considering patronisation and pity from an institutional perspective

Institutional discrimination can be explicit in nature such as obstacles to gaining physical access to a building or the type of issue outlined in the previous section on the provision of a support mechanism such as Braille. Barriers to music education and performance can also take more subtle forms however such as discouragement and pity. Shakespeare argues that ‘Charities operate by presenting extremely demeaning images of disabled people, intended to engender pity and sympathy in ‘normal’ people, who are then motivated to donate money’ (1997, p.222) and I would add that pity and patronisation are common forms of attitudes experienced by many disabled people (Swain and French, pp.569–582; Cameron, 2011, p.2; Thomas, 2004, p.1). These arguments are supported by the data in my PhD project as pity and patronisation are referred to frequently in the interviews as the PhD project participants recall specific instances of social interaction, especially with charities. As a disability activist, PhD project participant Donna expresses her feelings vehemently and makes no exception when referring to incidents and situations where she feels she was regarded with pity. An incident Donna refers to is relevant to subordination, patronisation and specifically pity:

Donna- I got given this activism award by the people who run [the In-group] (.) for my sex rights work. But what I would- again I just couldn't work out whether they would've awarded it to the organisation that year anyway, (.) or, whether they were doing it because I happen to be disabled and they quite like patronising disabled people. So, they thought, 'oh, that's interesting, this organisation has a cripple, you know, up near the front

Donna; guitar, voice, composer

Donna had received a prestigious award for her work in the sex rights field but was reluctant to collect it because she believes the organisation who were presenting her with the award engage in patronisation and discrimination. Donna describes how she felt at the time:

Donna- there's that knowledge, they love running that plug and humiliating us, so I just kept saying 'I don't wanna take this fucking award, they run a really bad group that I fucking hate'

Donna; guitar, voice, composer

Therefore, without the pressure from her colleagues to go and accept it, Donna would not have accepted the award, and this highlights a different aspect of the issues that can arise as disabled people work towards or gain an award; the need to use their achievements and qualifications to resist negativity and patronisation in relation to their achievements. The drive to gain qualifications evident in most of the participants in my PhD project may also be a consequence of the lower expectations of disabled people's abilities referred to by Lubet (2010, p.16). However, in this instance Donna felt compelled to set aside her resistance for the benefit of her organisation despite the consequences. Donna also refers to patronisation when discussing her daughter who is also disabled;

Donna- my daughter was- was a young disabled person so I went and did something sort of quite unusual which was sought out (.) I think I went to a parents' group and I hated it (.) it was awful, patronising. I'd had patronising stuff from the minute my daughter was visibly different in the womb and I was already pissed off with it

Donna; guitar, voice, composer

In this instance Donna did not defer her resistance to patronisation and instead left the group and sought out people who she believed would be able to give her a non-patronising view of her daughter's disability:

Donna- So I then went off seeking people with the same impairment as my daughter, to go and see what hell they had to say because seriously what the parents had to say was a bunch of shit you know?

Donna; guitar, voice, composer

Ultimately Donna decided to demonstrate her resistance by becoming a disability activist and is now heavily engaged in demonstrations and other ways of highlighting the difficulties disabled people face.

In addition to Donna's references to patronisation in the interviews, Abbie also mentions patronisation and exhibits a similar desire to resist it. Abbie refers to a specific event she attended;

Abbie- I was doing a gig for em the ~Eaglesfield Hawks charity, em sort of a do-good thing and em, there was this one person who did this big long spiel after I played the keyboard about my medical things. It was almost like (.) using me as a sort of fund raising ploy

George- oh right,

Abbie- and the problem was he didn't even email me or telephone me to ask, it was ugh,

George- it was just done,

Abbie- yea it was just done on the spot. A wee letter was written, don't you worry!

Abbie; Clarsach player, pianist, singer, composer

When asked how this incident affected her Abbie replied:

Abbie- Disappointed cause sometimes you have such high expectations of people and then they just do something or patronise you basically.

Abbie; Clarsach player, pianist, singer, composer

Abbie's reference to patronisation shows that it can have a significant adverse effect on disabled people, an effect that can influence the way in which disabled people believe they are valued in society. The following reflective comment serves as an example of how being subjected to patronisation can impact on how a disabled person's view of a particular situation:

Reflective Comment

Donna and Abbie's comments chime with how I used to feel when I was awarded a prize in a piping competition. Although I was happy to be in the prize list, this happiness was accompanied by doubt and uncertainty; I would ask my wife 'do you think I was given a place in the prize list because the judges felt sorry for me or it makes them look good to be giving the token disabled person a prize?' During my piping career I had many tutors and the actions of one tutor in particular added to my concerns about being given a prize out of sympathy. The tutor in question was a senior judge on the piping circuit, who would phone the other judges on occasion to tell them that I would be competing in a competition they were judging. One phone call was made during one of my tuition sessions, he said to one of the judges due to adjudicate at my next competition; 'George will be competing in front of you at Strathcalder¹ next Saturday, you know, the crippled boy²'. Hearing this came as a shock to me. I was aware that others in the piping world saw me as different or as a problem, but I did not realise that my tutor saw me in this way too. The emotional impact was made worse by the fact that he did not have any second thoughts about describing me this way in my presence. During a subsequent discussion about my impairment, my tutor told me that it was best to 'forewarn' the judges so that they would not be 'put off' by the fact that I used crutches and played sitting on a high stool. He also told me that I would have to work twice as hard as other competitors to reach my goal and that I would have to make sure my pipes sounded 'ten times better than everyone else to offset any issues resulting from the chanter being closer to the ground. It was made clear to me therefore that no allowance would be made for the disabilities resulting from my impairment and to reach my goal of competing in the Gold Medal at The Northern Meeting, I would have to work harder than my competitors. These issues created added pressure for me as I competed and left me feeling less secure in my ability as a player, despite having been a successful competitor before I became disabled. They also left me feeling that I was always 'catching up', that the other competitors had an unfair advantage and I would have to play twice as good as them to get in the prize list.

¹ The name 'Strathcalder' is used to preserve the anonymity of those concerned

² Although the phrase 'crippled boy' might initially appear to be an instance of discrimination infantilising (Robey et al., 2006, p.442) as I was in my late thirties at the time, in this case it can be divided into two separate elements; the discriminatory element which is the use of the word 'cripple', and the use of the colloquialism 'boy' which is commonly used in place of 'guy' or 'bloke'. At the time, I was affected not by my tutor's use of the word boy but was very disappointed by the ease with which he used the word cripple as an adjective to describe someone who was a very close associate and friend.

This reflective comment shows how self-doubt is created through previous encounters with patronisation, but it also shows that there can be clear tensions between different types of discrimination. During the same conversation, the tutor was attempting to use my impairment to influence the competition judges and at the same time was trying to make them aware that I might be

at a disadvantage because of my impairment. Through good intentions he was effectively attempting to take 'positive action' to support a person he believed was at a disadvantage which is permitted under the Equality Act (2010, p.102). However, by seeking to influence the judges my tutor was also engaging in 'positive discrimination', a phrase which Jarrett describes 'actions that seek to redress historical inequalities through a reverse principle of discrimination in favour of a disadvantaged group' (2011, p.3). According to Jarrett positive discrimination is usually unlawful, as discrimination that gives advantage to one group of people usually results in unlawful discrimination against another group who are treated less favourably in contrast (2011, p.3). Aside from being unlawful, my tutor's actions left me with doubts about my ability as a piper and the validity of my past success in competition. Questions such as 'did I win that competition because the judges felt sorry for me' and 'do the other players and officials at competitions see me as a cripple?' would come into my mind on a regular basis. Because my tutor was a senior member of The Piobaireachd Society, the body that sponsors and set the rules and regulations for most of the piping competitions (The Piobaireachd Society, n.d.), I feared that the rest of the Piobaireachd Society members, who were mostly senior judges, would also regard me as a cripple, someone to be pitied. In that respect, I would be treated differently, regarded as 'other' (Shakespeare, pp.218, 227), and singled out from the other competitors and my achievements would be cast in doubt. However, my fears of segregation and devaluation could, I believe, be avoided to a certain extent if adjustments were implemented in such a way that both judges and other competitors could see that I was not being pitied or given special consideration because of the disadvantages I experienced.

My example outlining my fears that I would be singled out due my impairment shows how institutional discrimination can be generated by a lack of reasonable adjustments and has resulted in a disabled musician being regarded with pity. Research question 3 asks **How do disabled musicians experience institutional discrimination?** and the quotes from PhD participants Donna and Abbie demonstrate how disabled people can be patronised by charities in an effort to solicit pity from the public. However,

I have also shown that institutional discrimination, through a lack of reasonable adjustments, can elicit pity within the organisation itself. Although they are generated in different ways and act upon different sections of society, the public and the members of an institution, these instances of pity have the same outcome: they impact on the confidence of disabled musicians and devalue their efforts to succeed as musicians. Given the adverse effects of institutional discrimination (MacPherson, 6.17), it is logical that disabled musicians will develop concerns related to these effects. The next section considers how disabled musicians react to these concerns and the implications for their development as musicians.

6.1.2.3 'You just got on with it', disclosure of impairments

To benefit from the effects of any adjustments that are implemented to help negate any inequality, disabled people are usually required to disclose details of their impairment. However, some disabled people may be reluctant to disclose their impairment, especially if they are from a generation where it was deemed inappropriate to talk openly about disability. PhD project participant Don refers to this in his description of the problems he experienced while attending music college;

Don- you come from a sort of a background where, or, a period of time where em, if you had something like that you didn't sort of eh, trumpet out about it and tell everybody about it. You just got on with it you know

Don; guitar, voice, composer

Don is referring here to his reaction to not being permitted to continue his degree in singing at college because his piano skills were not perceived to be at an acceptable level. Don explains that he did not try to resist the institutional discrimination perpetrated by the college whose regulations were not flexible enough to allow him to continue his studies and gain a degree. Don's comment shows that during that period, the early sixties, it was less common for people to complain and this in turn made it more difficult for disabled people to complain or highlight issues they were facing. As Don says, 'you just got on with it'.

Reflective comment

Although Don's comments refer to his experiences in the 1960's and 70's, Don's reluctance to speak up about the problems he faced as a disabled person chime with feelings I have had throughout my competing career, even up to the early part of the 21st century. I believe that I was constantly pressured by social conventions into downplaying the issues I encountered as a competing piper with a mobility impairment. I did not feel confident enough to say to the organisers of The Northern Meeting that I believed their entry requirements were discriminatory, even although I felt strongly about this issue. I was always fearful that if I disclosed the extent of the issues I was facing I would be seen as a problem and would be avoided by the event organisers and judges. Therefore, like Don I was driven by ambition and the desire to reach a specific goal but was being held back by the discriminatory practices and procedures of the establishment, in Don's case the music college and in my case The Northern Meeting.

Therefore, despite the gradual improvements in access that Barnes (2009, p.6) refers to, social conventions and structures still compel disabled people to divert attention away from issues relating to their impairments through a desire to 'fit in' and avoid being regarded as 'other'. The concept of disabled people being regarded as 'other' is discussed by Shakespeare who argues that 'disabled people could [...] be regarded as Other, by virtue of their connection to nature; their visibility as evidence of the constraining body; and their status as constant reminders of mortality' (Shakespeare, 1994, p.228). This often leads to 'passing' (Goffman, 1963, p.57), where a person who is stigmatised will attempt to conceal elements of their identity that they feel will discredit them (Barnes, ch.7, p.6). Although Barnes recognises the stigmatisation of disabled people but approaches this from a different perspective 'there is a wealth of literature from a variety of sources showing that how people deal with physiologically debilitating conditions is not only about the nature of the condition itself, but also about their access to resources: medical, material and social' (2003, p.17,18); thus Barnes's focus is on the structural barriers disabled people face. Mike Oliver also adopts a materialistic approach to impairment by focusing on the performative aspects of impairment for example (Shakespeare, 1994, p.283) but I would argue that the reluctance to speak up voiced by PhD participant Don and myself does not originate from performative issues but instead is a form of passing, an attempt to avoid 'prejudice, in the context of everyday interaction' (Shakespeare, 1994, p.249).

The analysis of issues related to the disclosure of impairments therefore has shown that individuals with impairments that are not immediately obvious such as PhD participant Don's skin condition will sometimes choose not to disclose their impairment and try to pass as 'normal' because they are worried that being labelled as a disabled person will expose them to all the issues that accompany this identity, such as discrimination and inequality. However, as Shakespeare argues, 'where a person claims to be "really normal" and tries to minimise the importance of impairment in their lives, perhaps by concealment [...] this involves considerable tensions and difficulties of managing information or interaction' (Shakespeare, 1996, p.100). In PhD participant Don's example, his perception that it was not acceptable to inform the conservatoire of his impairment meant he failed his piano exam. The difficulties of managing interaction Shakespeare suggests can arise from passing emerge later in my interview with Don when he talks more about the consequences of failing his piano exam;

Don- two or three of my friends, after I had been let go by ~Portland Music College said eh (.) 'what's going on, why were you eh, why did they put you out?' you know. I said, 'oh I don't know' I said, 'I'm not, I'm not earning or anything ##' and there were theories going around (.) it was about the ~student political activities that were happening at the time, there were certain things that were happening on the student >I wasn't in the maelstrom of that at all< mm, I really was just trying to get through my exams

Don; guitar, voice, composer

It is clear that Don had difficulty explaining to his friends why he had been asked to leave the college, so the act of passing as 'normal' (Goffman, 1963, p.57), which is described in Chapter 2, has not only stopped Don from continuing as a student of music, but has also impacted on his social circle, his interaction with others. However, because PhD participant Don's experience happened in the 1960's, context must be taken into account when considering the issues he faced.

I believe Don's decision not to disclose his impairment was driven by the worry that he would be dropped from the music course, that he would be subjected institutional discrimination. Given the fact that Don's experience at music college happened over fifty years ago and rhetoric like former Prime Minister Tony Blair's claim that it is the Government's aim 'to take down the barriers that hold people

back from fulfilling their potential' (Blair in Oliver, 2004, p.7), it could be argued therefore that time and changes in social attitudes would prevent this scenario in the present-day as universities and colleges are perceived and claim to be more open minded with regard to impairment and disabled students. However, as is demonstrated in PhD participant Rose's comment institutional discrimination can still occur:

Rose- Definitely not being able to do standard grade was one of the low points because I remember coming out of the parents' evening and crying because they wouldn't let me do the grades

Rose; digital software, composer

Rose is a woman in her twenties so the instance she relates to happened in 2005. Further, and more recent evidence of this type of institutional discrimination is provided by PhD participant Abbie who describes a comment made about her abilities in 2012 by a member of staff in the school she attended at that time:

Abbie- I think the one thing that was (.) well negative from the blind school side of things was someone saying 'oh, she'll never do exams, she'll never get up to like standard grade level ok. But actually, I did @@!

Abbie; Clarsach player, pianist, singer, composer

Abbie's comment shows that even if institutional discrimination had been eradicated in 2012 just after the comment made about PhD participant Abbie's capabilities, there would still be disabled musicians today who have been subjected to institutional discrimination. The examples shown in this discussion have demonstrated that such discrimination can have a significant impact on disabled people who wish to gain a qualification in music and I argue that one of the consequences of this institutional discrimination is that disabled people are actively dissuaded from seeking a qualification in music. Given the importance placed on qualifications and high levels of achievement by disabled people that are outlined in the following discussion, disabled people will be reluctant to engage in music

performance without a music qualification to help validate their status as a competent musician. This in turn will contribute to the under-representation of disabled people in the music world.

6.1.2.4 'I just remind them that I've got up to doing an honours year', using qualifications to validate status as a musician

Finding ways to avoid discrimination and progress in a particular field of interest is a common occupation for disabled people. Given that the music community sees impairment as a greater barrier to competence than many other fields of endeavour (Lubet, 2010. p.16), the difficulty in maintaining status as a musician is an issue that impacts on the lives of all musicians but having an impairment or injury can make this even more challenging (Schoeb and Zosso, 2012, p.134). From the data gathered in my PhD project, it has been deduced that gaining a qualification in music is one way participants have chosen to advance their music career. This resistance to prejudice can be understood as 'a social strategy employed by the research participants who are claiming authority over the nominal identity by reconstructing the label and telling stories of competence and abilities.' (Björnsdóttir, 2010, paragraph 21)

All but one of the PhD project participants have received music education at some level and eight have gained some form of qualification in music. These facts coupled with some of the comments show that most participants place a great deal of importance on music qualifications. For example, Abbie says she tells people who show her pity that she is doing her honours degree:

Abbie- I just remind them tactfully that em, I've got up to doing an honours year

Abbie; clarsach, Piano, voice, composer

This raises the question: Why do the participants place such a high degree of importance on gaining a qualification in music? One answer may be that for any individual who wishes to become a professional classical musician, a formal education in music is required (National Careers Service, N.D.) Therefore, this may be one aspect of establishing oneself as a musician that drives the

participants in this PhD project to gain high level qualifications as some are involved in classical music performance. However, not all the participants fall into this category; of the participants who have music qualifications, Suzie, Rose, Martin, Robert, Adam and Matt do not participate in what is generally regarded as ‘classical’ music (Chambers Dictionary of Music, 2006, p.132). Therefore, the motivation to gain a qualification in music cannot be explained by the requirements of a career in classical music alone. Analysis of the data suggests that disabled people do have a strong desire to gain a qualification in music.

Many of the participants have high level qualifications such as an Honours Degree and others have attended college or university, even although they did not gain a qualification. Carol describes in her interview that it took her nine years and several attempts to gain her music degree, Abbie is proud to tell people who regard her with pity that she is doing an Honours degree and Adam explains with pride that he is regarded as a ‘go to’ person at school when it comes to music;

Adam- my opinions and decisions, pretty much in school, are taken on board about that- like I- to be- to be honest I am the person people come to like (.) if they want me to- to do a certain thing for say a s- a school production or something

Adam; percussion

Therefore, for disabled people in the music world, there is a belief that having qualifications lends support to the process of validating, establishing, and maintaining status as a musician and is one way of resisting the consequences of the low expectations, and consequently low value placed on musicians who have an impairment. Treating individuals differently because they have an impairment is an act of discrimination (Equality Act, 2010, p.14) and the fact that disabled musicians feel they must gain a high-level qualification to counteract this discrimination represents an important finding that pertains to the impact institutional discrimination has on disabled musicians. which is the focus of research question 4: **How do disabled musicians experience institutional discrimination?**

6.1.2.5 'It's too much hassle', the perception in institutions and organisations that disabled people are a burden

As discussed in the previous section, the music world perceives impairment as a greater barrier than many other fields (Lubet, 2010, p.16) and in doing so compels disabled musicians to 'overachieve'. A closely related factor to the diminished value that results from the perceptions of the music world is the view that disabled people are a hindrance or a burden (Barnes, 1992, p.15). In Chapter 5 the perception by individuals that disabled people are a burden is discussed. This section will look at the same topic but with a focus on the perceptions of institutions and organisations. In addition to misconceptions regarding the lived experiences of disabled people and phenomena such as the spread effect, the data in my PhD project show that there is the perception that interaction with a disabled person will result in extra work, time and effort. In the U.K. euthanasia and assisted suicide have increasingly become the topic of debate as some disabled, elderly and physically ill people consider travelling to the Dignitas clinic in Switzerland to end their lives (Brown, n.d.). Disabled people are often regarded as being a burden (Barnes, 1992, p.15; Hollomotz, 2012, p.487) and it is clear from the instances of avoidance described in the previous chapter that some of the participants in this PhD project have first-hand experience of this attitude. Robert speaks about his views on the attitude of others towards wheelchair users and how this can impact on their opportunities:

Robert- when we go for jobs and contracts and stuff, if you're sitting there with a physical disability and there's someone there with a mental disability, the bloke with the mental disability's gonna get it because it's easier in terms of (.) they don't have to fork out for access and they don't have to fork out to- to make a difference to where things are and (.) a difference in setup because he's probably able-bodied. So that automatically goes against me before I even start talking to the guy [...] get a guy that can walk who's older than you, he might not be able to do what you can do but he walks, and he's got experience

Robert; percussionist, singer, comedian

Robert's comment above was made when he was discussing the problems he has when trying to get a job, but this attitude is something he encounters in his role as a performer too. Robert maintains that the managers and owners of bigger venues would rather avoid booking a disabled performer; they are

reluctant to change their set up as it is ‘too much hassle for them’. This avoidance comes in many forms and in many different scenarios; Robert gives some examples of this in Section 5.3 when he talks about how it ‘seems like too much hassle’ for venue managers to install a ramp for one night.

Reflective comment

Robert’s comment shows that the inconvenience and effort of making physical adaptations and accommodations can have a significant impact on the ability of performers who have a mobility impairment to find suitable employment. Employers, venue managers and event organisers find the act of changing venues or implementing adjustments too irksome as Robert says. However, I have found in my experience of performing that another factor that drives avoidance is the feeling that making adaptations will be too difficult or they do not have the knowledge to make the adaptations and would prefer to avoid the process altogether. I have experienced the attitude Robert describes where the organiser finds it too much hassle to make changes, but I have also experienced situations where organisers were ignorant of the specific requirements of disabled people and once they became better informed of my specific requirements were eager to make adaptations.

The problems Robert refers to are echoed in the writings of Allan Sutherland who, when referring to self-fulfilling prophecies, describes a similar attitude by a doctor towards someone with impaired mobility; “It’s intolerable for me to think of him making his parents’ life a misery” ... And what she means is, “If we can get rid of him into one of these dumps, we don’t ever have to think of him again.” (Sutherland, 1981, p.3).

Reflective comment

This type of negative attitude is something that I encounter regularly as a PhD student. One particularly upsetting episode I encountered was during my second year. I was made aware of a seminar that I wished to attend which was being held in a university building to which I could access but was not permitted to due to health and safety regulations. As is common in my experience with these situations, I was forced to contact the health and safety officer responsible for my school and ask him if he could find a solution to this problem. After several emails, I concluded that he was not going to respond; consequently, I could not attend the seminar. I believe that this scenario chimes with Robert’s comments, the disabled person in question is regarded as a problem or the cause of a problem and the easiest way to resolve that problem is to ignore it or push it away. A major consequence of my encounters with this attitude is the feeling that my needs are not important enough to be dealt with and that I am regarded as a burden.

Despite many changes in physical access to performance venues, schools and universities, it is obvious from the findings in this section that disabled musicians still encounter difficulties when performing

or interacting with music education facilities. Although specific to the music world, the persistence of these barriers disabled musicians face echoes the general trend in our society (Swain et al. 2004, p.1). These issues invariably arise from the way disabled people are perceived, as less valuable, less competent, or as a burden (Barnes, 1992, p.15). It is attitudes such as these that give rise to discrimination by institutions which in turn has a negative impact on the experiences of disabled musicians as they interact with the music establishment.

This section has demonstrated that institutional discrimination can be a significant barrier to performance and music education for disabled musicians. In the main, issues such as inflexible or short-sighted rules and regulations and the perception that disabled people are a burden, of less worth or are less competent create an environment of discrimination that has a significant impact on disabled musicians.

6.2 Reasonable adjustments

6.2.1 Introduction

Section 6.1 outlines some of the issues disabled musicians encounter as they interact with organisations in the music world and in the field of education. A key component of this interaction is the provision of reasonable adjustments which are designed to help negate barriers disabled people encounter. With respect to institutional discrimination, according to The Equality Act (2010, Chapter 15, p.63) ‘a duty to make reasonable adjustments applies to qualification bodies’ to negate any possibility of discrimination against disabled people, either indirectly or directly. In this section, the implementation, efficacy and impact of reasonable adjustments is discussed through a focus on examples provided by participants and my own experiences. To provide context for the analysis that follows in this section, the report on the Lawrence Inquiry is considered initially as it contains elements that are analogous with the kind of discrimination disabled people experience.

6.2.2 'The "traditional" way of doing things', relating instances of institutional discrimination found in the Stephen Lawrence Enquiry to disablist attitudes

In the report on the Stephen Lawrence Inquiry it is stated that 'Unwitting racism can arise because of lack of understanding, ignorance or mistaken beliefs. It can arise from well-intentioned but patronising words or actions. It can arise from unfamiliarity with the behaviour or cultural traditions of people or families from minority ethnic communities. It can arise from racist stereotyping of black people as potential criminals or troublemakers. Often this arises out of uncritical self-understanding born out of an inflexible police ethos of the "traditional" way of doing things' (MacPherson, 1999, 6.17). I would argue that although these observations refer to racism, they could also be used to describe the discrimination experienced by disabled people. As stated in the Lawrence Inquiry report 'such attitudes can thrive in a tightly knit community, so that there can be a collective failure to detect and to outlaw this breed of racism' (MacPherson, 1999, 6.17). For 'racism' substitute 'disablism' and this phrase describes the way in which institutions and organisations can fail to provide adequate services to disabled people. The close-knit community Macpherson describes in the Stephen Lawrence Inquiry also exists in other institutions such as hospitals, schools and universities, the places where patients, visitors and students are controlled to a certain extent (1999, Section 6.45). It is clear therefore that the implementation of reasonable adjustments is a crucial factor in enabling equitable access to facilities and services.

6.2.2.1 Don's experience of institutional discrimination in music education

In addition to the issues created by working practices and administrative procedures, some of the participants refer to barriers they faced that are created by inflexible rules and regulations. Don refers to the barrier he faced when working towards a degree in music at a music college;

Don- I did a year F.E. and e:h I got a couple of Highers, music and history because I hadn't got those at school. So, I had enough to get in after that year of F.E. to the ~Portland Music College. Got in to ~Portland Music College and e:m, I had hoped earlier to do guitar, but they lost their guitar teacher, I'm not sure of the story behind it. I ah, music (.) singing was my first choice

George- ok.

Don- and of course, I had to do piano as well as you always have to, you know, if you're a singer you have to have a certain amount of ability on the piano [...]. Em, the trouble for me in second year, eh, my singing was fine and everything else; piano - and of course what they did not take into account was, you can probably see I've got EB ((epidermolysis bullosa)) you know

Don, singer/songwriter, guitarist

Here Don refers to a situation where his impairment was not taken into account and the requirement to have a certain level of skill on the piano was an effectual barrier to his progression towards a degree. Don then goes on to explain that because this happened in the 1960's, it was not deemed appropriate at that time to highlight his impairment so that reasonable adjustments could be put in place. He then says that in more recent times it is accepted that people with impairments will ask for reasonable adjustments to be made in these situations:

George- [...] you mentioned eh, about the, your disability and your hands regarding the piano. Would you be able to talk a bit more about that?

Don- yes I could (.) it was a: a Mozart sonata and eh I had it I mean; my hands were not as bad as they are now. But of course, I had taken up piano just to do the higher, you know, do your harmony ((sniffs deeply)), your harmony exercises so on and so forth right. So that was kind of taking up, that was when I took it up, and I got through the higher and then I the:n (.) I liked the Mozart piece, I worked hard at it but just, you know there must have been some kind of interplay between e::h the psyche and, and my bodily, bodily movements you know right. E:h and, I learned to play the piece >I could play it<, but I couldn't play it consistently you know, sometimes I wouldn't, sometimes I would you know. E::h and of course, I mean nowadays, goodness gracious, you just walk into the top bloke's office and say 'look, I've got EB, you're gonna have to give me some (.) whether they do it by points method or whatever (.) they've got to take it into account yea.

Don, singer/songwriter, guitarist

It is clear that Don believes his experience at music college would be different now than his experience in the 1960's but it correlates with the issues raised in Stephen Lawrence Inquiry as it shows there are procedures that have been established over time that result in discrimination.

6.2.2.2 Compulsory use of the piano pedals; discrimination resulting from examination rules

An example from my own experiences shows that although some things have improved in relation to accessing courses and qualifications, situations still exist where disabled people are discriminated against through poor or non-existent adjustments:

Reflective comment

As an undergraduate student of music, I decided to learn to play piano and progress through the Associated Board of Royal Schools of Music (ABRSM) grades as I felt (and was also advised) that this would help me relate to the theoretical and notational aspects of music. Fortunately, I found a piano tutor who had wheelchair access to her teaching studio and was willing to help me through the grades. The ABRSM exam requires entrants to choose three pieces of music from a predetermined list of pieces for each grade. All went well until in 2007 I reached the point where I could enter for the grade five exam in which students are required to play at least one piece that incorporates the use of the piano pedals. As I was not able to operate the pedals and no alternative was obvious in the information provided by the ABRSM, I wrote to them to ask what could be done in this situation. The response was somewhat predictable as the respondent said, 'we haven't come across this before so could you leave this with me and I'll get back to you'. After several weeks, I phoned to ask if they had found a solution and the representative said they hadn't. The result was that I did not progress beyond grade four in piano.

Recently I revisited the ABRSM website to establish whether it was now possible to sit the grade five exam without playing a piece that required the use of pedals and found this information for candidates with disabilities;

Pedalling difficulties for pianists;

'Some piano candidates find that they are not able to use the pedals for various reasons, such as height, limited mobility, limb deficiency or amputation. With careful repertoire selection, this should not be an issue until around Grade 5, where pedalling is expected. From this point on it will become increasingly difficult to communicate the composer's intentions without use of the pedal.

What we can do:

We do have some information on pedal extensions, and various adaptations which may allow a candidate to operate the pedal with some other part of the body. Please contact the Access Coordinator for further information. We will pass on any details you provide us with to the examiner. Examiners always appreciate having this kind of information in advance, particularly when they may need to be sensitive while writing the mark form.

ABRSM (2017a)

It appears that people who cannot use the pedals are still required by the ABRSM to play a piece that incorporates the use the pedals in the Grade five exam (ABRSM, 2017a). While it is the case that the

use of pedals is an established and recognised element of piano playing (Chamber Dictionary of Music, p.484), and is integral to the playing of many compositions, it could be argued that this policy discriminates against those who cannot use the piano pedals. There are a great number of compositions that do not require the use of the pedals, just as there are many piano pieces that were composed to be played with one hand. Interestingly, the ABRSM website does supply information to one handed players and to avoid discrimination, the following extract describes the information;

We have examined a significant number of candidates at the lower grades who either do not have a right or left hand, or who are missing one or more fingers on one or both of their hands. We have also heard from candidates who have conditions such as syndactyly, which can limit their finger mobility. Each individual person and their particular disability will be different, and while for some candidates Grade 1 will be the highest level they can attain, others may be able to progress to further exams.

What we can do:

We will pass on any details you provide us with to the examiner. Examiners always appreciate having this kind of information in advance, particularly when they may need to be sensitive towards terminology during the exam or while writing the mark form.

Candidates are welcome to bring someone with them to assist with their music books or any page turns, as long as ABRSM is informed in advance.

If a point is reached where it is not possible to play the syllabus repertoire at the required speed or with the right legato effect, it is possible to enter for the Performance Assessment instead.

(ABRSM, 2017b)

Like players who cannot use the pedals, it could be said that one-handed players should also be able to sit ABRSM grade exams at all levels. Whether a pianist is a one-handed player or plays without pedals, they should have access to the same qualifications as players who can play with both hands and use the pedals. As previously mentioned, there are many piano pieces written to be played without the pedals or with one-hand; composers such as Bach, Saint-Saëns, Prokofiev, Rossini and Liszt all composed pieces of varying degrees of difficulty (IMSLP, 2017, n.p.). The catalogue of composers who wrote music for piano without pedals is too long to mention.

Another way in which inflexible practices and procedures impact on access to music education is highlighted in the comments of Carol. A large portion of Carol's interview includes references to the difficulties she encountered as she attended university that arose directly because of inflexible timetabling and a lack of awareness of the impact of Carol's chronic fatigue:

George- could you tell me what you think are the things that have played a part in shaping your journey through music?

Carol- eh, it's always been this time thing you know, that everything has to be full-time huge time commitments. There is not a conservatoire that offers a part-time course eh at undergraduate level, e:m and I've tried to get permission to do my teaching placement part-time and the- they gave it after eh (.) very close to court action

George- really, a:nd eh then didn't quite sort of follow through on it actually being part-time. Then there was the government requirements which were full-time agai:n and- so that is the repeated barrier for me in- in progressing is that you have to be capable of run- and particularly in music courses. They want to include non-music students in things like orchestra and choir and whatever, so you can have a nine o'clock lecture and choir at eight o'clock at night ok. So, the days are just ridiculously massive. Em, so that's got in my way over and over and over and over again and getting to that point with Niles University where they said 'yea you can come and do as much or as little as- as you want to do in order to qualify. If you want to do two afternoons a week we'll work round that, and that was so important

Carol; viola, violin, recorder, piano, bassoon, flute

6.2.2.3 Discrimination resulting from inflexible the structure of curricula

As previously mentioned, my experience at university was marred by the constant battle to make staff understand the things that were causing me difficulties and Carol also feels that she was forced to battle against established practices and procedures:

Carol- I went to ~Albany University a:nd (.) the course wasn't suitable and also, I didn't know what was going o:n, the days were too lo:ng, and I just totally went ((whistles and waves hand in a downward motion)) downhill fast

George- ok.

Carol- I mean I don't remember that who:le yea:r, it was that @@ em, eh I left after about a term and I spent nine months in # trying to get well [...] I ended up going b-back to ~Elmira University, actually to Fallon School to do an education degree ok. A:nd (.) for similar sorts of

reasons that didn't work out because it has a full-time placement on the end of it and I can't do full-time. E;m so I thought (.) I really want to finish this degree that I've been at since I was 18 years old and I still don't have one! Eh, so then I ended up going to ~Niles University and they did all my transfer credits from ~ Elmira and ~Albany and ~Orville University where I did some units via distance learning, put it all together and I did a few more @credits and @finally ended up with my music degree

Carol; Viola, violin, recorder, piano, bassoon, flute

Carol refers to 'going downhill fast' and this chimes with the way I felt when I decided I could no longer continue as a student. Carol speaks about 'trying to get well', something I could not do if I continued to experience the same issues I encountered on campus. In Carol's case, she decided to have a break of nine months to get well enough to return to university; it took less time for me to feel I could return, partly due to my decision to incorporate my experiences in this thesis, but also due to the support and encouragement of my current supervisors. My PhD project shows therefore that the working practices and procedures of organisations like universities can have a profound effect on disabled students to the point where they might give up trying to continue with their education. However, practices and procedures are not the only elements that can create barriers to access for disabled people in education. Rose's experience at school shows how people, through low expectations and misconceptions, can discourage a disabled person from progressing in music education;

Rose- definitely not being able to do standard grade was one of the low points because I remember coming out of the parents' evening and crying because they wouldn't let me do the grades'

Rose; digital software, composer

This quote by Rose is used in Chapter 5 to illustrate the issue of avoidance that many disabled people experience (Park et al., 2003, pp.65-87; Snyder et al. 1979, pp.2297-2306), but as with many of the themes that emerged from the data it overlaps with other themes. In this case Rose's experience also illustrates the barriers to music education that can be created from the attitudes and flawed perceptions of others. This premise is supported by Abbie's description of the way her teacher tried to avoid having her as a student because he said, 'perhaps composition isn't for you'. Like Rose, this was an emotional

experience for Abbie, one that could have resulted in her giving up composition were it not for her resistance.

The findings in this section help to answer research question 5: **How effective are reasonable adjustments at combating institutional discrimination?** by showing that in addition to instances of poor or inadequate implementation of reasonable adjustments, there are still situations where organisations such as universities and qualifications bodies assume they have done enough to meet the requirements of disabled people, but in fact have fallen short of providing the flexibility needed in its regulations and policies to provide access for all to their examinations or facilities.

6.2.3 'Making an entrance', the implementation and efficacy of reasonable adjustments

When considering disabled people and physical access, problems are in the main, easily recognised. However, PhD project participants mentioned other issues that are not specific to the physical aspect of access to facilities, for example; a lack of or poorly implemented reasonable adjustments, access to assistive technology such as Braille (RNIB, 2016, n.p.), rigid curriculums, negative attitudes of teachers, low expectations, and a lack of understanding of issues related to impairment and disability. However, although physical access was a concern for many of the participants, my expectation that physical access would be the dominant topic was not substantiated; it transpired that the factors mentioned above were given the same or more consideration. This may be the result of improved access more generally in the physical environment and the perception of disabled people that the physical barriers they face are less significant or have less impact on them than non-physical barriers. This view is supported by a research report commissioned by the Office for Disability Issues which shows that approximately twenty percent of respondents who wished to attend an education facility said that attitude and confidence were factors preventing them from participating. In the same report, it was found that only three percent cited difficulties in moving around the venue and two percent mentioned a lack of suitable toilets (Williams, et al., 2008, pp.1-245). However, although my

expectation that physical barriers would be the most dominant feature of the PhD project was not substantiated, they were nevertheless an important aspect of the interviews as they were discussed by Rose, Robert, Donna and Emily, they also had a major impact on my own experience as a full-time PhD student. What follows is an extract from my PhD journal which was written to record my experiences while working on my PhD at university. The extract below describes my introduction to full-time academia, my previous academic qualifications being gained through courses at the Open University, a distance learning university that did not require full-time study (Open University, 2018, n.p.). This form of learning also meant that, apart from monthly tutorials and exams, I did not have to physically attend a university building and so was somewhat protected from the issues I encountered during my PhD studies.

PhD Journal extract, September 2013

Prior to making a final decision as to which university I would like to undertake my PhD, I attended a postgraduate open day at a well-known Scottish university. The event began with a presentation and welcome talk in a hall which has steps up to the main entrance so on arrival I was informed that I would have to enter by a side door, a common experience for me. As this entrance is a fire exit it could not be opened from the outside so one of the event staff had to go into the building and open it from the inside which took some time. Consequently, I missed the beginning of the welcome talk even though I had allocated extra time for such eventualities. Another issue for me that resulted from this arrangement was that I was put in the situation where, as I must 'make an entrance'. This situation arises when everyone is already seated and settled in a dimmed room, the presentation or show has begun, and suddenly a noisy fire door mechanism is actuated, light streams in from the open doorway, and a wheelchair user and his support assistant are escorted along the front of the stage to the only adequate space located right at the front of the audience. At best this scenario makes me feel uncomfortable, at worst the resulting embarrassment can have a lasting impact on my confidence and makes me reluctant to attend such events.

The welcome talk at the open day was immediately followed by a networking lunch in a different building at a different location in the city, this meant a journey of over half a mile to reach the next venue. So, to ensure that visitors could move between the venues in a timely fashion, the university provided buses to transport visitors. However, these vehicles were not wheelchair accessible, so the event organiser apologised profusely and hastily arranged a for a taxi to transport my wife and I. Due to this last-minute arrangement, I was again late for the lunch and experienced the 'making an entrance' scenario again.

Reflective comment

Although these issues I encountered involved physical access, I feel there are other, equally significant barriers that caused me to have a poor experience. The access via the side door in question was level and the door itself was wide enough to accommodate my wheelchair and so it did not pose a problem. The main problem for me was the conspicuity of my entrance, the unwanted attention that was given to me as I entered the hall. A major factor in being a wheelchair user is the extra time needed to move around and travel between locations. Being late or last into a venue is a common experience for me and as in the example given, can result in a scenario that I find embarrassing. Therefore, to offset this as much as possible I routinely contact event organisers prior to my arrival to gain as much information about the venue and schedule of events as possible. I can then advise them of the best plan of action to suit my requirements and preferences and estimate the amount of extra time I will need. I regularly endeavour to ensure I am in position in the venue before the bulk of the audience as this minimises the disruption caused by my entrance. To this end I try to visit a venue beforehand as this allows me to ascertain the best entrance and seating position while the venue is quiet. However, in this instance the venue was too far to travel for this purpose alone, so I contacted the organisers of the event by email and phone, but it is too difficult to provide information and anticipate problems by these methods of communication and so my poor familiarity with the venue and its surroundings coupled with a lack of understanding of the barriers and issues wheelchair users face on the part of the organisers, was not possible to anticipate the issues that arose.

Comparable experiences are recounted by Rose and Donna. Rose refers to a performance she gave at a harp festival:

Rose- the other highlight was the Harp Festival. [...]

George- I'm sorry I missed that one, sounds really good.

Rose- yea, apart from the access.

George- right, so what were the problems with the access?

Rose- I thought that I'd been there before to see ~Catherine Ingles but I discovered afterwards that it was in a different building that concert so I had to get lifted up.

PA- yea we had to get some guys to come and lift the chair up so we could get you up the stairs. They had a- one of those stair-climber things but they don't- it wasn't working, or the chair wouldn't fit on properly or something, so we just roped in a couple of burly looking men to carry you up @@,

George- yea, right yea.

PA- And the problem with that one at the end was everybody wanted to speak to me, but the people wanted to get me down the stairs, so I had to- you had to scoot off.

Rose; digital software, composer

As can be seen in Rose's comment, she also relies on her own knowledge of a building and the surrounding area to avoid difficulties when attending a venue. In this case Rose was caught off guard as the concert was in a different building to the one she had expected so she had no prior knowledge of the venue. Like me, Rose's experience was marred by the time factor involved as she had to rely on others to help her out of the building and so was tied to their time schedule.

Regarding the inability to anticipate barriers for wheelchair users mentioned above, Rose goes on to describe another event she attended;

George- right, the last prompt I have for myself here is to ask you what factors you feel have the most impact on your life as a musician?

PA- yea, so ~Inclusion have come across a few issues in, mostly performances and just- it's always the other party isn't it that miss something, Inclusion are pretty on the ball but-

Rose- yea, yea

PA- your example was the concert you did for the Christmas lights on ~Dixon Street. They had a tent for the performers to go in, but they weren't able to get in because the organisers hadn't realised that- or hadn't thought about having to get wheelchairs into the (.) essentially what was a green room or backstage little tent, so you ended up outside in the cold.

Rose- freezing!

PA- freezing @@ yea.

Rose; digital software, composer

Thus, Rose's comments support my own interpretation of the cause of the problem in that she feels the organisers of the event were not able to anticipate or assess the needs and requirements of wheelchair users. This is a key finding, the failure to implement reasonable adjustments can have a

significant impact on the ability of disabled musicians to perform. Difficulties like the one experienced by Rose are not uncommon as can be seen in the following reflective comment:

Reflective comment

I have experienced numerous occasions where I was not able to access the stage at piping competitions. On these occasions, I was either forced to sit below the stage next to the audience or roll onto the stage and be helped onto my stool. The only alternative to these solutions was to withdraw from the competition or performance.

Insufficient knowledge of the physical access requirements of wheelchair users can also create problems that are not related to performance and stage access. Many aspects of daily life result in exclusion for wheelchair users who wish to further their career in music as illustrated in the following extract from the interview with PhD project participant Robert, who encountered issues while attended college:

George- ok Robert anything else you'd like to talk about before we finish?

Robert- em, let me think (.) well one- one thing that does annoy me is how some people think they know all about disability but really, they don't.

George- ok what do you mean [by that]

Robert- [well] here's something that bugged me, e:m I went to college 2 years ago- last year- 2 years ago and em I got accepted for college blah de blah de blah e:h they said access will be good, we've got a lift in the music building and (.) this that and the other and (.) different things a:nd when I started the course it wasn't in that building at all it was on top of the hill, e:m there was nobody to push me up it I had to carry a laptop and a bag full of medication a:nd em, they wouldn't allow me to put it the back of my chair, it would make the chair top heavy so I had to carry it over my neck e:m and then when I was in the music building I didn't have a fire evacuation plan. I didn't know who was coming to get me, I did know if there was an evacu-chair, this that and the other mm. I- I started that course in August, it was an August to May course, I got an evacuation plan issued on April 7th.

George- oh dear. So (.) when you applied for the [course]

Robert- [that] application was made for me by someone who didn't even know that college.

George- and did they know you?

Robert- nope, it was basically just a bit of paper, a bit of paper that says, ‘such and such said that they’ll come and get you’. But you could say that about most things when it comes to people like us, hmm, em organisations and em services and things like that. But it’s people in suits that make the decisions that don’t know the impact it has, they don’t know what it takes.

Robert; singer, percussionist, comedian

Robert’s comment at the beginning of the extract ‘some people think they know all about disability but really, they don’t’ encapsulates what I believe is the cause of many of the problems people with mobility impairments face when interacting with institutions and organisations. Most members of staff are well intentioned; they try to help and make things easier for people who have specific access requirements. However, I believe that a person who has no experience of the barriers people with mobility impairments face cannot fully appreciate the difficulties, challenges and frustration that can result from a minor issue such as a door being five centimetres too narrow or a building being located at the top of a hill. Hannam-Swain states that only her parents truly understand how much support and help she needs, (2018, p.139) and my PhD project shows that her view holds true in the experiences of the participants and my own experiences while attending university. Robert’s negative experience in his early days at college were caused by the lack of knowledge on the part of college staff and his comment that ‘they don’t know what it takes’ encapsulates my own experiences when dealing with staff in the university. Although individual staff members try to accommodate disabled students to the best of their ability, my PhD project shows that a lack of familiarity with the needs of people with specific requirements acts as a barrier to a satisfactory experience for these students.

The following extract details my first encounter with university staff and their efforts to provide access for me into the building in which I was to be based:

PhD Journal extract, September 2013

Before starting my full-time PhD course, I arranged to visit the building where I was to be based to ascertain the access and suitability of the room and environment in which I would be working. Before my visit I was informed that, as there were several stone steps at the main door of the building, a stairlift was in place to enable wheelchair users to access the building and this was the only way in which I could gain access to the building. A few weeks before I

was due to matriculate, I paid a visit to the building (which was at that time a three-hour return journey from my home) to familiarise myself with the building and the access to it.

Upon my arrival staff discovered that the stairlift was not working and so proceeded to attempt 'on the spot' repairs. After approximately thirty minutes the staff concluded that they could not repair stairlift and would have to call an engineer which would take several hours. Consequently, I was asked if I would be willing to access the building via a long metal ramp that was predominantly used to move pianos in and out of the building. Not knowing what to expect, and since I had travelled so far, I agreed, and the ramp was located and put in place. It was only once the ramp was in place I realised how precarious and frightening the experience was going to be as, once the ramp was in place, it was over ten feet long and sat over four feet above the steps at one point. As this ramp was not designed for wheelchair users there were no guard rails or similar safety features fixed to the ramp. However, I decided that I would take the risk and allow someone to push me up the ramp so that I could eventually get into the building.

Once at the top of the stairs the next barrier became apparent. Entry to the building is gained via a main doorway that has two sets of heavy, self-closing, narrow double doors. These doors are too narrow for a wheelchair user to enter by opening just one door, both doors must be opened to allow a wheelchair to pass through and so it is not possible for a wheelchair user to enter the building unaided. Entry for wheelchair users is also complicated by the narrowness of the doorway and the inner hallway. Both sets of self-closing doors must be held open by a third party, but that third party has difficulty in providing space for the wheelchair user to move forward and on several occasions one of the doors was let go inadvertently causing it to collide with my wheelchair.

Reflective comment

This extract shows how the university staff tried their best to get me into the building, but this resulted in a very poor experience for me. With hindsight, I feel I should have refused to use the ramp and postponed the visit until the access to the building was safe and less difficult. At the time, I was keen to see where I was going to be based for the next three years and this overrode my usual caution in these circumstances.

The following Journal extract also highlights the efforts of staff as they try to improve access to university buildings:

PhD Journal extract, October 2013

I was asked by the Estates Department to meet with a member of their staff in ***** to provide an opinion on improvements that could be made to the building to make it more accessible for me. I met with *** ***** who asked me to point out any major issues. The first point I made was the difficulty in getting my wheelchair through the main doors, he duly took

note of that along with some other minor points on the ground floor (I am not permitted above the ground floor in the building for fire safety reasons). We spoke about the possibility of installing a push pad on the doors to make access easier. Following this visit I emailed *** to ask if any progress had been made, he replied that nothing had been done yet but, he said 'I'll get back to you on that'. I heard nothing more from him on this subject.

Reflective comment

Ironically, even when the university appeared proactive by requesting feedback from users it failed to follow up on the recommendations. The statement 'I'll get back to you' became very familiar as I progressed through my time as a student. These extracts show how, despite measures being put in place to facilitate access for wheelchair users, difficulties can still arise if these measures are poorly implemented or there is insufficient communication with the disabled person concerned. The incident with the stairlift outside the university building arose as a direct result of a lack of maintenance of the equipment. The lift had not been used since the previous student who used a wheelchair left the school in question and consequently, staff had either not believed there was a need to keep the equipment in good order or, the more probable cause is that, because the lift had not been used or needed for some time, it had become irrelevant in the minds of the staff and other issues related to the fabric of the building were deemed more important. The latter explanation is described as the most likely because during my time as a student I have encountered situations like the stairlift problem at other parts of the university and in these situations, staff frequently explain the reason for the problem by saying 'we don't get many disabled students, so this hasn't been brought to our attention'.

The comment 'we don't get many disabled students, so this hasn't been brought to our attention' raises two major points of discussion. First, infrequent use of an access point or piece of equipment is not a valid reason for giving a low priority. For example, firefighting equipment and fire escape routes are rarely used, but need regular maintenance and inspection. If the same attitude was displayed towards these facilities, there would be serious consequences. Second, comments like these seem to indicate that there is an expectation that disabled people should police equipment and access, that the burden is with the user and not the facilitator. An interesting example of this presumption arose as I asked the university if a toileting facility could be installed for my assistance dog;

PhD Journal extract, August 2015

I was due to return from the training centre with my new assistance dog in July, so I asked the university if a dog toileting facility could be installed in time for my return. The university's Student Disability Services department agreed that this was possible, so I was asked to contact the university's Estates Department to make arrangements. The member of staff tasked with the job had never heard of a dog toilet, so I was asked if I could supply specifications and

requirements for the facility which I duly did. Unfortunately, a long and protracted dialogue ensued as the member of staff attempted to understand what was required and find a suitable location. It eventually took three months for the Estates Department to build the facility which is a bed of gravel four feet by six feet enclosed by four pieces of timber. Unfortunately, because it took so long for the university to provide the facility, I was left with a period where I had my assistance dog but had no toilet facility for him. This meant I could not work full-time on campus.

The dog toilet episode was extremely frustrating for me, especially since I had given the university three months' notice and was assured this would be ample time for the Estates Department to install the facility. During that period, I complained to senior members of staff them and asked why this had been such a problem and why the university did not have this facility in place already. I was told that, given the variety and severity of disabilities that exist, it is not possible for the university to anticipate every disabled student's needs. The university can provide some adjustments and facilities for its students, but it is up to each student to ask for less common adjustments and facilities.

Reflective comment

The PhD Journal extract regarding the dog toilet is significant for two reasons. First, I remember being surprised and disappointed that a senior member of staff in the university would believe that it was not the responsibility of the university to anticipate the need for certain facilities to be provided for disabled students. Obviously not every scenario can be anticipated, but assistance dogs are becoming more common with the launch and expansion of charities such as Guide Dogs, Canine Partners and Hearing Dog for Deaf People and organisations like colleges and universities have a duty to ensure that they make reasonable adjustments for the requirements of their students and staff (Equality Act, 2010). I believe that toilet facilities for any form of assistance dog is a basic requirement for any such organisation. Second, I was incredulous that the member of staff would believe it was acceptable to justify the failings of the university in such a way, I remember feeling patronised at the time but, in retrospect, I believe the member of staff was caught off guard because he/she did not have a good or detailed knowledge of this topic and was attempting to deflect attention away from that fact.

This incident with the dog toilet was frustrating and time consuming to the point where I felt that I had reached a point where I could no longer continue with my PhD because of these encounters. This was reinforced by another incident that happened in May 2016; as the coordinator of a disability research network based in the university, I was responsible for organising regular research seminars so in May 2016, I arranged for representatives from Drake Music Scotland, an Edinburgh based charity that provides support for disabled people who wish to engage in music making, to come to the school of

music and give a presentation of their work. The following extract from my PhD journal provides further explanation of the subsequent events:

PhD Journal extract, May 2016

One of the speakers is a wheelchair user and I anticipated that some of the audience would also have mobility impairments so, given that I also use a wheelchair, it was imperative that the building was wheelchair accessible. Since the music school at that time had a temporary ramp in place at the main entrance I felt this would be suitable. I also felt that as the focus of the seminar was on access to music the music school would be the most appropriate venue for the seminar. However, by chance I phoned the school secretary three days before the event to ask about seating and was told that the temporary ramp was to be removed the day before the seminar and there would be no wheelchair access to the building for the next twelve weeks. What followed was a round of phone calls to administrators and academic staff to try to stop the ramp being removed before the seminar. Fortunately, the contractors agreed to postpone work on the ramp for a few days so that we could gain access to the building for the seminar. This could have been an embarrassing situation for me, I had visions of the presenters and me arriving and not being able to get in to our own seminar!

As a result, I decided to phone a senior member of staff to complain. I was told that an email had been circulated to staff in the school to tell them to pass the information to any student they felt would need to know this information; however, the person responsible for informing me did not do so. To exacerbate my anger and frustration, the person responsible for organising the removal of the ramp was the person who had been tasked of helping me through the problems I was having with access to buildings, this person was described to me as my ‘go to person’. I was outraged that this go to person did not think to inform me of this action, especially since I was their only ‘go to’ student.

This ramp situation is the final straw. I’m going to speak to ***** and ***** (Senior staff members) and let them know I can’t continue like this. I think the best way to stop all this frustration and emotional stress would be to withdraw from the PhD programme. I’m sure it won’t come as a shock to either of them as I’ve been telling them for months that I’m really unhappy with my experience at the university.

This extract gives some insight into the cumulative effect of dealing with access difficulties and trying to make others understand how what seem to be minor inconveniences can cause emotional fatigue and impact on a person’s well-being.

Reflective comment

Although it might appear that the incident was minor, by the time this incident took place I had fought for three years to make the university staff understand the impact and cumulative effect of the constant need to explain my needs and battle against an attitude which I felt was endemic throughout the university. The ramp incident eroded any confidence I had left in the ability of the university staff to find adequate solutions to any of the issues I raised. In retrospect, I now

realise that I was suffering from what I would describe as ‘chronic attitude fatigue’, a fatigue that was induced by constant, heightened levels of anger and frustration with what I considered the trivialisation of the issues I raised by university staff generated by the obligation to adhere to the established practises and procedures of the university. Rules and procedures are necessary for a large organisation, however in my experience it is an inflexible attitude towards administrative procedures that can make life as a disabled student more difficult and frustrating. For example, as stated above, I asked for a push pad to be installed on the main doors of the school building and this did not happen. No reason was given at the time as to why this could not be done so I added this point to my stage two complaint against the university. This point was discussed during the investigation of my complaint and the following extract gives an insight into one aspect of the problem.

It can be seen from the issues discussed that although institutions implement reasonable adjustments they do not always result in a ‘level playing field’ for people with impairments. In a situation where a service user, in this case a university student, feels they have cause to complain, a complaints procedure is normally available to the user. Once I reached a point where I felt I could no longer fight against the issues created by the university I was advised to take out an official complaint. The following extract shows how the university’s administration system contributed to the frustration and fatigue I was experiencing and that staff at the highest level were aware of the situation but could not implement changes that would alleviate the immediate problems they were causing:

PhD Journal extract, January 2017

This month I received the final report from the investigator of my complaint [sixteen-point complaint against the university that highlights the poor experience I had as a PhD student]. Interestingly, ***** (senior staff member) was asked in their interview with the investigator if they should have intervened when a push pad was not installed on the main doors of the school building. The reply was ‘I explained that I was referring him to the Disability Office who then referred him to Fire Safety, they referred him to Estates and so it went on.’ This shows that the senior staff member was aware of the type of problems the university was causing me but either could not find a way to address them, or felt these issues were not important enough to warrant intervention. I feel that if that member of staff cannot resolve these issues who can? Where do I turn? Who do I talk to resolve these problems?

Reflective comment

The last comment in this extract show the growing resentment and exasperation I was feeling towards both the university and its staff. On reflection, I do not believe the member of staff in question was not willing to intervene because they felt these issues were not important enough, further thought on the matter has led me to conclude that a general culture of ‘if we can’t find

a solution, just ignore it and it will go away' had developed throughout the university. Hence the prevalence of the 'I'll get back to you on that' response to my requests for help.

As the issues referred to in my PhD journal and the comments of participants are experienced, it can be difficult to keep in mind that the members of staff dealing with the request or complaint are restricted by the working environment that is created and maintained by the institution they work for. It may seem therefore that many of these issues are created and perpetuated on an interpersonal level and the blame for the impact on the service user is down to one or two individuals. However, the comments of the senior member of staff in my PhD Journal extract outlining the fact that I was passed on to different departments show that there are limits to the influence of individuals within such organisations. This passing 'down the line' in itself can generate difficulties for the service user but can also be exacerbated by ambiguous policies and information such as that referred to in Chapter 2 of this thesis where the University of Edinburgh's statement that 'the duty to make reasonable adjustments is anticipatory and a continuing duty to what is owed to disabled students generally [...] the University should not wait until an individual disabled student approaches us before considering how to meet the duty [to anticipate reasonable adjustments]' is closely followed by the comment 'The Equality Act doesn't state that we have to anticipate the needs of every prospective student'. As stated in Chapter 2, this could be construed as a 'get out clause' whereby a member of staff at the university can say to a student that 'it is not possible to anticipate every student's needs' and still be aligned with the policies of the university. The issues discussed in this section have highlighted two key findings in this PhD project:

1. Although issues and incidents disabled students can appear to be minor, they can have a significant cumulative and overwhelming effect which impacts on the individual's well-being.

2. The attitudes and views of the individuals tasked with the implementation and control of reasonable adjustments impact on the implementation and anticipation of those adjustments.

In considering research question 4: **How do disabled musicians experience institutional discrimination?** these examples show that there are issues surrounding the implementation of reasonable adjustments and that their effectiveness in combatting institutional discrimination can be dependent on the attitudes of both the institution and its staff. However, another issue that is highlighted by the comments of the PhD project participants is the problems that can transpire if no reasonable adjustments are in place from the onset.

6.3 Chapter summary

The main focus of this chapter has been on the interaction between institutions and organisations and disabled people. It has shown that, from the evidence gleaned from participant observations and comments, issues such as patronisation and the attitudes of institutions and organisations have a major impact on the experiences of disabled musicians and music students. The PhD project shows that disabled musicians feel they must continually validate and justify their status as a musician and deal with the consequences of being viewed as a burden by staff in institutions and organisations. Therefore, it can be seen that disabled people still experience barriers as they attend college or university or try to gain a qualification in music despite efforts to address the inequality that disabled people can experience when interacting with institutions and organisations. Consequently, it is evident that The Equality Act (2010) and the implementation of reasonable adjustments are not answering fully the inequality and lack of inclusion that disabled people experience. Furthermore, inequality and lack of inclusion are also experienced by disabled musicians who take part in competitions, performance and charity events that are organised by organisations such as music qualification regulators and charitable organisations. Notable among the barriers and problems PhD project participants referred to are the specific nature of the barriers they encounter as they engage in performance or work towards a music

qualification at college or university. These findings highlight the unique nature of some of the barriers disabled musicians encounter and the need for reasonable adjustments that are specifically tailored to address these barriers (Equality Act, 2010, pp.1-250). An example of the specific problems encountered due to the inflexible way procedures and policies are regulated is the situation recounted by PhD participant Don who was unable to complete a degree in singing due to the requirement of students to play piano as part of their course. Another example of the specificity needed in the adjustments required for disabled musicians can also be found in music education, that is, the inflexibility of the curriculum. PhD participant Carol took nine years to gain a degree in music because the schedules dictated by universities were too arduous and tiring, an issue specific to music students as they are required to perform late into the evening and are expected to attend classes early the same or next day. There are many more examples of these types of barriers that could be included in this thesis but for the sake of brevity only one more is included, the physical uniqueness of music and the barriers that arise from that uniqueness. My experiences as a disabled musician has led me to encounter an array of physical barriers that are unique to the music world. PhD participants mentioned this barrier in their interviews - access to the stage and preparation facilities at venues. This has been a prominent feature in my music career and it throws up a wide range of issues such as having to tune up (Cannon, 1988, p.6) in a room that is unsuitable or too far from the stage, waiting in a cold environment before a performance, and having the instrument sound different to other players instruments because the acoustic environment is different on the stage from the area the disabled musician is forced to play in. Most of these issues are different to the everyday challenges that disabled people encounter in their everyday life.

This penultimate chapter of my PhD thesis has discussed the issues related to institutional discrimination and the reasonable adjustments that are expected to create a level playing field for disabled people. It has also described the problems that are unique to disabled musicians as they engage in performance or with music education facilities. The final chapter summarises the findings from all

of the data chapters with a view to providing recommendations to address the barriers commonly faced by disabled people and disabled musicians in particular.

CHAPTER 7 CONCLUSION

7.1 Introduction

This final chapter of my thesis provides an overview of the research undertaken in my PhD project and reviews the research questions in order to answer the main question that was the initial inspiration for this project ‘where are all the disabled musicians?’. Section 7.2 summarises the content of the literature review chapter and Section 7.3 discusses the findings and conclusions that emerge from my PhD project. A summary of Chapter 7 is presented in Section 7.4 which also includes sections on how this PhD project has contributed to the field, implications for future research, and concludes with a note of positivity.

The aim of my PhD project was to address gaps I have identified in the field of disability studies through my experiences as a disabled person in the parochial and conservative world of competing solo Highland Bagpipers, and as a student of piano and guitar. By focusing on the lived experiences of disabled musicians, my PhD project has avoided the tendency to examine the relationship between disability and music from a therapeutic perspective and instead gives an insight into the barriers that exist through the eyes of disabled musicians themselves.

Research question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** and question 2: **How do disabled musicians meet the challenges that arise when impairment impedes their ability to play their favoured instrument?** have impairment as their main focus. These two questions were addressed in Chapter 4 which was divided into two sections in order to answer the questions individually and differentiate between the attitudinal barriers and the physical barriers to making music. Chapter 5 is different in that it answers only one research question, question 3: **How does interpersonal interaction impact on the lived experiences of disabled musicians?** The reason for this format is to do with the subject matter; interpersonal interaction and the attitudes and perceptions of others proved to be a substantial

area of concern for my PhD participants and consequently emerged as a major theme during my analysis. For me, this is not surprising as I experience the same negativity during interactions with others as my PhD participants and other disabled people and so have an insight into the regularity and manner in which these instances occur. However, the most significant finding that emerged from the data was the way in which interpersonal interaction concentrates the effects of misconceptions and negative attitudes. Therefore, Chapter 5 moved the focus to interpersonal interaction and considered research question 3 in isolation.

The final data chapter, Chapter 6 focused on research questions 4: **How do disabled musicians experience institutional discrimination?** and 5 **How effective are reasonable adjustments at combating institutional discrimination?** and consequently looked at the experiences of my PhD project participants and myself in an educational setting. Chapter 6 therefore considered the issues that can occur as disabled people interact with institutions and organisations such as colleges, universities and national qualification bodies. The Chapter was divided into two main sections; Section 6.1 examined instances of institutional discrimination and the impact they can have on disabled people and Section 6.2 looked at the efficacy and implementation of reasonable adjustments which are designed to reduce instances of discrimination.

The data chapters, Chapters 4, 5 and 6, had either one or two research questions as their main focus; however, consideration of the research questions was not confined to these specific areas of the thesis. Constant reference to these questions before, during and after the process of analysis meant that my thesis as a whole focused on answering these five questions and ultimately the overarching question: ‘where are all the disabled musicians?’

7.2 The Literature Review

Throughout the three data chapters in this thesis, Chapters 4, 5 and 6, I considered the topics at hand by revisiting discussions in Chapter 2, the literature review chapter. Consequently, I will begin this final chapter with a reprise of the main points in Chapter 2.

7.2.1 The research questions

The literature review in this PhD project, Chapter 2, revealed a gap in five areas of disability studies. Despite works by Lubet, (2010, pp.1-208) MacDonald et al, (2002, pp.1-224) and Magee, (2002, pp.178–197), the way impairment is understood in relation to music and disability has not been fully considered from the disabled individual's point of view. This gave rise to research question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** Research question 2: **How do disabled musicians meet the challenges that arise when impairment impedes their ability to play their favoured instrument?** was posed in answer to the dearth of research into the lived experiences of people who have a physical impairment as they find ways to play a musical instrument. Very few writings were available at the time of writing this thesis that covered the difficulties in musical instrument adaptation and impairment apart from company websites such as MERU (n.d.) who manufacture devices to assist people hold or support musical instruments. A review of extant literature also revealed that interpersonal interaction with regard to disabled musicians is not a topic that has been examined in any detail. Interpersonal interaction emerged from the data as a significant concern for disabled musicians, so it was covered exclusively in Chapter 5 and the research question 3: **How does interpersonal interaction impact on the lived experiences of disabled musicians?** was posed in order to consider the topic in detail. Research question 5: **How effective are reasonable adjustments at combating institutional discrimination?** emerged as a topic that is not covered in current literature. There are works that cover the experiences of disabled students such as Riddell and Weedon (2014, pp.1-380) and Beauchamp-Pryor (2007, pp.1-462); however, a search of the literature did not reveal an

examination of the efficacy of reasonable adjustments specifically. Reasonable adjustments were an important factor in the experiences of both the participants in my PhD project and myself as I negotiated university education systems so the answers to question 5 were deemed crucial in understanding the issues disabled students experience in music education.

7.4 The data and findings

7.4.1 The models of disability

In order to provide an understanding of the complexities and issues surrounding the concepts of disability and impairment, a consideration of the various models of disability and the tensions between the medical and social models is presented in Chapter 2. The medical model is seen to define ‘disability’ as residing in the individual while the social model uses the opposite approach where ‘disability’ is the oppression of people who have an impairment through social constructs (Oliver, 2013, pp.1024-1026; Thomas et al., 1997, pp.1-3; UPIAS, 1976, pp.1-9). Before undertaking this PhD project, I was not aware of the various models of disability and at that time I was only aware of one approach to the concept of disability, the view that disability is a state of being, a consequence of having an impairment that my abilities in specific ways. Now that I am familiar with the medical, social, personal tragedy and affirmative models, I have a completely different view of my relationship with the society in which I live. The approach taken by the social model is by no means perfect, as can be determined from the discussion in Chapter 2. In fact, as discussed in Chapter 2, there are arguments in favour of abandoning the social model because of issues that have been highlighted in its approach; Shakespeare and Watson argue that the omission of ‘the experiences of the impaired body’ is a reason why the social model should be put aside (1996, p.8). In a later work, Shakespeare argues that an interactional approach would be a good alternative to the social model as his interactional approach would ‘acknowledge the importance of environments and contexts, including discrimination and prejudice’ and would not define disability solely as ‘the external disabling barriers or oppression’ (Shakespeare, 2014, p.75). There is another factor that must be considered when looking at alternatives

or improvements on the social model of disability; the perceptions, emotions and attitudes of disabled people themselves. As illustrated in Section 4.1.2.2 of Chapter 4, two people with similar impairments can perceive the limitations of their impairment differently and cite different factors as barriers in their lived experiences. Therefore, any approach that deems to speak to all aspects of disability as a concept must take into account all aspects life as a disabled person. This includes the fact that some forms of impairment have a greater impact than others and that individuals can be seen to cope differently to the effects of the same type of impairment. Shakespeare claims that his interactional approach does just that as it takes into account the fact that ‘For some individuals, impairment is a major limiting factor, which renders any social manipulation or barrier removal almost irrelevant. For others, impairment itself causes little restriction: it is the reaction of others that causes problems of exclusion and disadvantage’ (2014, p.81).

7.4.2 The use of language in relation to disability and impairment

Although there are no specific references to the use of language by participants in my PhD project, language use is a major point of contention with regard to disability and disabled people (Clark and Marsh, 2002, pp.1-17); it was also a point of concern in my own experiences in the music world. Therefore, it seemed appropriate to include a discussion on the role of language in shaping the concept of disability in Chapter 2 to introduce the topic which was subsequently discussed in Chapter 6. From the discussion in Chapter 2 it can be seen that the use of language is a fluid and constantly evolving phenomenon and commentators such as Clark and Marsh (2002, p.1) and Peters (1999, p.116) argue that the language that people use reflects what they think and can influence how they deal with situations.

7.4.3 Impairment and performance

The next section in Chapter 2, Section 2.3, looked at how disabled musicians deal with the issues related to having an impairment and maintaining the ability to perform. This was considered through a consideration of the transition from non-disabled to disabled musician that drummer Rick Allen

experienced and the implications that transition had for his career with rock band Def Leppard. The phenomenon known as ‘passing’ (Goffman, 1963, p.57) was also discussed in Section 2.3. Passing, or attempting to appear ‘non-disabled’ was not identified as a major theme in my PhD project but was referred to by a few of my PhD project participants so this topic was introduced in Chapter 2 in order to provide some understanding of how it manifests and the impact it can have on disabled people. Section 2.3 also included a deliberation on the use and efficacy of assistive technology developed to assist disabled musicians play musical instruments.

7.4.4 Social interaction and social identity

Section 2.3 was followed by a brief introduction in Section 2.4 to the topic of social interaction, and specifically, social identity. Social Identity Theory (Tajfel, 1970, p.97) was discussed to help contextualise the issues disabled people encounter as the theory provides a good insight into how social interaction with others is maintained. Although this theory was not developed with disabled people in mind specifically, it shows how individuals categorise or align themselves into groups and discriminate against those outside of their own group. Social identities are formed predominantly through social interaction (Andersen et al., 2002, p.159; Goffman, 1963, p.12) and one important aspect that influences our social identity is social comparison, the phenomenon whereby individuals assess their role or status in society through comparison with others and is explained in a clear manner in Social Identity Theory. Much of the literature that discusses disabled people’s identities suggests that it is a sense of difference, or as Shakespeare puts it ‘otherness’ that drives people to segregate disabled people from the rest of society (Shakespeare, pp.218, 227).

7.4.5 Perceptions of disabled people

In Section 2.5, the way that disabled people are commonly perceived was the topic of discussion. In this section, I underlined the fact that perceptions of disabled people exist on spectrum, that disabled people are subjected to stereotyping that places them somewhere between what Shakespeare describes

as ‘superhuman’ and a ‘tragic cripple’ (2016, p.1138). The discussion in Chapter 2 on how disabled musicians are perceived turned in the next section to how they perceive themselves.

7.4.6 Reasonable Adjustments and the Equality Act (2010)

Finally, Section 2.6 moved on to look at the provision of reasonable adjustments and the interpretation of obligations set out in the Equality Act (2010). The approach taken by two Scottish universities, the University of Edinburgh, and the University of Strathclyde, was used to exemplify the tensions that exist in the provision of reasonable adjustments in order to provide some background for the discussion to follow in Chapter 6.

7.5 Findings and conclusions

7.5.1 The impact of stereotyping on disabled musicians

Research question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** is addressed in Chapter 4 through a consideration of the negative and discouraging attitudes. I have shown that impairment is commonly understood through media imbued perceptions such as ‘supercrips’, and the personal tragedy model of disability. I argue that this polarisation of perceptions holds more significance for disabled musicians because the threshold between being classed as ‘normal’ and ‘disabled’ is lower in the music world than it is for the rest of society. Therefore, surmounting the ‘tragic but brave invalid’ stereotype that can accompany identification as a disabled person (Shakespeare, 1999, p.164; Barnes 1992, p.7) and being recognised as a successful musician, is a greater challenge in the music world than in the rest of society. This finding builds on the work of both Lubet, who argues that impairment holds more significance for musicians than in many other walks of life (2010, p.16) and Shakespeare’s assertion that disabled people slip into three main categories; the tragic but brave invalid, the sinister cripple and the ‘supercrip’ (Shakespeare, 1999, p.164). The data in my PhD project show that that the stereotype ‘sinister cripple’ would be incongruous with disabled people who are trying to succeed in music and

this leaves a gap between tragic invalid and supercrip that I believe, in conjunction with the already established low expectations they experience, imbues in disabled musicians a sense that they must work harder than their non-disabled peers.

7.5.2 Barriers to music making created by low expectations

Low expectations of disabled people emerged as a major area of concern for disabled musicians as it erodes confidence and the motivation to progress or continue as a musician. Additionally, I have shown that for disabled musicians, low expectations have a greater impact than on non-disabled musicians due to expected norms and established traditions (Lubet, 2010, p.16). PhD participant Rose makes music with an iPad and computer software which, although becoming more acceptable as a valid form of music making, still has to be ‘justified’ by Rose as a valid way of making music that requires a high level of skill. Expectations are known to affect student outcomes and, unsurprisingly, low expectations can have a negative effect (Benner and Mistry, p.151). Thus, my PhD project shows that the lower expectations that exist in the music world, together with issues of stereotyping, play a greater part in the lives of disabled musicians than both non-musicians, and non-disabled people. Consequently, for a disabled person making the journey through music education, the extra effort to establish validity as a musician and the perpetual struggle against low expectations actively discourages disabled people from engaging with music making. This is a significant finding, one that builds on the work of Lubet (2016, pp.1-234) who suggests that the music world sees impairment as a greater problem than other walks of life, and commentators in disability studies who argue that disabled people are viewed as tragic (Swain and French, 2000, pp. 569-582) or are ‘made the subject of stereotyping judgements and condescending assumptions’ (Cameron, 2011, p.2) and a finding that contributes to the under-representation of disabled musicians in the music world.

7.5.3 Misconceptions and the downplaying of impairments

Another important finding that emerged in my PhD project is the significance of how impairments are understood, or rather, misunderstood by others. As shown through the contrast between French’s

experiences as a person with a sight impairment (French, 1999, p.21) and that of PhD project participant Suzie, Chapter 4, the impact of an impairment can vary from person to person, it can also affect the way a disabled person is perceived and how attitudes manifest towards them as the significance of an impairment can often be underestimated. The data in Chapter 4 also revealed that the underestimation of an impairment is also more common if it is believed to be familiar to the observer. Two examples in Chapter 4 demonstrated the derogation or underestimation of impairment; the case of PhD project participant Carol who comments that people think her chronic fatigue is the same as their feelings of tiredness, and the negative experience I had while trying to discuss the implications of my sight impairment with a member of staff in the university. Having the impact of our impairments derogated in this way caused both Carol and I emotional distress in the shape of anger and frustration. This derogation also resulted in reasonable adjustments being delayed or neglected because the impact of our impairments was downplayed.

The downplaying of the effects of an impairment are not the only way in which misinterpretation can impact on an individual. The opposite is also true where an impairment is assumed to have greater implications for an individual than is actually the case, as discussed through the experiences of PhD participant Carol in Chapter 4. The assumption that an impairment has greater implications than they actually do is also evidenced through the example given in Chapter 5 which referred to a blog post by George Takei who assumed all people who use a wheelchair cannot stand or walk (Ryan, 2017, n.p; Levis, 2014, paragraph 1). Carol believes there is a perception that deaf people cannot teach music because they cannot 'hear' the music, a common assumption about deaf people (Whittaker, 2012, p.2). Carol's belief that others do not see her as a competent music tutor is an obvious area of great concern for her because she earns a living from teaching music. Therefore, for PhD participant Carol, common assumptions about the abilities of deaf people impact on her confidence and represents another finding that has emerged from the data in my PhD project.

7.5.4 The impact of impairment on the ability to perform

Section 4.1 of Chapter 4 concentrated on how the beliefs of others impact on the lived experiences of disabled musicians. In Section 4.2 of Chapter 4 I focused on the more physical aspect of life as a disabled musician by looking at the reality of the challenges that arise from having an impairment and making music. Through the experiences of four disabled musicians and myself, I found that an individual's ability to continue playing a musical instrument can vary greatly depending on; the instrument they favour, the technological adaptations available to them, and the environment in which they usually make music. For PhD participant Matt, the main difficulty he encountered was the size, shape and weight of his tenor saxophone. He has difficulty playing this instrument from a sitting position and playing other instruments is also difficult due to the development of an essential tremor, which Matt experiences as an uncontrollable shaking of his hands (National Tremor Foundation, n.d.). Consequently, Matt is experiencing barriers to making music that are difficult to surmount due to the nature of his impairments and the design of the instruments he favours. PhD participant Don also has difficulties in playing his favoured instrument, the guitar. Don has a skin condition called epidermolysis bullosa (EB), which is a general term used to describe a group of rare inherited skin disorders that cause the skin to become very fragile (NHS Choices, 2015, paragraph 1) and prevents him from playing steel strings but a charity Don attends that facilitates engagement with music for disabled people helped him find a guitar that allows him to continue playing in a style he prefers. Rock musician Rick Allen is also included in the discussion on the challenges that arise from having an impairment and making music. Like PhD participant Don's example, Allen, being a drummer and losing an arm in a road traffic incident, is also used as an example to show how some challenges that can arise from the conjunction of impairment and musical instruments can be negotiated. However, what also emerges from the data analysis is that a change in playing style or technique invariably occurs when this happens for a variety of reasons. For Don, this means using picks as opposed to his

fingers to pluck the strings, for Allen it means using a foot to compensate for the lost arm. In both of these cases there is a notable change in the style of playing by the performer but perhaps the best example of impairment affecting style is that of Django Reinhardt whose limited finger dexterity had a profound impact on his playing style (Cramer, M., 2013, n.p.). This unique style of playing has become ‘the blueprint for a thriving, steadily evolving musical sub-genre’ (Barrett, 2017, p.1).

7.5.5 Assistive technology

Another method of circumventing the barriers to playing an instrument for disabled musicians is the use of dedicated assistive technologies. As discussed in Chapters 2 and 4 of this thesis, Sheldon (2003, p.155) argues that the use of technology has become an important aspect in the lives of many disabled people. Braille, a tactile method of reading developed for people with a sight impairment (RNIB, 2016, n.p.), and computer software are the two methods I discussed in Chapter 4 since these are devices used by PhD participants. Braille Music Notation is a version of Braille that allows blind musicians to read music (RNIB, 2016, n.p.) but as I explained in Chapter 4, neither of the PhD participants who are blind mentioned it and I was left to assume that it was not offered as an option to them during their music education. PhD participant Suzie does mention Braille but not Braille Music Notation and only in relation to her non-musical education. PhD participant Abbie did not mention either Braille or Braille Music Notation. I have concluded therefore that Braille Music Notation is conspicuous by its absence from the PhD interview transcripts and that Braille Music Notation is either not deemed useful, or is not widely known about, discussed, or made available to music students who have a sight impairment. This however would have to be confirmed through further investigation since it is beyond the scope of my PhD project.

The other method of making music discussed in relation to assistive technology is computer software. Sheldon covers this topic in her Chapter ‘Changing Technology’ (2003, pp.155-160) but does not feature music productivity specifically so the findings in my PhD project on this topic build on Sheldon’s work. Music generated through the use of computer technology was found to be an

important aspect of PhD project participant Rose's engagement with music as she makes music using this method. Rose composes, arranges and performs music using tablet computers and specially developed music software. Although Rose did not describe any issues with the playing of her instrument, she did express concern about how she feels her skill levels and validity as a musician are regarded because the level of input needed to make music using this method is not obvious to observers. This concern Rose feels is an important finding as it shows that disabled musicians face attitudinal barriers that impact on their self-worth and as such helps to answer two research questions. Question 1: **How is impairment understood and how does this understanding impact on disabled people as they engage in music making?** is answered as Rose's cognitive ability is not recognised by her audience as they do not understand the skill required to play her music and that lack of understanding generates an emotional reaction in Rose's that helps answer Question 3: **How does interpersonal interaction impact on the lived experiences of disabled musicians?** The consideration of music and assistive technology in my PhD project has also built on the work of Sheldon (2003, pp.156-160) by adding a music and disability dimension to her examination of assistive technology.

In Section 4.2 of Chapter 4 I examined what I have described as 'the actual experience of making music with a physical impairment' by considering examples of the lived experiences of PhD participants, the difficulties I experienced as a competing piper, and an exploration of the techniques and methods used by other musicians who have a physical impairment. I concluded that due to the unique nature of impairment, its impact on each individual, and the environment or background circumstances of the individual, there are no 'one shoe fits all' solutions to the challenges faced by people who have an impairment and wish to make music on a specific instrument.

7.5.6 The role of attitudes in relation to impairment and performance

Another factor that emerged from my analysis in relation to the challenges people who have an impairment encounter when making music is the impact of attitudes. For example, Rick Allen was

actively encouraged to continue drumming. Allen's impairment was not seen as a barrier by the other members of his rock group and he was accepted back into the performance arena with encouragement and affection. My experience was very different. I faced judges and audiences who questioned my decision to play in competition while sitting on a perch stool despite the fact that my arms and fingers were not affected by my impairment at that time. Given the findings of my PhD project, I would argue that if Allen had not been encouraged and accepted in the way he was he would have felt less enthusiastic about returning to the performance arena.

Combining elements of the answers to the two research questions asked in Chapter 4 helps to provide an answer to the overarching question 'Where are all the disabled musicians?' as it can be seen that there are many factors that can actively discourage a disabled person from engaging in music making ranging from the negative attitudes of others, through misconceptions related to the impact of impairment, to the technical challenges of playing a specific instrument.

Chapter 4 answers research question 1: **How is impairment commonly understood and how does this understanding impact on disabled musicians?** by showing that impairment is often misunderstood. There is a tendency for impairments to be categorised and the effects of that impairment to be seen as either greater or less than they are in reality; the impact of an impairment is therefore often misjudged. The consequences of this misjudgement answer the second part of research question 1: **how does this understanding impact on disabled musicians?** as my PhD participants describe how being subjected to stereotyping and low expectations erode their confidence and make them feel angry, disappointed and under-valued.

7.5.7 The 'spread effect' and its impact

In Chapter 4 there are examples which show how the impact of an impairment on an individual can be misunderstood. Chapter 5 expands on this area of concern by considering phenomena known in the USA as 'the spread effect' (Wright, 1960, pp.1-408). The spread effect was determined to be a

significant source of concern for my PhD project participants and one that I have experienced on many occasions. My consideration of the spread effect could easily have been included in Chapter 4 as that chapter looked at how impairment is often viewed and how it actually impacts in reality. However, I decided to include my discussion on the spread effect in Chapter 5 as in my experience it manifests invariably during interpersonal interaction; this hypothesis is confirmed by the accounts of my PhD project participants who describe instances of the spread effect through recollections of conversations with others. When the participants in my PhD project were asked to recall negative experience related to their involvement in the music world, Carol, Abbie, Don and Rose all spoke about comments or behaviour from others that fit well under the heading of the spread effect. The evidence in my PhD project shows therefore that disabled musicians are angered, disappointed and feel undervalued when people they interact with in social situations ignore them and speak to the person accompanying them or deny them access to the same opportunities as others. This builds on the work of Keany and Glueckauf, 1999, pp.139-152; Shontz, 1984, pp.77-84; Dion and Walster, 1972, pp.285-290; Wright, 1960, pp.1-408, all of whom have contributed to the study of the spread effect. A significant finding in my analysis therefore is the fact that the spread effect most commonly manifests during interpersonal interaction and as such, has a significant emotional impact on disabled people. This, in part, answers research question 3: **How does interpersonal interaction impact on the lived experiences of disabled musicians?** by showing how the attitudes and perceptions of others can be misguided to such an extent that they cause anger and frustration in disabled people (Pierce, 1998, p.120). For disabled musicians, there is a likelihood that they will encounter such misguided perceptions while at music events or when performing making that experience a negative one.

7.5.8 The perception that disabled people are a burden

In addition to the spread effect, another strong theme that emerged from the data was the perception that disabled people are a burden, (Barnes, 1992, p.15), this was discussed in Section 5.3 of Chapter 5. Some PhD project participants were very emotional when describing the ways in which they

experienced the attitudes of individuals. Suzie speaks about her step mother and her intolerance of issues arising from Suzie's blindness; Robert laughs in exasperation at the attitudes of venue managers he encounters when trying to book a venue for his show because putting a ramp at the end of the stage would be 'too much hassle' and Abbie describes her anger at the attitude of the teacher who she believes was trying to avoid teaching her as he thought she would be 'a bit of a challenge for him'.

Abbie's account of her teacher believing she would present too much of a challenge is another way of saying he believed she would be a burden. The teacher believed having a student who has multiple impairments would increase his workload; it is also possible that he was not confident in his ability to provide Abbie with appropriate support which is essential for disabled people as they journey through the education system (Beauchamp-Pryor, 2007, p.1; Barnes, 2009, p.vii). Abbie's example leads appropriately to the next topic discussed in Chapter 5, avoidance. My PhD project has shown that if a disabled person is perceived as a burden, someone who will cause extra work, they will often be avoided by others, a common occurrence for many disabled people (Park et al., 2003, pp.65-87; Snyder et al. 1979, pp.2297-2306). Therefore, avoidance is a negative aspect of being disabled that has a corresponding negative impact on the lived experiences of disabled music students. My recollection of the avoidance I experienced during the seminar is vivid and Abbie's account of being avoided by her teacher is detailed and emotional which shows that such incidents are significant junctures that punctuate the path through music education for both Abbie and myself.

7.5.9 Objectification, patronisation and the role of disability charities

To compound and exacerbate the emotional stress caused by avoidance, being seen as a burden and factors such as the spread effect, other perceptions of disabled people emerged from the data in my PhD project analysis, namely, objectification and patronisation. I merged my analysis of these factors in Chapter 5 as I felt they are very closely linked. Also, my own experiences have taught me that objectification invariably results in the victim feeling patronised. This was illustrated in my example that recounts the comments made about putting me in the lockable trolley compartment in a

supermarket. At the time, I felt the man who made the ‘joke’ was regarding me as an object and at the same time I saw his need to make a joke about me being a wheelchair user as patronising and oppressive, something disabled people are frequently subjected to (Brune and Wilson, 2013, p.158). Consequently, my PhD project shows that being subject to such objectification and patronisation can deter disabled people from venturing out into the world, and this would pose problems for a disabled person who wants to obtain an education in music.

A particular topic that is discussed in many writings on disability is the work of charities and their methods of eliciting pity for the people they are set up to assist. In Chapter 5 the analysis shows that the work of charities is a concern that also arises in the music world with respect to disabled musicians. PhD project participants Abbie and Donna both referred to charities and the manner in which they attempt or have attempted to use disabled people to elicit pity, a topic that was introduced in Chapter 2. Abbie found it disturbing when she was used as an example of the people a charity helps and Donna felt the necessity to warn me of a particular charity she believes engage regularly in patronising and objectifying disabled people for their own ends. Taking advantage of a situation by using the particular circumstances of an individual to promote the work of a charity is, to my mind, a form of bullying which is the next factor considered in Chapter 5.

7.5.10 Bullying

The interview with PhD project participant Adam stood out from the others with regard to bullying. Although several other participants referred to bullying, Adam’s account of the bullying he experienced was very emotive and occupied a large portion of his interview. During his interview Adam makes specific reference to how his musicianship was questioned and used as a device to ‘make him feel terrible’, my PhD project shows therefore that bullying therefore can take a specific form in the world of music education. Carol’s comments on how her musical ability was targeted in a peer review process helps to substantiate this argument. This finding represents another factor that impacts

on the lived experiences of disabled musicians and another barrier for disabled music students to overcome if they wish to become a performer or music teacher.

Given the plethora of negative factors that have emerged from my analysis so far it is perhaps understandable that much of the resultant negativity would be internalised by disabled musicians, a fact evidenced in the data and discussed in Chapter 5. Comments from PhD participant Suzie dominate the discussion as she made comments in her interview that illustrate well how the process of internalisation manifests. Suzie speaks of ‘baggage’ being carried out into the real world which I believe is an apt way of describing how the opinions and perceptions of others can be absorbed and influence our self-image. In Chapter 5, I posit that if these opinions and beliefs are that the individual in question is a burden, they will discourage that individual from engaging in an activity that by nature encourages criticism and judgement. Musical performance is an activity that falls neatly into this category so the internalisation of all the negativity I have described in Chapter 5 will consequently impact on how a disabled person feels about starting or continuing a career in music.

The examples of negative factors that I have provided in Chapter 5 show that disabled people, and consequently disabled students and musicians, can be emotionally compromised by the attitudes and actions of others. For disabled students, these attitudes and actions may impact on their resolve and stamina which in turn may cause them to give up trying to get a qualification they believe they need to validate their musical ability. The final section of Chapter 5 is more positive in nature as it discussed some examples of the positive aspects of being a disabled musician. The two main areas of discussion are PhD participant Suzie’s feeling of ‘being in control’ when she sits behind the piano, and the message of encouragement that was delivered by many of the project participants to other disabled people who may be considering engaging in music making. Suzie feels she is able to use her status as a performer to shape how others see her, if only for the brief time she spends on stage. Suzie uses her stage persona to deflect attention away from her impairment and instead focus that attention on her

status as a performer. This works to create a bridge between Suzie and the non-disabled members of her audience and reduces her 'otherness' in their eyes.

The final topic discussed in Chapter 5 is the propensity of the PhD project participants to deliver the same message of encouragement to other disabled people which chimes with the sentiment of Sutherland's article entitled 'Disabled we Stand' (1981, pp.1-11) outlining the difficulties attitudes create for disabled people and referred to in Chapter 2. As mentioned in Chapter 5, there are too many examples of this to quote in my thesis, but this proved to be a very strong theme throughout the interviews and one which could not be ignored. Despite all of the negativity they have encountered, the participants in my PhD project felt that engagement in musical performance and working towards a qualification in music is a worthwhile endeavour.

7.5.11 Institutions and the efficacy of reasonable adjustments

Although my PhD project shows that disabled people who are involved in music making feel other disabled people should follow their lead and engage in music making, this brings us back to the negative aspects of music and disability. A consequence of increased engagement in music making will customarily increase the possibility of interaction with organisations and institutions, which in turn will increase the chances of encountering negative aspects of being a disabled person such as institutional discrimination.

Chapter 6 addressed the issues surrounding institutions and reasonable adjustments and consequently contains the greatest concentration of autoethnographic content, mainly because it is concerned with issues that I am currently experiencing as I work as a student on this PhD project in the University of Edinburgh. Interaction with institutions invariably means encountering what are described as 'additional support needs policy and practice' (Riddell and Weedon, 2014, p.364) and the analysis of data in my PhD project shows that it is the implementation of these factors that can cause serious difficulties for disabled people. PhD project participant Carol experiences chronic fatigue and reported

that she could not continue her education at a university because her levels of stamina could not meet the requirements necessary to attend every class. Carol tried to persuade the university to make adjustments that would allow her to continue her studies but was met with resistance and was ultimately unsuccessful as the university ‘did not follow through’ on their agreement to allow Carol to attend part-time.

Carol had no choice as to whether she disclosed her impairment to the university as it is a necessary requirement for people who need adjustments to be implemented to facilitate access to services (Beauchamp-Pryor, 2007, pp.29,70). However, as discussed in Chapter 6, PhD participant Don decided not to disclose his impairment when he attended music college, a decision that ultimately led to Don failing his exam. Don’s example was used in Chapter 6 to highlight the dilemma disabled people can be faced with when they have to decide if they wish others to know about their impairment. Social conventions and pressures influence this decision to a large extent (Beauchamp-Pryor, 2007, p.201) and this is evidenced by Don’s comment ‘you come from a sort of a background where [...] if you had something like that you didn’t [...] tell everybody about it’. PhD participant Rose’s account of a parents’ night meeting where Rose’s parents were told by her school that she could not do a music Standard Grade is an example of what can happen if an impairment is not concealable. The symptoms of Rose’s Cerebral Palsy are obvious and not possible to hide; this resulted in others judging her capability and making decisions for her. So, Rose was not allowed the freedom to make her own decisions regarding her music career in this instance and was effectively barred from getting a qualification in music. Therefore, my PhD project shows that some disabled people are actively excluded from seeking a qualification in music and do not receive the assistance they need to complete their education due to issues related to the disclosing of impairment.

There is importance placed on the level of qualification and achievement by the disabled musicians who participated in my PhD project. The data shows that the participants feel it is necessary to seek a music qualification to help validate their status as a competent musician. The participants turned to

schools, music colleges, universities and other qualification providers to gain that validation and as a result were exposed to barriers that could hinder or halt their progress towards becoming an established musician. The majority of the participants in my PhD project have a degree in music or have tried to gain a degree; this may be related to how the participants were recruited for my PhD project or the type of person who responds to calls for participants, but analysis of the data suggests this is a strategy to claim authority over their disabled identity by demonstrating their competence and abilities (Björnsdóttir, 2010, paragraph 21). This strategy is a reaction to the lower expectations of disabled people in the music world (Lubet, 2010, p.16) and a significant finding in my PhD project.

7.5.12 Interaction with disabled people means extra work

Analysis of the data in my PhD project also shows that low expectations to be a factor that triggers the belief that interaction with disabled people will be difficult and result in additional work. The perception that disabled people are a burden was discussed in Chapter 5. However, because Chapter 6 focuses on the interaction between disabled people, institutions and organisations, I felt a discussion on how institutions can view disabled people as a burden was necessary to explore this issue from the perspective of a disabled music student. It was shown in my PhD project that, although institutions are guided by The Equality Act (2010), disabled people still experience discrimination while attending universities and colleges and a considerable proportion of that discrimination stems from the perception of staff and venue managers that disabled people equate to problems and more work. This perception leads to another negative factor that impacts on disabled people, avoidance. Analysis of my experiences as a PhD student shows that disabled students are subjected to discrimination through inaction; my example in Chapter 6 of having my request for assistance ignored by the health and safety officer is just one in a catalogue of similar incidents that I experienced while attending university. Perceiving a disabled student to be the source of extra work or problems may be construed as something that can be attributed on an individual level and not something the institution is responsible for. However, staff are subjected to, and constrained by, rules and practices established by the

institution they work for and are often reliant on other departments or members of staff for support. Examples were given in Chapter 6 to show the reliance of staff on established practices and the guidelines of an institution such as the PhD Journal extract in Section 6.2.3 where a member of staff reiterated the information provided in the university's website on anticipating reasonable adjustments.

It is also the case however that institutions can discriminate against disabled people who use their services through adherence to established practices. In Chapter 6 I discussed the Lawrence Inquiry which found that an inflexible ethos of the 'traditional' way of doing things can give rise to 'unwitting racism' (MacPherson, 1999, 6.17). I compared the racism discussed in the Lawrence Inquiry with disablism and provided an example of 'unwitting' disablism from my experiences as a disabled music student. I recounted a situation whereby a seminar would not be moved as it had always been held in a particular venue. This shows how I was subject to institutional discrimination because of an established practice that the senior member of staff believed could not be changed. The discussion answers research question 4: **How do disabled musicians experience institutional discrimination?** and question 5: **How effective are reasonable adjustments at combating institutional discrimination?** as it shows how I experienced discrimination at university and how in this case reasonable adjustment failed to combat this discrimination.

In Chapter 6 I continued my discussion on institutional discrimination by looking at the subject area that instigated the 'unwitting disablism' of a senior member of staff, poor physical access to buildings. My physical presence on campus was invariably the factor that instigated the majority of problems I encountered as a PhD student. There are too many incidents to recount in this thesis but suffice it to say that almost every day I faced a new challenge in the shape of inaccessibility and these challenges began even before I started my PhD course. However, as discussed in Chapter 6, although the issues I experienced on campus were usually generated by physical barriers, it was the emotional impact of these issues that I found the most difficult to deal with. 'Making an entrance' is how I describe one of the particular sequence of events that disabled people encounter on a regular basis. I gave examples of

this embarrassing scenario from my own experiences and those of PhD participant Rose, who describes a typical example of this when an external lift was out of order and she had to be lifted up a set of stairs. This can be an extremely embarrassing and frightening experience, one which I have endured on many occasions. It is embarrassing because it makes the disabled person the centre of attention and it also makes the disabled person look vulnerable and helpless, akin to the stereotype described in much of the literature reviewed in Chapter 2 such as Swain and French (2008, pp. 569–582; 2008, p.4) and Sutherland (1981, pp.1-11). It can be frightening because usually the disabled person has to rely on people they do not know, who is not familiar with their wheelchair or with their levels of pain or anxiety. So, the disabled person in these situations both looks and feels vulnerable. Therefore, my PhD project has shown that inadequate access and access technology can play a major role in eroding confidence and instilling insecurity in a disabled person and represents another barrier to engaging with the physical world and ultimately, for disabled musicians, access to music education. It also helps to answer research question 4: **How do disabled musicians experience institutional discrimination?** as it provides an insight into a disabled musician's experience of university, and it also answers research question 5: **How effective are reasonable adjustments at combating institutional discrimination?** in that it shows how, although reasonable adjustments can be initiated, they can be ineffectual if the equipment is not properly maintained or is defective.

7.5.13 Absent or inadequate reasonable adjustments

Despite the prevalence of issues related to physical barriers, the greatest barrier referred to by the participants in my PhD project were attitudinal. The final discussion in Chapter 6 referred to absent or inadequate reasonable adjustments which are responsible for ensuring disabled people meet as few barriers as possible. In Chapter 6 I revealed through PhD participant Don's experience that, in the 1960's when the implementation of reasonable adjustments was not as widespread as it is currently, disabled people could be effectively excluded from higher education. I also demonstrate in Chapter 6 that even although there have been many changes implemented since that time (Barnes, 2009, p.v),

disabled people can still be excluded from music education. In Don's case it was the pressure of social convention that leads Don to believe that drawing attention to his impairment was not the 'done thing'. I provided several examples in Chapter 6 to show that there is a continuance of such discrimination. PhD project participant Rose was not permitted access to a standard grade in music because the school did not believe she would be capable of completing it. I was not able to progress past Grade 4 in the Associated Board of Royal Schools of Music (ABRSM) because there was no provision for people who could not use the pedals in their piano exams from Grade 5 onwards, and PhD project participant Carol was effectively excluded from degree courses because a university did not recognise that their inflexibility with regard to their curricula was a barrier to people who experience chronic fatigue. My PhD project shows therefore that in answer to research question 5: **How effective are reasonable adjustments at combating institutional discrimination?** reasonable adjustments are only a part solution to negating the barriers that exist for disabled people who wish to engage in music education or performance and that there are many areas where their provision either falls short or does not exist.

7.6 Chapter summary

Research into performance and career differences shows that self-confidence is a factor that 'carries some to achievement and, when missing, causes others to fail, or even fail to try' (Hollenbeck and Hall, 2004, p.254). Therefore, I suggest that being exposed to such attitudes could be part of the answer to the over-arching question of this PhD project **Where Are All The Disabled Musicians?** The results of my PhD project have shown that disabled people experience a plethora of barriers that dissuade or discourage disabled people from engaging in music performance or seeking an education in music. Through both interpersonal and institutional discriminatory practices and attitudes disabled people have a more difficult path to becoming an established and respected musician than their non-disabled peers and the evidence produced in my PhD project analysis shows that it is the attitudes and behaviour of individuals and institutions that generate the greatest barriers to music for disabled people. The belief that disabled people are a burden and will not have the same level of ability as non-disabled

people can block access to education. The tendency to avoid, patronise or view disabled people with pity can cause emotional distress which in turn can discourage engagement with music and a heightened level of low expectations in the music world drives disabled people to seek qualifications through an institution that is likely to present additional barriers to the ones they already experience in their daily lives.

7.6.1 Contribution to the field

7.6.1.1 Bringing together music literature and disability studies

In terms of conceptual contributions, my PhD project has brought together the fields of disability studies and music literature. For example, I have taken ideas discussed in music literature and considered them in relation to data collected from my PhD project. Lubet's argument that the music world sees impairment as a more significant challenge to overcome than society in general (Lubet, 2010, p.16) was discussed, as was Magee's observations on the concept of transcending impairment (2002, p.180). By bringing ideas from music literature together with theories from disability studies literature my PhD project fills a gap in current research through a consideration of the lived experiences of disabled musicians. Most of the issues and barriers disabled musicians face are described in disability studies; issues such as passing (Goffman, 1963, p.57; Honisch, 2009, p.5), which is discussed in Section 2.3.1, and the impact of perceptions of social identity through Social Identity Theory (Tajfel, 1970, p.97), discussed in Section 2.4.1, have been drawn upon to describe and illuminate specific aspects of the lived experiences of disabled musicians. Although passing is not unique to disabled musicians, it does have significance given the exposure and public scrutiny playing a musical instrument brings and is a strategy that PhD participant Don employed when asked by his fellow students about the reasons he was not permitted to continue his studies at the conservatoire. However, passing is just a reaction to other factors in the lives of disabled musicians such as the tendency for humans to identify with others and form 'in-groups' and 'out-groups' (Tajfel, 1970, p.97). The tendency to discredit people who appear different adds to the pressures disabled musicians feel as they

try to conform to expected norms and this in turn leads to passing. My PhD project has taken the ideas discussed in disability literature about passing and related them to the world of music, an arena where physical attributes are under constant scrutiny (Woody, 2013, *Do Better-Looking Musicians Make Better Sounding Music?*). The coming together of music and disability studies literature in this PhD project has prompted me to conclude (as discussed in Section 4.4) that the factors that impact on a musician's ability to play fall into two categories; embodiment, and socially created barriers. These are factors that impact on the lives of most people but, for disabled people who wish to engage in music making, my findings show that for the participants in my PhD project, socially created barriers are just as significant as the issues that arise from embodiment. For example, in Section 2.5.1 of this thesis, I explored the concept of what Shakespeare describes as the tendency to regard disabled people who reach high levels of achievement as 'superhuman' and disabled people who do not reach these levels of achievement as 'tragic' (2016, p. 1138). In this thesis I use Shakespeare's hypothesis to help explain why the disabled musicians who participated in my PhD project feel the need to justify their role as music teacher and musician.

The research carried out in my PhD project also connects music literature and disability studies by looking at the models of disability through the experiences of disabled musicians. The research in my PhD project relates the theories of disability studies writers such as Shakespeare, Barnes and Swain, to the experiences of both the participants in my PhD project and my own experiences as a disabled musician. For example, Section 5.5 uses the personal tragedy model of disability to help understand how objectification and patronisation can impact negatively on the feelings of disabled musicians. Several examples of objectification and patronisation are presented in Section 5.5; using the personal tragedy model helps to provide an understanding of how these attitudes can manifest in varying contexts such as in individual interaction or through the promotions of disability charities.

7.6.1.2 Complex and multiple forms of discrimination

In addition to bringing together music and disability studies, my PhD project adds to the discussion on institutional discrimination by highlighting the correlation between institutional racism, as shown in The Stephen Lawrence Inquiry (1999), and institutional discrimination that exists in relation to disability and music education facilities. As such, my PhD project contributes to literature that focuses on the complex and multiple forms of discrimination and describes how different forms of discrimination can overlap and intersect.

By considering existing information from both The Stephen Lawrence Inquiry and the Equality Act (2010), I have shown that music education providers can unwittingly discriminate against disabled people indirectly through their practices and procedures. In Section 6.6.2, I discussed what McPherson described as the ““traditional” way of doing things’ (1999, 6.17) adopted by the police and argued that such an inflexible ethos can also result in discrimination against disabled people by music education establishments such as colleges and universities. An example of this inflexible ethos is given in Section 7.6.4 where I discuss the ‘traditional way of doing things’ and imbued discriminatory practices that I experienced as a disabled student such as holding to a tradition of having music seminars in the school of music building because they have always been held there. PhD participant Don also recounted an experience he had with a conservatoire that demonstrates how adhering to established practices and being inflexible in procedures and regulations can impact negatively on disabled students. In Section 6.1.2.3 recalled how he did not meet the requirements to continue his course at the conservatoire because at that time (the 1960’s) to gain a degree in singing, there was a requirement at that specific conservatoire to be able to play piano to a proscribed standard.

My examination of the impact of institutional discrimination has shown that in addition to interpersonal interaction, disabled musicians can experience discrimination that stems from a variety of sources. I have shown that one of the most significant sources of discrimination is that generated by the practices and procedures of institutions such as universities and music qualification organisations.

Despite measures to avoid discrimination such as reasonable adjustments, disabled musician's specific requirements are not always being met; therefore, significant barriers still exist in the music education world for disabled musicians. Research examining the impact these barriers have on the lived experiences of disabled musicians was limited; my PhD project helps to expand this area of research and provides a springboard for future research in this field.

7.6.1.3 Disabled musicians and Social Identity Theory

In addition to bringing together disability studies and music literature and adding to the discussion on intersectionality, my PhD project contributes to the literature that considers Tajfel's Social Identity Theory (SIT) (1970, pp.96-102) by incorporating ideas from SIT into my examination of the social interaction aspect of the lived experiences of disabled musicians and music students. Tajfel's SIT does not refer to disabled people or any other minority group explicitly but it can be applied to any form of social separation such as race or sex discrimination. In this case I applied SIT to the social aspect of disability as I felt it provides a clear understanding of the social tensions and dynamics that can occur in the lives of disabled musicians. Using Tajfel's idea of 'in-groups' and 'out-groups' gives a new perspective on how disabled people, and disabled musicians specifically, can be perceived and helps to explain how some of the participants in my PhD project feel they must prove their worth as musicians to counter the lower expectations of others who in this case are the 'out-group'. Social Identity Theory is explained in more detail in Section 2.4.1.

7.6.1.4 A non-therapeutic approach to disability and music

Much of the existing literature approaches the topic of disability and music from the perspective of music therapy. This is an approach that, by concentrating on outcomes and clinical measurement, is rooted in the medical model of disability. My PhD project was not conceived with the benefits of music engagement for disabled people in mind; it was designed to explore social interactions and the things that inhibit access to music in a non-medical way. As such, my PhD project fills a gap in both music and disability literature given the aforementioned concentration on music therapy in music

literature, and the shortfall of research in disability studies on the lived experiences of disabled musicians. This approach means my PhD project looks at music and disability not from the perspective of clinicians and researchers, but through the experiences and opinions of disabled musicians themselves.

7.6.1.5 Barriers to engaging in music and music education

In examining the lives of disabled musicians, my PhD project has identified several barriers that impede or prevent them from developing or advancing a career in music. Material barriers are a major consideration for most people who have a physical impairment, a fact reflected in the findings of my PhD project which shows that disabled musicians and music students experience barriers that are unique to the music world and music education. However, the predominant theme related to barriers that emerged from the data is concerned with the attitudes of others. Extant literature covers the attitudes of others but often in more general terms; my analysis has revealed issues that are specific to disabled musicians and disabled music students. Interaction between human and musical instrument brings physical considerations that can be difficult to surmount, but my analysis has shown that in many cases, it is not the material aspects of musicianship that of concern to disabled musicians, but the way in which they and their impairments are regarded by other musicians. My PhD project has also revealed that impairment is regarded as a greater problem in the music world and that this perception creates a significant barrier to music engagement for disabled people.

7.6.1.6 Encouraging other disabled people to engage with music and music education

Another significant finding that emerged through the interviews with PhD project participants, is the fact that there appears to be a tendency for disabled people to encourage other disabled people to engage in social activities. Friendship and a sense of isolation regarding disabled people has been referred to in previous literature, for example Shakespeare writes, ‘while disabled people may have greater needs of friends, they are less likely to be well integrated into networks and friendship circles. Disabled people differ from most other disadvantaged groups because they experience significantly

greater isolation and loneliness' (Shakespeare, 2014, p.191). My PhD project builds on this argument by showing that there is a general awareness among disabled people of the isolation and loneliness they each can experience. This awareness has inspired my PhD project participants to let other disabled people know that engaging in social activities such as music making is not only possible, but beneficial for them.

For music students who have a physical impairment, my PhD project has shown that the education system falls short in providing a level playing field. Established practices, avoidance of issues related to disabled students, inadequate access and institutional discrimination all contribute to creating a difficult path for disabled students to tread. My analysis shows that the disabled musicians who participated in my PhD project feel that they must justify their status as a musician. It also shows that these musicians sought such justification or validation through gaining high level qualifications, a process that can only be accomplished through interaction with an institution such as a conservatoire, college, university or qualification body such as Trinity College or the Associated Board of Royal Schools of Music.

Analysis of my own experiences as a disabled music student has provided an insight into the efficacy and implementation of reasonable adjustments in a large and highly regarded university in Scotland. In doing so, I have shown that even an institution can have a collective attitude that has a detrimental impact on the provision of reasonable adjustments and consequently the experience a disabled student will have at that university. I have also demonstrated that two similar institutions can have a different view of their responsibilities regarding reasonable adjustments and how that view can influence their response to issues that students bring to their attention.

7.6.2 Limitations of the project and reflection on approach

Some points of interest arose during the course of my analysis that would benefit from further study, but the breadth of topics already investigated meant that these topics could not be given proper

consideration in my PhD project. For example, as discussed in Section 4.1.2.4 of Chapter 4, it became evident in my PhD project that knowledge of an impairment affects how people act towards someone who has that impairment; further study of this phenomenon could prove valuable. In Chapter 4 another interesting finding was discussed, the impact an audience's lack of familiarity with the use of software and computers to make music can have on the performer. This unfamiliarity with the skills required to make music with modern technology is an important factor for musicians who use this method of producing music and so would benefit from further investigation. It was also noted in earlier in this chapter that neither of the two participants in my PhD project mentioned Braille Music Notation which, given that both of these participants are accomplished musicians seemed surprising. As with the other topics mentioned in this section the use and efficacy of Braille Music Notation would be a useful and important topic for future research.

During the initial stages of my PhD project I felt it would have been useful to include a comparison or at least some form of consideration of cognitive impairments and musical engagement. However, an assessment of the workload involved showed that it would not be feasible to incorporate issues relating to cognitive impairments and music engagement into my PhD project. Consequently, I feel there is potential for such a study in future research.

A final reflection on my PhD project as a whole has enabled me to identify some things that I would have done differently, especially with the benefit of hindsight. For example, the interview with PhD participant Suzie took place in a pub at lunchtime which was quiet at the beginning of the interview but as patrons came in for lunch it became very noisy making the interview and consequent transcribing difficult. Some other interviews took place in a room in a university building which was much more suitable. Another factor that made interviewing difficult was the use of Skype. Three of the participants in my PhD project were interviewed on Skype and all proved difficult due to internet connection issues and interruptions from participants family or pets.

In relation to time limitations imposed by PhD course regulations, I feel that on reflection, it may have been less stressful to have enrolled as a part-time PhD student rather than a full-time student. As I am not employed I had every day to work on my PhD project, so part-time working would have given me more time to complete the writing up of the thesis which due to my progressive sight-impairment became increasingly difficult.

Other changes in the approach I would have taken while working on my PhD project are related to the issues I experienced as a disabled student. As mentioned in Chapters 1 and 3, I felt compelled to change schools and both supervisors due to these issues; however, if I had known about the problems I was about to face I do not feel I would have applied for a place on the PhD programme. I would also have taken a different approach to the subject of my PhD project and focused exclusively on the experiences of disabled music students in music education. However, these reflections are made with the benefit of hindsight and there would have been less breadth of data available for the PhD.

7.6.3 Implications for future research and recommendations

The topic of music and disability has not been overly researched, therefore there are many areas that would benefit from further investigation. Consequently, my PhD project has found several opportunities for future research in the field of disability studies, music, and music education. For example, the point of interaction between a person with an impairment and a musical instrument is an area of concern for many disabled musicians and research into aspects such as; the issues raised by the specificity of impairments and their impact on ability to play a particular instrument, finding alternatives to a specific instrument and looking at the way adapted or electronic instruments are perceived in the music world and by audiences.

The next area of discussion I have identified as a gap in current research is the impact that the phenomenon whereby impairment is perceived to have a greater effect than usual on the ability to make or teach music. Lubet has discussed the perception that impairment is regarded differently in the music world (2010, p.16) and I believe this argument should be carried forward in order to include an investigation of the impact the music world's perception of impairment has on disabled people's experiences in music making and music education.

In addition to perceptions within the music world, perceptions of disabled musicians in general is an under studied area. Although my PhD project has examined several elements related to how disabled musicians are perceived, I believe there are many factors of what it means to be a disabled musician that need further investigation. PhD participant Rose intimated that people do not understand the level of skill required to play her music via an iPad and computer software which suggests that playing an electronic instrument in place of an acoustic or 'traditional' version is still not fully accepted or understood. An examination of how disabled people source such technologies and find support as they learn to play them would also be a worthy project. Research into the physical aspect of music making should not be restricted to musical instruments however. I would argue that a more extensive examination of access to stages, practice areas, recording facilities and performance venues should also be made.

Analysis of the data in my PhD project shows that for disabled musicians, the area of highest concern is the attitudes and perceptions of others, especially in music education. For this reason, I suggest that research into the world of music education for disabled people should be made a priority. All but one of my PhD participants referred to issues related to music education, whether at university, school, or via a private music tutor. Only two of these participants were attending an education facility at the time of the interviews, suggesting that it is not current circumstances that compels the PhD participants to draw attention to their difficulties during their music education, but the significance and impact of these difficulties. I believe that the concerns raised by the participants in my PhD project, coupled with

my own experiences as a PhD music student, suggest that an examination of the way music education is delivered to disabled people is not only warranted but essential in order to improve the experiences of disabled music students, and to improve the uptake of music education by disabled people.

7.6.4 Closing comments

As remarked in Chapter 1, negativity pervades the tone of this thesis. This negativity is purely due to the fact that being a disabled person in the world of music and music education means exposure to negative attitudes and barriers that result in negative experiences. Thinking back to my four years as a PhD student, it is the attitudes of others that always come to the fore. When I informed them of my decision to make an official complaint against the university, one member of staff remarked, ‘it hasn’t been *all* bad, we gave you a nice office with a good view’. My experience as a disabled student was constantly punctuated by comments such as ‘it has always been held here’, ‘we don’t see many disabled people’ and ‘I never thought of that’. These were comments made when I highlighted the fact that I could not attend concerts or performances by other music students due to poor access to venues, something all music students were encouraged to do. Life for a disabled person can be full of such offhand comments but for a person who is at the end of their tether, who has endured the cumulative effect of constant discrimination and institutional apathy, comment like this have a deep and lasting effect. I would have preferred to end this thesis on a more positive note, but recent events have put paid to this intention. Weeks before writing these final few words I had to organise a seminar on the university campus. I contacted my ‘go to’ person in the timetabling department to arrange this telling them again that I am a wheelchair user and require an accessible room. It came as no surprise to me that the room was on the third floor with no lift in the building. To add insult to injury, a few days later I received an invoice from the university for the extension I had been awarded to compensate for the time out I had taken due to the difficulties the university had created for me. I received apologies for both of these incidents, but the point is that despite a major review of disabled student experiences, the university are still creating physical and emotional barriers for their disabled students. It is my hope

that by documenting the difficulties my project participants and I have faced, this thesis will serve as a guide on how to avoid creating these physical and emotional barriers for disabled people and in doing so, encourage more disabled people to engage with music making and seek an education in music. Therefore, the overarching question asked in this thesis ‘where are all the disabled musicians?’ can be answered by saying; there are some, but due to physical and attitudinal barriers created by both individuals and music institutions, they are not only disabled but dissuaded, discouraged and disavowed by the music world.

7.6.5 A positive note

The participants in my project were eager to convey a message to disabled people that, despite all of the trials and tribulations that come with performing or learning music as a disabled person, it is possible to gain a qualification in music and/or become a successful performing musician. The participants in my project are testament to that and the fact that this thesis exists also supports that sentiment.

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