WHAT IS THE EFFECT OF ACTIVE MUSIC PARTICIPATION ON WELL-BEING AMONG ADULTS WITH DOWN'S SYNDROME?

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ABSTRACT

All known cultures experience music and the healing properties have been acknowledged for over 30,000 years. Research has indicated that music participation has the potential to support a range of well-being benefits, for example among older adults, people with dementia and people experiencing mental ill-health. Despite encouraging anecdotal reports, however, adults with learning disabilities have typically been under-represented in well-being research and there is very little literature examining music participation within this community. Those studies that do exist have tended to focus on separate components of well-being, which has presented an incomplete picture.

This multiple methods research investigated how music participation can support the well-being of adults with learning disabilities, with a particular focus on adults with Down's syndrome. The research was conducted via three studies: (1) an ethnographic case study of four students attending regular music sessions via the Music Man Project UK, (2) a survey study exploring the prevalence of music usage within the UK Mencap network, and (3) a within-subjects intervention study to investigate the impact of a 10 week programme of music-making, delivered and supported by the Music Man Project UK, on well-being among adults with Down's syndrome.

The results indicate that active music participation can indeed enhance positive well-being and reduce negative well-being for adults with Down's syndrome. Study 1 highlighted the wide ranging well-being benefits experienced by participants and their families, for whom music-making was a regular ongoing activity. Four overarching themes emerged: positive emotions; educational development; meaning; and, accomplishment. Study 2 provided an

insight into how Mencap (the largest UK charity supporting people with learning disabilities) used music as part of its programme and identified barriers that potentially inhibited music-making. Study 3 demonstrated improved well-being scores following a 10 week intervention programme of music-making with participants who had not participated in regular music sessions previously. Implications from the research could inform accessible music intervention strategies to support and enhance well-being in this often marginalised group in society. In so doing, this research contributes to providing equal opportunities to music-making and its associated well-being benefits to people with learning disabilities, comparable to their non-learning disabled counterparts.

ACKNOWLEDGEMENTS

ABBREVIATIONS

WB – Well-being

LD – Learning disability

DS – Down's syndrome

MMP UK – Music Man Project UK

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CHAPTER 1: INTRODUCTION

Well-being (WB) has become the new 'buzz word' in many research domains including the workplace; educational environment; healthcare; local community; and more recently, within specific target groups of the population. However, WB as a concept (or a variation thereof) is certainly not new and has been the concern of many philosophers since the time of Aristotle writing about the 'good life'. WB is arguably one of the most significant factors in a person's life and it can have a major influence resulting in either negative or positive life outcomes. It concerns far more than in-the-moment happiness and it can be difficult to identify exactly what it means on a day-to-day level (Diener and Seligman, 2004). Academics have, and still are, continuing to debate a workable definition of WB. In general terms, however, WB can be understood as how a person feels about themselves; how they function personally and socially; and, how they evaluate their lives as a whole (Ryan and Deci, 2001). The majority of people would probably say they strive for WB and that it is an important aim in their life. High levels of WB are linked with developing resiliency and the ability to cope with difficult circumstances and the challenges of life. In many ways WB can be equated to the very meaning of human existence.

The quest for WB can help to create an optimal life experience, with the opportunity to lead a fulfilling and happy life. It is not just the removal of negative influences, such as poverty or ill health, that is beneficial. It is also the inclusion of positive factors which can lead to personal enjoyment and satisfaction (Seligman and Csikszentmihalyi, 2000). WB is a subjective concept based on the perceived health and life experiences and these are unique to each person and they can change over time, place and within each different situation.

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Therefore WB has the dynamic capacity to be altered and indeed improved upon when necessary. A variety of intervention opportunities for supporting WB should ideally be available to facilitate autonomy in making life choices, thus enabling people to take control and responsibility for their own lives.

An effective method to enhance WB in an accessible and readily available format is advantageous for everybody in need of some level of support. The importance of WB has now been acknowledged by psychologists, medical professionals and healthcare workers and additionally, many Governments are seeking cost-effective plans for its long-term management. An appropriate way in which to maintain WB levels is desirable not only for the individual but also for the collective functioning of society. The financial and social implications of poor levels of WB have the potential to be significantly damaging, particularly for the health service. Therefore, it is not surprising that researchers have recently shown an increased interest in an understanding of what actually contributes to providing good levels of WB (for example, Dolan, Peasgood and White, 2007). Despite a growing number of studies emerging, there are groups in the population that have been largely absent in the research literature resulting in an incomplete picture. The learning disabled (LD) community is one such group that has been omitted from the research field and this community will be the focus of this thesis.

Historically adults with LDs have been under-represented in the academic literature, particularly regarding the complex concept of WB and its effective support and management. The majority of research to date has tended to focus on children or adolescents and within developmental, educational (such as the work of Down Syndrome Education International) or

medical areas of interest. However, once outside of the supportive educational environment and living within the community, adults with LDs often experience a significant regression in their life skills. This potentially results in declining levels of WB, with fewer participatory opportunities and no further educational input readily available. This is an ongoing area of concern that requires further research into likely support strategies. The varied life challenges surrounding LDs has made research in this population complex and plagued with problems at every level. A combination of these difficulties and the subjective nature of WB has resulted in very few studies being undertaken. A focus on one single LD will help to eliminate a degree of this uncertainty, thus this thesis will focus on adults with Down's syndrome (DS) as a target group.

Turning towards enhancing WB, the arts (in particular music) has recently been at the centre of many studies and this has provided encouraging results. There is a burgeoning raft of evidence in support of the use of music as an intervention strategy for supporting WB in many different groups of the population, (for example, a systematic review carried out by Daykin, 2017) so this would appear to be an intervention strategy worthy of further exploration for the LD population. An encouraging foundation has been laid in the world of music therapy and LDs, which further supports the likely successful outcome related to music participation strategies. There are some individuals, however, for which music therapy has proved ineffective or is inaccessible for a variety of reasons, for example, financial restrictions or geographical location. This leads onto identifying other music-related interventions which could potentially offer support for managing and enhancing WB in these specific LD groups. People with DS are one of the groups that have not always responded particularly successfully to music therapy, despite anecdotal evidence suggesting an enjoyment of music participation in a variety of forms (Music Man Project, 2016).

Therefore, this research will explore the potential benefits of participating in musical activities on the WB of adults with DS. It is essential to provide equal access opportunities to music-making and its associated WB benefits to people with DS, comparable to the non-LD community.

1.1 RESEARCH QUESTION(S)

In consideration of the introduction presented above, the following research questions are addressed throughout the project:

Overarching research question:

1) What is the effect of active music participation on well-being among adults with Down's syndrome?

This overarching research question can be further sub-divided into the following individual questions:

2) What is the most appropriate method for assessing well-being among adults with Down's syndrome? (See research aim (i))

3) What counts as effective active music participation for adults with Down's syndrome? (See research aims (ii), (iv), (v) and (vi))

4) To what extent does the PERMA model fit the emerging data from the participants? (See research aim (iii))

1.2 RESEARCH AIMS

The individual research questions are explored through the following specific research aims, linked to individual studies (Pilot study, Study 1, Study 2 and Study 3):

(i) To scrutinise potential tools to measure WB among adults with LDs, recognising a lack of validated measures for this target group (see Chapter 4, Section 4.5.1, Pilot study).

(ii) To obtain an in-depth understanding of what taking part in regular active music sessions means for four adults with DS, and their families (see Chapter 4, Section 4.5.2, Study 1, Chapter 5).

(iii) To explore how well the PERMA model fits the data from the participants (see Chapter 4, Section 4.5.2, Study 1; Chapter 5).

(iv) To investigate the prevalence of music participation as an activity within the Mencap organisation and to provide an insight into their view of music-making on WB for their adult members (see Chapter 4, Section 4.5.3, Study 2; Chapter 6).

(v) To investigate the impact of a one-off music intervention on WB among adults with DS (see Chapter 4, Section 4.5.4, Study 3; Chapter 7).

(vi) To investigate the impact of a 10 week programme of music-making on the WB of adults with DS (see Chapter 4, Section 4.5.4, Study 3; Chapter 7).

1.3 BRIEF OUTLINE OF THESIS STRUCTURE

The thesis begins with introducing the concept of WB, followed by a literature review of WB and the arts (Chapter 2), before moving onto a review of the literature concerning WB, arts (in particular music) and LDs (with a focus on DS; Chapter 3). Methodology and methods

are then presented, with attention given to LDs and ethical considerations (Chapter 4). Three main studies are undertaken utilising a multiple methods strategy:

1) Study 1 (Chapter 5): To obtain an in-depth understanding of what taking part in regular active music sessions means for four adults with DS and their families.

2) Study 2 (Chapter 6): To investigate the prevalence of music participation as an activity, within Mencap groups. This will help to establish the view of this national organisation on the benefit of music on WB among their adult members.

3) Study 3 (Chapter 7): To investigate the impact of both individual sessions and a 10 week programme of music-making on the WB of adults with DS.

The final chapter (Chapter 8) offers discussions and conclusions including strengths and limitations of the project, practical applications and contributions to knowledge.

CHAPTER 2: WELL-BEING AND THE ARTS

Chapter 2 introduces the concepts of defining and enhancing WB. Following this, WB and the arts are discussed including visual art, drama, dance and finally music. The chapter concludes with a discussion on the impact of music-making on WB.

2.1 DEFINING WELL-BEING

2.1.1 Introduction to well-being

Throughout history happiness has been viewed as a defining motivation for human action and purpose and has subsequently been explored in great depth by both philosophers and psychologists. As a result, the field of general psychological health has recently attracted much interest from researchers, particularly during the last three decades. This growth is also representative of a larger societal trend concerning the value of the individual and the importance of subjective views in evaluating life. Two significant periods have been identified with regard to WB research: the 1960s witnessed an increased interest in psychological growth and health, when the human potential movement swept throughout America and, more recently, the turn of the century saw considerable attention being given to positive psychology and the resulting associated health and WB benefits (Seligman and Csikszentmihalyi, 2000).

Throughout the 1960s interest in general and psychological health increased and several theories were suggested as to what makes people happy. Wilson (1967) presented a generalised overview entitled 'Correlates of Avowed Happiness'. Although available data

were limited at this time, he concluded that a happy person is a 'young, healthy, well-educated, well-paid, extroverted, optimistic, worry-free, religious, married person with high self-esteem, job morale, modest aspirations, of either sex and of a wide range of intelligence' (p. 294). Wilson's review contained two main conclusions: (1) that those with the most advantages were the happiest; and (2) that theoretical progress in understanding happiness had been extremely limited and progressed very little since the time of the Greek philosophers. This review was highly influential at the time it was produced and offered several conclusions as to what characteristics or requisites were essential in order for an individual to experience 'happiness'. Several of these conclusions, such as youth and modest aspirations, have since been dismissed (Diener, 1984; Ryan and Deci, 2001).

The 1980s saw a move towards focussing on theories that stressed psychological factors, rather than relying heavily on objective factors such as health[1]. Arguably one of the most important advancements at this time was in the accurate measurement of happiness (or WB, as it was now referred to), which was central to gaining a scientific understanding of the components of WB. According to Diener (1984), WB had three central components: (1) it was subjective and each individual experienced life differently - objective conditions were potentially influential but no longer viewed as inherent or necessary; (2) it now included positive measures, rather than just the absence of negative factors; and (3) measures now included a global assessment of all areas in an individual's life. Veenhoven (2007) suggested that happiness may act as a buffer to stress and concluded that society is more likely to flourish with happy individuals. The benefits of happiness and WB were now recognised as important for the greater functioning of society as a whole, rather than just for the individual

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[1] It should be noted that health can be identified as a subjective factor – the concept of 'good' health can vary dramatically between individuals and the subsequent effect it has.

concerned. With this recognition of the significance of positive aspects of life and the contribution this makes to WB, the research focus shifted away from negative factors alone, and positive psychology became the new centre of interest.

Positive psychology 'is the study of the conditions and processes that contribute to the flourishing or optimal functioning of people, groups, and institutions' (Gable and Haidt, 2005, p. 104). The Positive Psychology Movement was an attempt to focus new research into the previously neglected areas of what makes life worth living and what makes people 'happy'. The idea of positive psychology is not new and its origins can be traced way back to long before the work of Seligman and Csikszentmihalyi. For example, Aristotle (384-322BC) wrote on morality, virtue and a good life; the Utilitarians Jeremy Bentham (1748-1832), and also John Stuart Mill (1806-1873), who argued for 'the greatest good for the greatest number of people'; William James (1842-1910) and his theory of happiness, that suggested happiness depends on choices that we are able to make; and the humanist Maslow (1908-1970), who used the term 'positive psychology' in his renowned book 'Motivation and Personality' (Anand, 2016). The Positive Psychology Movement rapidly gained momentum following the end of the Second World War, which helped to recreate an interest in the positive aspects of human nature (Compton, 2005).

In 1998 Martin Seligman was elected President of the American Psychological Association (APA) and during his term the main theme became positive psychology. Even though he was not the first positive psychologist, he is generally viewed as the pioneer of contemporary positive psychology (Compton, 2005). Today positive psychology has expanded into many different areas, such as sport and performance, and is linked with the optimal functioning and

WB of the individual and/or group in society. The broad concept of WB is now intrinsically linked with positive psychology and this has influenced the definition of WB, which has subsequently received much discussion among researchers and psychologists and is the issue to which we now turn.

2.1.2 Definition of well-being

As a result of several governments (including that of the UK) recognising the significance of WB, not only for the benefit of the individual but also for society as a whole, the past decade has seen an explosion in the number of studies concerning WB. It is now acknowledged that, for example, income alone is not an adequate measure that secures the WB of the individual. The idea that wealth and economic growth are both significant indicators of progress and subsequent WB is now considered out of date and inadequate (Diener and Seligman, 2004). Many nations have become increasingly financially prosperous throughout the last five decades although research indicates that, for example in the United States, life satisfaction has remained constant. According to Diener and Seligman (2004), there now exists 'distressingly large, measurable slippages between economic indicators and well-being' (Diener and Seligman, 2004, p. 1). Even though an abundance of public services and material goods are widely available in many developing countries, this does not reflect the WB of the members of society. This phenomenon is described as the 'progress paradox' (Easterbrook, 2003).

The concept of WB is complex and frequently used as a general term for how individuals think and feel about their lives (Diener, Suh *et al.*, 1999). The diversity in the vast array of approaches in WB research has created blurred and sometimes overly generalised definitions.

The term 'well-being' has frequently been used synonymously with 'happiness', 'life satisfaction' and 'quality of life'. Ryff's (1989) definition of psychological WB combines three areas of psychological theory: (1) personal growth models, including those of Jung (1933) and Maslow (1968); (2) life-span development perspectives, including Erikson (1959); and, (3) positive mental health (Jahoda, 1958). In line with current research, WB can be defined as 'a dynamic process that gives people a sense of how their lives are going through the interaction between their circumstances, activities, and psychological resources' (Abdallah *et al.,* 2009, p. 3).

The complexity of WB cannot be overlooked, however, and has made research in the field problematic. According to Ryan and Deci (2001), WB is a 'complex construct that concerns optimal experience and functioning' (p. 141). The debate about what components actually combine to produce a 'happy life' is ongoing and has huge implications on both a practical and theoretical level. Ryan and Deci (2001) investigated two perspectives of WB that relate to two distinct philosophies. The first can be broadly labelled as hedonism and reflects the idea that WB consists of the subjective experience of happiness or pleasure. The second perspective acknowledges the understanding that WB consists of more than happiness alone. This eudaimonic perspective involves human potential, including optimal psychological functioning and self-realisation. Previous research has tended to centre on *either* the hedonic perspective, focussing more on positive affect and greater life satisfaction (Diener and Lucas, 1999), *or* on the eudaimonic perspective, focussing on psychological WB and a fully functioning person (McGregor and Little, 1998; Ryan and Deci, 2000). Ryan and Deci (2001), however, argued that WB is a multidimensional phenomenon and as a result studies concerning WB should take both these perspectives into account.

Indeed, the World Health Organization (WHO) defines WB as 'a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community' (WHO, 2014). In line with Ryan and Deci (2001), this view identifies subjective happiness and life satisfaction (hedonic perspective) as separate from positive psychological functioning (eudaimonic perspective). Therefore the important issue here is the identification of a means whereby individuals can seek hedonic and eudaimonic outcomes, which are not detrimental to the rest of society.

One theoretical approach offered by Seligman helps our understanding of the components of WB and thus offers an insight into the successful management of WB. Seligman (2002) claimed that three subjective facets combined to produce a 'happy' individual: positive emotion; engagement; and meaning. Happiness could be achieved through one or more of these facets. In 2011 Seligman revised his theory to include two additional facets: positive relationships and accomplishment. He also redefined the goal of his theory as 'well-being', rather than 'happiness', to reflect the multifaceted characteristics of human growth and development. According to Seligman's new theory, WB consists of the nurturing of one or more of these five areas: (1) Positive emotion; (2) Engagement; (3) Relationships; (4) Meaning; (5) and, Accomplishment (abbreviated to the PERMA model). Seligman suggested that these five factors are what individuals pursue for their own sake. This theory goes some way to reconciling the previously differing perspectives on theory and measurement of WB, as it incorporates both hedonic and eudaimonic aspects (Seligman, 2011). This thesis will

adopt the PERMA model as a foundation for the definition of WB[2]. This model is highly

regarded and has also been widely used in WB research (for example, Ascenso, Perkins and

Williamon, 2018; Nebrida and Dullas, 2018). Although it should be noted that the PERMA

model has not been without its critics – predominantly concerning an over-emphasis on

happiness and positivity, rather than looking at a more balanced perspective of a combination

of positive and negative factors (Friedman and Robbins, 2012). There is also no mention of

physical health as a factor, which Seligman argued was ultimately linked to the other

constructs rather than standing in its own right. However, due to the highly complex nature

of human beings, a theoretical model of WB will always have challenges and limitations.

2.1.3 Enhancing well-being

Having thus far introduced the development of WB research and outlined the definition to be

used in this thesis, this section considers how WB can be maintained or indeed, improved

upon. Researchers have developed a greater understanding of the components of WB and

have thus tended to focus their efforts on the underlying processes rather than simply

describing associated objective or subjective characteristics. A detailed literature review

covering the majority of large-scale research works carried out since 1990 (Dolan, Peasgood

and White, 2007) examined all the potential influences on WB. These were then categorised

into seven main areas: (1) income; (2) personal characteristics; (3) socially developed

characteristics; (4) how we spend our time; (5) attitudes and beliefs towards others/self/life;

(6) relationships; and (7) the wider economic, social and political environment. The

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[2] Other models of WB are acknowledged, for example the Two Continua Model Across the Lifespan (Westerhof and Keyes, 2010), however, the PERMA model was selected as it is the model of choice used by the British Institute of Learning Disabilities and is particularly suitable for people with LDs.

researchers concluded that the interaction of these categories is a significant factor in determining WB.

Government interest in WB has not surprisingly increased substantially due to the direct impact upon mental health outcomes and financial implications (Department of Health, 2011). Improved WB is associated with a range of better outcomes for individuals from all backgrounds and in all age groups. These include: improved physical health; longer life expectancy; increased educational achievement; increased life skills; better employment rates and productivity; higher levels of social interaction and participation; reduced risk behaviours such as smoking and alcohol abuse; reduced risk of mental health problems and suicide; and, reduced anti-social behaviour and criminality (Department of Health, 2011).

Recent strategies to improve WB have suggested a variety of approaches. Government acceptance of the importance of WB has led the UK National Health Service (NHS) to suggest five essential steps to promote positive mental WB for the individual (NEF, 2008):

Connect – connect with people around you and spend time developing these relationships.
Be active – find an activity you enjoy and make it a regular part of your life.
Keep learning – learning new skills provides a sense of achievement and a new confidence.
Give to others – whether it's a smile or volunteering, it can improve mental WB and lead to new social networks.
Be mindful – be more aware of the present moment, including your feelings, thoughts, your body and the world around you. Mindfulness can positively change the way you feel about life and how you approach new challenges.

NHS guidelines suggest that the actions an individual takes and their thought processes have the most significant impact on WB. If an individual feels good about themselves and the world around them, they will be able to achieve their best life outcome.

Alongside positive psychology, research has made some progress in understanding areas such as engagement, flow and optimal self-functioning, which has increased our knowledge of what constitutes WB (Seligman and Csikszentmihalyi, 2000; Howard, 2008). The use of positive psychology interventions are often considered a useful complementary strategy in mental health management and as a support for WB. These strategies aim to create positive emotions and can be highly diverse, for example, socialising, practising optimistic thinking, replaying positive experiences or writing letters of gratitude (Lyubomirsky and Sin, 2009; Cohn and Fredrickson, 2010). Bolier *et al.* (2013) carried out a meta-analytical study of the effectiveness of positive psychology interventions, covering forty articles and in excess of 6,000 participants consisting of the general public and individuals with more specific psychosocial issues. Their results showed that positive psychology interventions aimed at increasing positive feelings, positive cognitions or positive behaviours can all be effective in the enhancement of WB. Nonetheless, further research into accessible and cost effective strategies for the successful management of WB is desirable at both an individual and national level.

The field of sport and its associated benefits for psychological health and WB has also received considerable research interest (Penedo and Dahn, 2005; Biddle and Mutrie, 2007; Sherry, Schulenkorf and Chalip, 2015; Taylor *et al.*, 2015). According to Taylor *et al.* (2015)*,* 'wellbeing is the manifestation of the catalytic role that sport plays in stimulating

social impacts. There is evidence of a positive relationship between sport participation and well-being' (p. 9). Governments throughout Europe and many western countries are aware of the potential benefits that sport can provide to physical and mental WB. For example, research carried out has indicated that the more time people spent practising sport, the better their mental WB, particularly when engaging with family or friends (Marlier *et al.*, 2014; Fujiwara, Kudrna and Dolan, 2014). Findings such as these have led many governments to create policies suggesting recommended levels and intensity of physical exercise and thus equating health with WB. If these guidelines are met the WB of the individual has the potential to be enhanced. However, it remains unclear whether it is the health benefit or the pleasure factor that produces the desired result (Downward and Dawson, 2015). Indeed, some findings have suggested that it is the cultivating of positive emotions that optimises health and WB, irrespective of the intervention strategy employed (Fredrickson, 2000).

In sport, however, some individuals can experience difficulties or barriers to participation. Physical disability, age-related health limitations or even a lack of interest can be restrictive for some people (Sallis, 2000; Allison *et al.,* 2005) and it is thus advantageous to create a variety of options when suggesting pathways for enhancing WB. To this end, the field of arts and health has seen a burgeoning interest from researchers:

> The practice of using the arts to promote healing and happiness is as old as the arts themselves. For early civilizations, aesthetic beauty in objects or surroundings and the soothing rhythms of words, movement and music contributed to the balance and harmony between bodily systems and environment which was believed to maintain good health. (Royal Society for Public Health, 2013, p. 4)

The subjective nature of WB allows the individual the opportunity to seek their most effective intervention – what is beneficial for one person may have little or no effect for another. The arts is one area that has received a considerable amount of recent attention with regard to WB and is the focus of the following section.

2.2 WELL-BEING AND THE ARTS

Research discussed in Section 2.1 has highlighted the importance of WB both for the benefit of the individual and for the optimal functioning of society as a whole. The ability to facilitate the enhancement or restoration of WB is an area of significant importance to health professionals, particularly those involved with mental health care. With the recognition of the importance of positive psychology interventions for promoting WB, the arts have received considerable ongoing interest from researchers, particularly with reference to how the arts and public health can benefit each other (Cameron *et al.*, 2013; Noice, Noice and Kramer, 2013). There is now a sizeable body of research suggesting that the arts can improve the health of people with mental or physical health issues, often referred to as 'Arts in Health'. A recent report by WHO Europe found considerable evidence of:

> The contribution of the arts to the promotion of good health and the prevention of a range of mental and physical health conditions, as well as the treatment or management of acute and chronic conditions across the life-course. (WHO, 2019, online)

The WHO report argued that the arts can be a cost effective answer that can utilise existing resources. In addition, the arts can serve to support challenges for which there are no current healthcare solutions (WHO, 2019). In what follows, literature reporting on the impact of a

range of creative arts (including music) on WB, is critically examined, before a gap in current knowledge is identified.

2.2.1 Well-being and visual art

A systematic review on the WB outcomes of engaging with visual art in adults with mental health conditions has provided a useful insight into this issue (Tomlinson *et al.,* 2018). Published studies from the last 10 years were reviewed. The researchers concluded that engagement with the visual arts can reduce depression and anxiety; increase self-respect, self-esteem and self-worth; encourage involvement with society and support ways to improve identity. Some negative aspects were identified, such as feeling a pressure to create. Overall, they concluded that there was some evidence but the field of research is weak with a lack of resources and infrastructure for sustainable practices. Examples of research into visual arts that have provided encouraging results are highlighted below.

Various studies have suggested that visual art can affect health, including physiological and psychological aspects, and can lead to an enhanced sense of WB (Bolwerk *et al.*, 2014). Exposure to art in a healthcare setting has been shown to reduce symptoms of anxiety and depression (Daykin, Byrne *et al.*, 2008; Nanda *et al.*, 2010). Furthermore, although research into art-making is limited and has tended to focus on professional artists, results have suggested that art-making for amateurs is beneficial for WB. Reynolds (2010) studied 32 older women (aged 60 – 86 years) who took up art after retirement. Participants described how their art-making enriched their mental health through enjoyment of the sensuality of texture and colour and how it presented them with exciting challenges and new ambitions. It also provided highly valuable connections with a world outside of their home environment

and family. Reynolds suggested that art-making encouraged the women to give attention to the beauty of the physical world around them; promoted relationships of equal status among the group; and gave opportunities for validation. Art-making gave the women an identity which allowed them to resist the common stereotypes and exclusions frequently experienced in later life. Further evidence suggests that visual art production has a different effect on the brain compared to cognitive art evaluation and this was related to psychological resilience (Bolwerk *et al.,* 2014).

2.2.2 Well-being and drama

Further evidence for arts-based influences on WB can be found in studies relating to drama and theatre within certain populations (Kemp, 2006; Wilson, 2012; Low, 2012; Dolling and Day, 2013; Wimpenny and Savin-Baden, 2014). According to Wimpenny and Savin-Baden (2014):

> Theatre and performance provided opportunities for diverse marginalised members of a community to connect and participate in a shared activity and transform their views of themselves and others in ways that were beneficial for health and well-being. (p. 47)

Kemp (2006) found that using community-based drama initiatives improved the social and emotional WB of young black men living in south London. Both self-esteem and a sense of agency were increased through creating an opportunity for self-expression, reflection and self-understanding. The relationships that developed between the participants were based on trust and reciprocity (Kemp, 2006). As a result of a drama workshop project facilitated in a women's prison in Johannesburg, Low (2012) explored how focussing around role models and hopes for the future helped the women to manage their situation. Low proposed that

through these moments, where an individual was acknowledged rather than de-individualised, the individual had dignity and achieved a level of recognition which was crucial to sustaining their sense of WB (Low, 2012). The value of arts-based approaches in encouraging and promoting WB is demonstrated, highlighting the need for further resources to be employed in this field of research.

2.2.3 Well-being and dance

A recent systematic review including the impact of dance interventions on the WB of young adults, dated between 2006 and 2016, concluded that the amount and quality of research was low (Mansfield *et al.,* 2018). The authors suggested that dance may serve to enhance WB in this group but evidence was limited and better designed studies were needed. The majority of studies were small scale and limited in design. Despite these findings, there has been some research into the impact of the benefits of dance within different groups which has provided interesting results on the potential impact of this expressive art form (Murcia *et al.*, 2010; da Costa, 2012). For example, a dance project delivered a six week programme and examined factors including frequency of participation and quality of life on community-based adults over the age of 50 years. Although initial statistical analysis did not highlight any significant difference regarding participation in the programme and quality of life, focus group data indicated that the participants had enjoyed the programme and subsequently experienced perceived enhanced physical ability; improved emotional and psychological WB; and, increased activity participation (O'Toole *et al.*, 2015). Murcia *et al.* (2010) argued that dancing has potential positive benefits on WB in several respects, particularly with reference to emotional, physical, social and spiritual dimensions. What is evident from the arts-based research to date is that participation in the arts has a significant impact on the WB of

individuals from a wide variety of social situations, cultural backgrounds and age/gender groups (Daykin *et al.*, 2008; Reynolds, 2010; Kemp, 2006; Low, 2012; O'Toole *et al.,* 2015). Music, in particular, has received growing attention, and is the creative art form on which we now focus.

2.2.4 Well-being and music

The healing aspects of music having been recognised for over 30,000 years, for example, in the Shamanic culture music allows access to the spirit world which facilitates the healing process (Moreno, 1995). However, it is a relatively new and under-researched factor regarding its impact on WB. Dating back to the start of the twentieth century, Eva Vescelius founded the National Therapeutic Society in New York and stated 'when the therapeutic value of music is understood and appreciated, it will be considered as necessary in the treatment of disease as air, water and food' (Vescelius, 1918, p. 376). Following the two world wars, community musicians visited hospitals to play for the thousands of injured and traumatised veterans. Both the physical and emotional responses of the patients led the medical world to start exploring the beneficial healing effects of music (American Music Therapy Association, 2015).

Ansdell (2015), a music therapist with over 25 years' experience, suggested that music can help individuals in a host of different ways:

- Music can help us because we are all musical.
- Musical experience is something done with others, not something that happens privately.
- Our musical experiences help us explore, create and enhance our lives.

- Music helps by addressing our basic human needs – for recognition as persons, identity, relationship, community, transcendence. There is a musical core to these basic needs. (Ansdell, 2015, p. 295)

Ansdell (2015) suggested that music is 'being seen not just as therapy or treatment, but also as a natural part of health prevention and promotion, conflict resolution, and social development work' (Ansdell, 2015, p. 18).

Indeed, music therapy is known to address many issues including emotional WB, physical health, social functioning, communication abilities and cognitive skills, all through musical interactions, (Solli, Rolvsjord and Borg, 2013; Hanser, 2014; Teut *et al.*, 2014) but this is beyond the remit of this thesis. Music therapy and music education are two different forms of intervention and this distinction requires clarification. Music education concerns the teaching and learning of music and a music teacher is an education professional that teaches music. In comparison, music therapy is a therapeutic relationship between a client and a music therapist that focusses upon a specific goal. A music therapist is a health professional who often works as part of a team including physiotherapists, speech therapists, paediatricians, specialist consultants, social workers etc. Music therapy tends to be delivered in a clinical setting, such as hospitals, special schools, hospices or care homes, whereas music education can take place just about anywhere. There can be barriers to music therapy and its effectiveness for some individuals, for example, financial cost, geographical availability, age, effectiveness for an individual, and an individual's willingness to participate. *This thesis is concerned with music education and active participation in music-making.* Music education and active music-making are a viable potential alternative to music therapy for those individuals for whom music therapy has proved inappropriate or ineffective.

A systematic review of WB outcomes for music and singing in adults was undertaken to investigate the role of music is supporting WB (Daykin, Mansfield *et al., 2017*). The authors sought to identify robust evidence to underpin policy and practice. Music listening and group singing were the two most commonly seen activities, with very few studies addressing WB in marginalised groups within the community. They concluded that although there was robust evidence for positive effects of music and singing on WB in adults, there was a need for research within sub-groups who were at a greater risk of low levels of WB, and the processes by which WB may or may not be achieved. A recent meta-ethnography (Perkins *et al., 2020*) highlighted the fact that there is very little research that has scrutinized the processes by which music has an effect on WB. The authors concluded that people benefit from participating in musical activities by engaging with specific and multiple processes that meet their individual needs and circumstances. The following studies reported are by no means intended to be a comprehensive list of available literature, but instead seek to provide examples of relevant music and WB studies within the various music-related categories.

2.2.4.1 Well-being and music listening

Evidence suggests that listening to music has the power to affect mood, lower levels of depression and pain and contribute to the listener's WB (Stratton and Zalanowski, 1991; Hanser and Thompson, 1994; Siedliecki and Good, 2006). Music has been used to induce moods in an experimental setting and research has demonstrated that listening to certain styles of music can evoke strong moods and the associated physiological responses, such as lowered heart rate and reduced levels of the stress hormone cortisol (Etzel *et al.*, 2006). Fancourt and Williamon (2016) examined the impact of attending a public, live concert and the subsequent effect on stress hormones. They found significant changes in the cortisol,

cortisone and progesterone levels indicating a lowering of stress levels. This was the first evidence to suggest attending a cultural event can have an impact on endocrine activity in this way.

A raft of research has also explored the impacts of listening to music in older adulthood. Laukka (2007), for example, assessed the uses of music in everyday life among community living older adults (aged 60-75 years) in Sweden. He investigated the associations between listening to music and WB, for example, affective WB, life satisfaction and eudaimonic WB. Although personality and health status were the two most important predictors of WB, some listening strategies were also significantly associated with psychological WB. These listening strategies included the experience of positive emotions, pleasure and relaxation. The results also indicated that mood regulation, enjoyment, and identity and agency were consistently positively associated with WB. These results provide further evidence to support the concept that music is beneficial to WB and give a useful insight into possible relationships between WB and musical activities. According to Edmonds (2009), neurological studies of the brain and music have indicated that we are prewired to understand and respond emotionally to music. Babies as young as five months old react to happy songs and physiological states induced through music are known to intensify as we mature.   The exploration of any longer term benefits within the real world is still in its infancy (Västfjäll, Juslin and Hartig, 2012, cited in McDonald, Kreutz and Mitchell, 2012) and there is a need for further research in the field.

2.2.4.2 Well-being and singing

Music has not historically been pursued for purely health reasons alone. Nevertheless, as seen in multiple studies (Siedliecki and Good, 2006; Stratton and Zalanowski, 1991; Hanser and Thompson, 1994; Etzel *et al.,* 2006; Warran, Fancourt and Wiseman, 2019) it can have positive beneficial effects on physical and mental health, thus creating an enhanced sense of WB. This is particularly the case for amateurs who seek music for pleasure and who are not under the constant scrutiny of judgement as in performances, or with the added pressure of having to earn a living. Several studies have suggested that singing, particularly with others in a choir, has positive effects on physical, mental and social WB (Bailey and Davidson, 2005; Clift and Hancox, 2010). Research has indicated that singing (solo and choral) creates a positive physiological response (Beck *et al.*, 1999) resulting in less tension and improved mood (Valentine and Evans, 2001). Choir singing has been found to positively influence emotional affect significantly more than passively listening to the same choral music (Kreutz *et al.*, 2004).

In 2009 a trial singing programme known as the Singing for Health network was established and has since involved over 100 individuals with a history of poor mental health. Findings have suggested that regular community singing promotes WB and helps individuals to develop strategies for dealing with depression and isolation (Arts, Health and Wellbeing, 2009). This type of group musical activity is an inherently social act, which allows people to engage with others and therefore reduces feelings of isolation often associated with depression, alongside other factors that may negatively influence WB. Group participation and commitment are encouraged, which subsequently creates a sense of belonging and a greater sense of identity. According to Cooper, Okamura and Gurka (1992) 'social activity

has been identified as one of the most consistent predictors of peoples' subjective reports of happiness' (Cooper *et al.,* 1992, p. 573).

In fact, there is a growing body of research linking group singing with enhanced levels of WB (Skingley, Martin and Clift, 2016; Stewart and Lonsdale, 2016). Kreutz (2014) studied the psycho-biological effects of amateur choral singing within a mixed group of novice and experienced singers. Kreutz suggested that singing enhances psychological WB along with inducing a socio-biological bonding response. Singers, even without any formal training, can experience 'flow' (a concept linked to perceived happiness) during group singing. Evidence also supports the effect of singing itself, particularly in a low stress performance situation. Fancourt, Aufegger and Williamon (2015) found that professional singers showed a significant decrease in both cortisol and cortisone levels within a low stress condition, indicating the actual act of singing is stress reducing.

There are a wide variety of specific groups that have reported benefits from singing. For example, recent evidence has emerged concerning the impact of singing among cancer patients and carers on mental health and WB. Fancourt, Williamon *et al.* (2016) found that singing was associated with significant reductions in negative affect and increases in positive affect, including cytokine response. Fancourt, Williamon *et al.* argued that singing improved mood and modulated certain aspects of the immune system for these patients and carers, although further research is required to establish the effects on more specific groups, and whether more longitudinal interventions could provide longer-lasting benefits.

There is also some evidence to suggest that playing musical instruments can improve certain aspects of physical WB. For example, teenage instrumental wind players exhibited fewer asthmatic and broncho-constrictive symptoms than non-wind players (Lucia, 1994). However, there has been very little reported concerning overall WB and instrumental playing. If found to be beneficial, this could provide another alternative non-invasive method of allowing individuals to take control of their own lives and achieve a sense of empowerment. Empowerment can create enhanced levels of WB through improvements in self-esteem; personal satisfaction; and, achievement levels (Woodall *et al.*, 2010; WHO, 2014).

One area that has received some research into active music-making and WB is among the older generation. Creech *et al.* (2013) investigated the role of making music in older people's lives. They focussed on how participation in making music might enhance social, emotional and cognitive WB. Results identified three relevant factors: (1) Purpose (having a positive outlook); (2) Autonomy and control; (3) and, Social affirmation (positive social relationships, competence and a sense of recognised accomplishment). A comparison of those involved in music-making activities with those participating in other activities showed a statistical significance in all three factors for the music group. Creech *et al.* (2013) acknowledged that the mechanisms through which music is able to achieve these results are difficult to isolate and identify, however they suggest the following factors may be involved:

- Music can provide a sense of purpose through progression in music and creative expression.

- Control and autonomy may be enhanced through the holistic nature of musical engagement.

- New musical challenges involve physical and cognitive application.

- Social affirmation may be supported through social interactions; giving and obtaining support from peers; a sense of status through performance; giving to the community and receiving positive feedback.

Perkins and Williamon (2014) explored the role that learning a musical instrument can play in serving to enhance levels of WB in older adulthood and suggested that learning to make music has significant implications for health. Perkins and Williamon concluded that learning music serves to enhance both hedonic and eudaimonic perspectives of WB, through six mechanisms: (1) subjective experiences of pleasure; (2) enhanced social interactions; (3) musically-nuanced engagement in day-to-day life; (4) fulfilment of musical ambition; (5) ability to make music; (6) and, self-satisfaction through musical progress. Additionally, making music served to enhance some health promoting behaviours, further highlighting the potential impact that music-making can have within the older community.

There is an increasing pool of evidence to support the notion that active music-making within other groups of the general population is beneficial to WB. Studies to date have produced encouraging results, for example among 'at risk' young people. Faulkner *et al.* (2012) developed the DRUMBEAT (Discovering Relationship Using Music, Beliefs, Emotions, Attitudes and Thoughts) programme, which used drumming to engage 'at risk' adolescents in a form of musical expression. The adolescents were alienated from the school system and were at risk of becoming alienated from society. Themes relating to healthy relationships

with others were incorporated and discussed at the sessions. Pre and post-intervention data were collected with regard to self-esteem, school attendance, antisocial behaviour, and levels of cooperation and collaboration. The young students who participated in the DRUMBEAT programme increased their scores across a broad range of social indicators, which resulted in an increased interaction within the school community. Faulkner *et al.* concluded that a combination of musical expression with basic cognitive behavioural therapy can result in improved social learning outcomes including emotional control, improved relationships and increased self-esteem – all important contributors to a positive WB experience.

Further recent research has found evidence to suggest that group drumming can help modulate the cytokine response in mental health service users (Fancourt, Perkins *et al.*, 2016). Individuals with mild/moderate mental health issues took part in weekly group drumming sessions over 6 and 10 week periods. Significant improvements were found for depression, WB and social resilience across the entire intervention. After a single session, stress and tiredness levels were rated as significantly lower and happiness, relaxation and energy levels increased. The concentrations of four cytokines were significantly lower after the programme, demonstrating a reduction in the pro-inflammatory response. This study was the first of its kind to identify that group drumming for mental health service users can create a reduction in cortisol levels and immune enhancement over both individual sessions and the 6 and 10 week programmes. This type of musical engagement can thus help to reduce inflammation, which is frequently associated with depression and mood disorders, and thus enhance WB. The researchers suggested other music-based psychosocial interventions be explored in future research.

Furthermore, group drumming sessions have been shown to promote WB among different sections of the population including: within a psychiatric hospital setting, where positive mood changes were identified (Tague, 2012); among social workers, who experienced lower levels of stress and increased levels of energy and empowerment (Maschi, MacMillan and Viola, 2013); in young female commercial sex workers in Mumbai, where positive and progressive changes were identified as part of the rehabilitation process (Venkit, Godse and Godse, 2013); and finally, among university students in USA (Mungas and Silverman, 2014). Studies concerning other instrumental activities are less in number but nevertheless, the results are encouraging. Seinfeld *et al.* (2013) found that playing piano and learning to read music can be a beneficial activity for older adults to help cognitive reserve and improve WB.

2.3 CONCLUSION

In conclusion, the significant effect of music on WB is evident from various studies investigating specific target groups of the population, particularly the elderly (Creech *et al.,* 2013; Seinfeld *et al.,* 2013; Perkins and Williamon, 2014) and the young (Faulkner *et al.,* 2012; Mungas and Silverman, 2014). Research can also be found concerning sufferers of depression and other mental health issues (Siedliecki and Good, 2006; Stratton and Zalanowski, 1991; Hanser and Thompson, 1994; Kreutz *et al.,* 2004; Etzel *et al.,* 2006). Music has been shown to be an important resource for achieving psychological, cognitive and social goals in particular groups such as dementia sufferers (Raglio *et al.*, 2014); for reducing anxiety symptoms in anxious adults, for example in female alcoholics (Gardstrom and Diestelkamp, 2013) and in supporting the WB of people suffering from life limiting illnesses, such as cancer patients (Fancourt, Williamon *et al.,* 2016).

Although many individuals have been shown to benefit from various musical interventions, there are some important gaps within the literature. One group that is currently under-represented in this field of research is individuals with LDs. According to Sheehy and Nind (2005), for people with a LD there has been 'an historical failure to acknowledge their human status; deficit-based services; a lack of voice and communication barriers' (p. 34). Although the application of music therapy is fairly well recognised among this population, the use of music education and active music-making is largely absent, particularly with reference to WB. Chapter 3 begins by introducing LDs, with a focus on Down's syndrome (DS), before turning to consider how arts and music have, and can be, used to enhance WB among this population.

CHAPTER 3: WELL-BEING, LEARNING DISABILIITES (WITH A FOCUS ON DOWN'S SYNDROME) AND MUSIC

Chapter 3 covers a brief history of LDs, including definition and prevalence. DS is then discussed in more detail. LDs and WB are discussed, before reporting more specifically on DS and WB. The impact of music for people with LDs is addressed, before presenting a review of the literature. Finally, the focus turns to WB, DS and music specifically, followed with a statement of the overarching research question.

3.1 INTRODUCTION TO LEARNING DISABILITIES

Research discussed in Chapter 2 has focused on the arts, and in particular music, and the effect this can have on WB. This has highlighted gaps in the literature with regard to certain groups within the population; the LD community has largely been omitted from WB research and this group is now discussed.

3.1.1 Brief historical background to learning disabilities

LDs have been extensively recorded in England since the mediaeval period, with support at this time being provided not by the state but within the church community (Jarrett, 2012). Researchers in the field of LD are now generally agreed that the historical background of LDs can be split into the following six periods (Hallahan and Mercer, 2001):

European Foundation Period (c.1800-1920) – publications during this time focused on the relationship between brain injury and behaviours, primarily language disorders.

U.S. Foundation Period (c.1920-1960) – during this period, education rather than aetiology became the focus of research.

Emergent Period (c.1960-1975) – researchers developed tools to identify and educate students with LDs and organisations emerged to provide support.

Solidification Period (c.1975-1985) – this period saw the solidification of the definition and laws regarding LDs.

Turbulent Period (c.1985-2000) – debates concerning definition and placement erupted and the number of students identified with LDs doubled as a result.

Current Period (c.2000-present) – coming full circle and research focussed on biological basis of LD again, alongside dramatic developments in education and intervention strategies.

Research has tended to drive these periods of development and this has led to far wider opportunities today for people with a LD. However, it is essential to continue the path of progress to ensure that these individuals can lead as rich and fulfilling a life as is possible. One area of contention that has continued is the definition of what a LD is.

3.1.2 Definition and prevalence of learning disabilities in the UK

To date there appears to be no single definition or consensual agreement. Different countries and organisations adopt different viewpoints which can lead to confusion and over-generalisation. A current working definition of 'learning disability' was stated in the 2001 White Paper 'Valuing People':

A LD includes the presence of:

A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development. (Emerson and Heslop, 2010, p. 1)

Mencap, a leading UK charity supporting individuals with a LD, suggests that 'a learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life' (Mencap, 2015). According to Gregg (2009), the definition for an adult with a LD is an individual who is 'disordered as compared to age-expected behaviors, and requires evidence that the individual be substantially limited in major life activities' (Gregg, cited in Swanson *et al.,* 2013, p. 85). Typically, people with a LD may require support to develop new skills, comprehend complex instructions and socially interact with others. In comparison, a learning 'difficulty' tends to be a specific learning problem that does not affect intellect, for example dyslexia or dyscalculia. Mental health problems, such as depression or bipolar disorder, should also not be confused with LDs. These tend to relate to how a person feels and behaves, although they can be chronic in nature. Mental health problems can often be helped with treatment, which is not the case for LDs (Mencap, 2015). This investigation is concerned with people with a LD and for the purposes of this thesis is defined as quoted by Emerson and Heslop (2010). Both 'learning difficulty' and 'mental health' issues are beyond the remit of this thesis, except for when they interact directly with WB and LDs.

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There are a lack of data available on the prevalence of LDs in the UK. There are no national statistics and current figures are based on individuals known to social services, GPs and schools. It was estimated, however, that in the UK in 2019, 1,500,000 people had a LD. This included 1,130,000 adults (18+ years; Mencap, 2020). It is generally assumed that approximately 2% of the population have a LD but only around 20% of this figure actually use specialised social care services in England. It is predicted that the number of individuals with a LD will increase over the coming decades. Contributing factors include the increased survival rate of young people and children with severe and complex disabilities and the increased longevity of older adults with a LD (Hatton *et al.,* 2014).

3.2 INTRODUCTION TO DOWN'S SYNDROME

One of the most common causes of LDs are chromosomal anomalies and the most frequently occurring chromosomal abnormality among live births is DS. The incidence of DS is approximately 1 per 700-1000 births (McDevitt and Ormrod, 2013), although it is estimated that approximately 1% of foetuses have DS (Hernandez and Fisher, 1996). DS typically presents with multiple health issues, certain physical abnormalities and a LD. The presence of individuals with DS is not a modern phenomenon – Saxon remains have been documented showing individuals with likely DS features, as have European paintings from the Renaissance period. However, the clinical and scientific acceptance of this syndrome only began in the middle of the 19th century when John Down (1866) described a series of characteristics now recognised as DS. As early as the 1930s there were suspicions that DS might be due to a chromosomal disorder and in 1959 the cause of the DS phenotype was identified by the French doctor Jerome Lejeune as being a duplication of chromosome 21 (Hernandez and Fisher, 1996). DS is a numerical chromosomal disorder whereby an

individual possesses an extra copy of chromosome 21, thus it is often referred to as trisomy 21. DS is typically caused by a nondisjunction where a pair of chromosomes fail to separate correctly during the egg, or more rarely, sperm formation. As a result, each cell has three copies of chromosome 21 instead of two, which makes it difficult for the cells to correctly control how much protein is produced and this can have serious consequences on foetal development. The type of chromosomal nondisjunction associated with DS tends to occur more frequently in older mothers and the risk of having a baby with DS is greater among mothers over the age of 35 years (Genetic Science Learning Center, 2016). Further to the biological foundation of DS (trisomy 21), an understanding of the characteristics, health concerns and behavioural phenotype typically associated with the condition is beneficial when considering research in this area of LD and WB.

3.2.1 Characteristics of Down's syndrome

According to the National Health Service (NHS, 2015), each person with DS is affected differently, although they share several physical characteristics and developmental problems. Physical characteristics include: hypotonia; flat nasal bridge and small nose; small mouth and tongue protrusion; up-slanted palpebral fissures and Brushfield spots; flat facial profile; broad hands with single transverse palmar crease (simian crease); and, below average weight and length at birth. Although all people with DS will have some degree of developmental delay and a LD, this will vary widely between individuals (NHS, 2015).

3.2.2 Health concerns associated with Down's syndrome

Certain health conditions are more frequently seen in people with DS and may require specialist medical treatment or intervention. The US National Institute of Child Health and Human Development (NICHD, 2014) has summarised the most common conditions and these are shown in Table 3.1.

Table 3.1: Health concerns associated with Down's syndrome (NICHD, 2014)

MEDICAL ISSUE	COMMENTS
Heart defects	c50% will experience congenital heart problems.
Vision problems	60%+ will experience sight problems (including cataracts and strabismus).
Hearing loss	c70-75% experience some degree of hearing loss.
Infections	12x more likely to die from an infection.
Hypothyroidism	c10% produce little or no thyroid hormone or experience other endocrine problems.
Blood disorders	10-12x more likely to suffer from childhood leukaemia; higher incidence of anaemia, polycythaemia and other blood disorders.
Hypotonia (weak muscle tone)	Contributes to developmental delays e.g. feeding, walking.
Problems with upper region of spine	10-20% of children have misshapen bones beneath the skull leading to increased injury risk.
Sleep disorder	Many have obstructive sleep apnoea leading to poor sleep quality.
Dental problems	Develop teeth more slowly, have fewer teeth often misaligned, periodontal disease often develops due to poor oral hygiene.
Epilepsy	More likely to have epilepsy, usually present before 2 years.
Digestive problems	Higher incidence of structural defects in gut and Coeliac disease.
Mental health/emotional problems	May experience behavioural/emotional problems including anxiety, depression, ADHD, autism, aggression, psychosis and social withdrawal.

Given the lengthy list of potential medical concerns for people with DS, effective healthcare management is necessary to ensure that each individual remains as healthy as possible, so that WB is not undermined through inadequate or inappropriate support. A holistic approach from the GP can provide a good foundation upon which to develop an effective healthcare programme. Patients with DS can have an unusual presentation of an ordinary illness and a behaviour change or loss of function may be the only indication shown (Smith, 2001). As from 2015, all people aged 14 years upwards with DS are entitled to a free annual health check (DSA, 2016a) and this can be seen as an important factor in maintaining WB.

Increased life expectancy for individuals with DS has led to increased health risks which require specialist planning. For example, premature aging is a characteristic of DS, along with dementia and memory loss/impairment. It is generally agreed that the average age of onset of dementia for people with DS is 51-56 years (Prasher and Krishnan, 1993; McCarron *et al.*, 2014) and by age 60 years approximately 50% of this population will be affected (Tyrell *et al.,* 2001; McCarron *et al.,* 2014). Diagnosis can be fraught with complications due to the variety of symptoms and atypical presentation in people with a LD and this should be given adequate consideration when assessing individuals. Other conditions such as epilepsy, vitamin B12 deficiency, metabolic problems, poor hearing/vision or depression can all mimic dementia type illnesses and should be ruled out before making a diagnosis (Mills, 2013). The early onset of dementia can be a significant contributing factor to reduced levels of WB if not supported through healthcare and specialist interventions.

3.2.3 Cognitive profile and behavioural phenotype of Down's syndrome

Individuals with DS are predisposed to exhibit a specific behavioural phenotype. An understanding of the pattern of strengths and challenges in functioning is helpful when consideration is being given to management and enhancement of WB. It has been argued that a developmental approach towards the emerging behavioural phenotype will allow research to support the specific needs of this population (Fidler, Most and Philofsky, 2008). Suggestions have been made that early intervention in infancy can specifically target this developing profile (Fidler, 2005).

Cognitive abilities for most people with DS fall in the mild to severe range of intellectual disability and they typically display a profile of relative strengths and weaknesses (Wishart, 1993; Chapman and Hesketh, 2000; Fidler *et al.,* 2008). Cognitive development tends to begin relatively normally and then slow down after the age of two years, potentially as a result of delayed rates of brain myelination (Koo *et al.*, 1992; Fidler, Philofsky *et al.*, 2005). By school age and adolescence, visuospatial processing skills, receptive language and nonverbal social functioning ability are relatively strong (consistent with mental age) in comparison to verbal processing abilities (expressive language) and gross motor skills. Language delays are characteristic of DS, with an acceleration of language learning observable between the ages of two and four (Fidler, 2005). By middle childhood, the discrepancy between receptive and expressive language becomes more apparent. Syntax is often an area of particular difficulty, whereas pragmatics is an area of relative linguistic strength. There appears to be no 'ceiling' of cognitive development for individuals with DS and research has indicated that progress continues well into adolescence and adult years (Chapman, Hesketh and Kistler, 2002), highlighting the need to develop effective

interventions to facilitate continual development and thus help minimise any regressive patterns of behaviour or learning during adulthood.

With regard to social development, this is generally thought of as an area of relative strength for individuals with DS. Research suggests that social understanding, empathy and social interactive skills are strengths for both children and adults with DS (Buckley, Bird and Sacks, 2002). It can be argued that social development is fundamentally important for an individual's WB, so this area of strength needs to be developed to its maximum potential. The ability to socialise, to build friendships and take care of one's self all affect everyday life. Often social confidence and competence can be more important than academic achievements for becoming independent, finding employment and functioning within the wider community. These skills can be built on throughout life and incorporated into the development of any intervention strategies. This can promote social inclusion and lead to an enhanced quality of life. In light of the general assumptions often made about the behavioural phenotype of DS, it is important to note that there are a wide range of differences at every possible level, including: genetic, cellular, neural, cognitive, behavioural and environmental. Each person with DS is highly individual and their diagnosis should not define who they are or what they can achieve (Karmiloff-Smith *et al.*, 2016).

In summary, the presence of DS is associated with certain physical characteristics (NHS, 2015) and health concerns (NICHD, 2014) which all require appropriate levels of management to prevent any compromise in level of WB. An increased life expectancy for people with DS has led to further health problems associated with ageing, such as dementia (Prasher and Krishnan, 1993; McCarron *et al.,* 2014). An understanding of the strengths and

challenges of the specific DS behaviour phenotype can be used to facilitate the development

of WB intervention strategies (Buckley *et al.,* 2002; Fidler, 2005; Fidler *et al.,* 2008), whilst

bearing in mind the wide variety of differences seen at every level within this population

(Karmiloff-Smith *et al.,* 2016). Whilst issues such as, for example health, all contribute to

supporting WB, there is very little research available that actually focuses on the concept of

WB in its own right as a single but multi-faceted construct within this community. This is the

area which is now examined, starting with general LDs and then moving to focus on DS.

3.3 WELL-BEING AND LEARNING DISABILITIES

As far as WB is concerned, a person with a LD has exactly the same needs as a person that

does not have a LD (Foundation for People with Learning Disabilities, 2016)[3]. Historically

speaking, people with LDs have had very little independence about making their own life

choices which has doubtless had a negative impact on WB. With person-centred planning

now in place, this is steadily improving but there is still some way to go. Having control over

one's own life, for example regarding choices about healthcare and housing, is central to

maintaining a good level of WB. An appropriate level of independence should be strived for

with support and intervention strategies easily accessible.

3.3.1 Inequality of healthcare

Despite the significant health improvements concerning people with LDs and an increase in

life expectancy, research indicates that people with a LD still tend to have poorer health and

die younger than members of the population who do not have a LD. They are also more

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[3] As mentioned in Chapter 2, the PERMA model (Seligman, 2011) is frequently the model of choice when referring to the WB of those with LDs.

likely to smoke tobacco; less likely to access health services and more likely to be exposed to various social determinants of poorer health, including greater material hardship; greater neighbourhood deprivation; and, reduced community and social participation (Hatton *et al.,* 2014). Mortality statistics published in the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (Heslop *et al.*, 2013) found that men with a LD died approximately 13 years younger than men within the general population and women approximately 20 years younger than their non-disabled counterparts. A combination of over-medicalisation and an overshadowing of health problems by the LD itself, coupled with low value and expectations from healthcare professionals, can all contribute to a second class healthcare provision (Disability Rights Commission, 2006; Elliott, Hatton and Emerson, 2003; Nocon, Sayce and Nadirshaw, 2008). Policy responses such as easy-read health promotion leaflets, regular health screening and health staff training have all proved to be inadequate in removing healthcare inequalities for the LD community (Hall, 2007). It is also important to consider the impact of individual differences when assessing quality of life and WB issues. Felce and Perry (1995) proposed a model of quality of life that integrates individual values and differences alongside an awareness of problems caused by difficulties in understanding and communicating.

Further, research has suggested that people with LDs are at a much higher risk of experiencing mental health problems. Emerson and Hatton (2007) reported that 36% of young people with LDs will experience mental health problems, compared to 8% within the non-disabled community. The risk factors that contribute include a combination of those internal to the individual (genetic influences, IQ, physical limitations and communication difficulties), alongside external environmental sources (socio-economic disadvantage, discrimination, loss and family breakdown). According to Huntington and Bender (1993),

adolescents with LDs are at a significantly increased risk for severe depression or suicide and emotional development is often poorly managed. There is a large body of research concerning the WB of family members and carers of people with a LD, rather than focussing on the individuals themselves (Giallo *et al.*, 2013; Werner and Shulman, 2013).

3.3.2 Research progress in the field of learning disabilities

The majority of research to date has centred on health and medical issues, predominantly among children and young people. There has also been considerable research progress with regard to development and education, as highlighted by the work of Down Syndrome Education International throughout the last 30 years. However, as mentioned previously (see Section 3.2.3) there is often not the typical 'ceiling' in learning capacity for people with LDs, which is seen in the non-LD community. In addition, rather worryingly, there is frequently a regression in both cognitive and social skills in people with LDs, once they leave the supportive educational environment. They often find themselves far more isolated with relative fewer opportunities in comparison to when attending school, which can have a serious negative impact on WB. Further exploration of the understanding of WB within the LD community will facilitate its successful management.

Emerson and Hatton (2008) investigated the association between indicators of WB and personal characteristics, socioeconomic position and social relationships of a sample of 1273 English adults with a LD. The researchers examined five subjective indicators of WB and found that the mean overall level of happiness was only marginally lower than within the general population. Variations in WB were linked to socioeconomic disadvantage, as was social relationships. Stable relationships with friends who had a LD helped to protect against

feelings of helplessness. However, the reported levels of happiness with life may stand in contradiction to the objective life circumstances. As noted previously, adults with LDs are at an increased risk of poverty, social deprivation, lower health expectations, exclusion, disempowerment and abuse (Disability Rights Commission, 2006; Elliott *et al.*, 2003; Nocon *et al.*, 2008). As argued by the Nobel Laureate prize winner Amartya Sen (2001):

> Concentrating exclusively on mental characteristics (such as pleasure, happiness or desires) can be particularly restrictive when making interpersonal comparisons of well-being…Our desires and pleasure taking abilities adjust to circumstances, especially to make life bearable to adverse situations…Deprived people tend to come to terms with their deprivation because of the sheer necessity of survival, and they may, as a result, lack the courage to demand any radical change and may even adjust their desires and expectations to what they unambitiously see as feasible. (pp. 62-63)

Although the study by Emerson and Hatton (2008) does add to the limited literature on the WB of people with LDs, it also highlights the complex issues that arise when dealing with this target group. These findings are also inconsistent with previous research which suggested that individuals with a LD are more likely to report symptoms of psychological distress than their counterparts who do not have a LD (Huntingdon and Bender, 1993; Bender, Rosenkrans and Crane, 1999; Emerson and Hatton, 2007). A possible explanation for this is that although WB and psychological ill health are interrelated, they may be two distinct constructs (Greenspoon and Sasklofske, 2001; Ryan and Deci, 2001). The understanding of WB in people with LDs is still in an early stage and further research is required to address the multiple issues related to investigations within this field and to enable an appropriate level of support.

The field of WB is complex and problematic in its own right and with the added complication of a LD, many researchers have perhaps not surprisingly avoided the topic. For example, interviews and self-report questionnaires are two traditionally used methods employed in researching WB. However, for people with a LD, question type and phrasing, content and response format all need careful planning to ensure validity (Finlay and Lyons, 2001). According to Emerson and Hatton (2008) the potential reason for the lack of research is twofold. Firstly, there are very few validated measures of quality of life for people with LDs that contain an 'uncontaminated' measure of WB. Secondly, the majority of research undertaken to date has focused on people with more severe LDs, who may not be able to provide valid responses to questions. As a result, research in this area is fairly sparse, particularly concerning adults, with the majority of studies to date focussing on children and adolescents and emotional development, rather than the broader concept of WB.

However, a growing interest in the promotion of WB for people with LDs is finally beginning to emerge. A fuller understanding of the case for using WB to address the poor health outcomes experienced by people with LDs is necessary as previous healthcare initiatives have largely failed to remove inequalities in services and support provided. A shift in focus from individualised objective ill health of people with LDs to a much wider notion of WB has the potential to allow this group to flourish and optimise their quality of life.

3.3.3 Well-being and Down's syndrome

The same can be said for research into DS and WB, with the majority of research to date concerning aetiology, genetics and health concerns. Since 1979, the National Down Syndrome Society (NDSS) has been considered to be at the forefront of DS research and is

keen to ensure that 'people with Down syndrome have the opportunity to enhance their

quality of life, realize their life aspirations, and become valued members of welcoming

communities' (NDSS, 2012a). However, their main focus of research programmes to date

has been medical, as demonstrated by their current list of research studies (e.g. evaluation of

the efficacy, tolerability and safety of memantine hydrochloride on young adults with

Down's syndrome). None of the current studies mention WB or quality of life (NDSS,

2012b). The importance of medical care research should not be under-estimated, but this

should not be the only avenue of investigation with regard to supporting WB.

Although there has been considerable literature presented on adults with DS and dementia

(Prasher and Krishnan, 1993; Tyrell *et al.,* 2001; Mills, 2013; McCarron *et al.*, 2014), there

has been comparatively little published on the epidemiology of other mental health issues

(Mantry *et al.*, 2008). Research has indicated that that individuals with DS experience fewer

mental health issues than other people with LDs (Mantry *et al.,* 2008; Maatta *et al.*, 2006).

This could potentially be biologically determined, or alternatively there are other unidentified

protective factors, or even a lack of ability to successfully identify the symptoms due to the

complex nature of diagnosis. The most frequent mental health concerns include: general

anxiety, obsessive-compulsive and repetitive behaviours, oppositional, impulsive and

inattentive behaviours, depression and autism spectrum conditions (NDSS, 2012c). Despite

the incidence of mental health problems being less in DS than typically seen in other LDs, the

incidence of depression is at least equivalent to the frequency seen in the general population

so this is not an insignificant concern (DSA, 2016b). The genetic aetiology of a specific LD

creates different psychiatric characteristics in the individual, highlighting the need for

targeted psychiatric care (Vicari *et al.,* 2016). The mental health problems in DS tend to vary

with age and developmental stage of the individual. The NDSS (2012c) has suggested that

adults with DS are more likely to experience the following conditions:

- Depression, social withdrawal, loss of interest and diminished self-care.

- Generalised anxiety disorders.

- Regression with decline in cognitive and social skills.

- Dementia.

These conditions are more likely to occur as a reaction to an external stressor (psychosocial

or environmental), for example, illness, loss or separation. According to the NDSS, much of

the current knowledge is based on clinical experience and there is a need for a broader

evidence base with expanded research into the mental health aspects of DS (NDSS, 2012c).

Finally, the DSA (2016a) has recently initiated a campaign to support health and WB for their

community members. The factors that support WB in people with DS are exactly the same as

for the general population. The development of self-esteem and self-confidence are essential

to facilitate the management of WB, and this is equally important for people with DS. An

understanding of their condition according to individual ability, having positive role models

with DS, and friends both with and without DS, will all contribute to boosting self-worth.

The opportunity to be able to make life plan choices is also valuable in developing

confidence (DSA, 2016b).

In summary, people with DS are now living longer and leading much fuller lives than ever

before. Many are in employment, living semi-independently and are actively involved within

their local communities. Improved health care and specialised support programmes have all

contributed to the effective management of WB and the significant progress made to date. It

would be prudent to focus on the relative strengths of the DS behaviour phenotype when considering likely successful intervention strategies for supporting WB. As discussed in Chapter 2 (see Section 2.2.4), musical interventions have been the centre of much attention on WB and other target groups in the population, so the impact of music requires further exploration for this group of people. An outline of the WB benefits of music participation within the LD community is now presented. According to Mencap 'music is often called the language of emotion and it has amazing power to change lives' (Mencap, 2009). Despite this, there has historically been a lack of research linking WB, LDs and music. There is a particular lack of, for example, the benefits of music participation, despite widespread anecdotal evidence highlighting the multiple benefits for this target group.

3.4 THE IMPACT OF MUSIC FOR PEOPLE WITH LEARNING DISABILITIES

The majority of LD related studies to date have focussed on music therapy (Hooper *et al.*, 2008a, 2008b; Pavlicevic *et al.*, 2014) rather than music education and this has provided a useful insight into the benefits that music participation could potentially provide for people with LDs. Owing to the successes that music therapy[4] has reported for people with a wide range of LDs, it would not be unreasonable to expect that equally positive outcomes could be achieved through using music participation in a variety of different environments rather than just within the therapeutic setting.

Juliette Alvin (1897-1982) was a pioneer in the world of music therapy within the UK. Her own experiences of working with people with LDs can be summed up by her following

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[4] The term 'music therapy' may be used differently in different situations. For example, in the US the term 'music therapy' is often used to describe any musical intervention strategy, rather than the more clinical definition used in the UK.

comment: 'We know that music is an essentially flexible means of communication which can work at every mental, emotional, and social level' (Alvin, 1975, p. 2). A systematic review of the music and LD literature published between 1943 and 2006 was carried out by Hooper *et al.* (2008a; 2008b). The researchers identified studies that investigated musical aptitude within people with LDs (Down's syndrome, musical savants, autistic spectrum disorder and Williams syndrome) and how these individuals responded to active and receptive (passive) music interventions. The researchers argued that a wide range of interventions and outcomes reflected the diverse nature in which music therapy and musical activities can benefit individuals with a LD and the vast array of functional skills that it facilitates.

Investigations into the musical profile of diagnostic subgroups can help further understanding of the cognitive profile and likely successful musical resources. It can be argued that the current literature leaves many questions unanswered, particularly concerning how active music therapy interventions can effect physical systems. For example, playing the guitar stimulates the tactile system, visual system and auditory system (Hooper, McManus and McIntyre, 2004) and more consideration could be given to evaluating this aspect of musical intervention. The wide reaching impact of music therapy has laid a very useful foundation upon which to further explore the use of music participation for people with LDs. The successes (and failures) of music therapy can be utilised to further understand the benefits of music being used in a wider range of settings outside of the music therapy domain.

Following on from this, there have been many anecdotal reports of the substantial benefits that music can offer people with LDs. For example, choral singing has been shown to create improvements in self-esteem and self-confidence (Joyful Noise, 2013) and in mood elevation

and enjoyment (Ward and Parkes, 2015). Various professional ensembles are committed to helping people with LDs (London Chamber Orchestra, 2011; Armonico Consort, 2016) through workshops and educational programmes. Projects such as these doubtless provide a potential network of WB support opportunities, although they tend to be aimed at children and younger people. In addition, these projects are typically offered as a one-off event rather than on an ongoing, regular basis. There is a need for research to investigate the nature of the benefits of attending regular music interventions, particularly for adults and the older community with LDs.

Despite these significant anecdotal findings, the number of empirical studies supporting this is still seriously lacking. In particular, there are very few arts-based intervention studies focusing specifically on WB and adults with LDs. There are even fewer available when seeking intervention studies concerning DS and WB. Although this thesis is focused on DS, WB and music participation, the wider LD, WB and arts-based literature has been examined to best inform this work and provide the broadest research base possible. To obtain an up-to-date clarification of research in the field, a review was undertaken and is reported in the following section.

3.5 REVIEW OF ARTS-BASED INTERVENTIONS MEASURING WELL-BEING IN ADULTS WITH LEARNING DISABILITIES

3.5.1 Methods

A review was undertaken to collate research literature in the field of WB, LD and the arts. Database searches were carried out using Google Scholar, PubMed, Cochrane and Web of Science as these are the main sources of research in the field. The review sought to identify new studies involving adults with LDs taking part in an arts-based intervention with the aim of improving WB. All LDs were included in order to identify as many studies as possible. Searches were made using keywords relating to three concepts: Outcome measure (keywords 'well-being' or 'quality of life'); target population (keywords 'learning disabilities' or 'cognitively impaired'); and intervention type (keywords 'music', 'singing', 'art(s)', 'dance' or 'drama'). This study did not include dementia-related studies or those involving music therapy, as these are both beyond the remit of this thesis.

After the initial search a total of 1330 studies were identified. Following an examination of these abstracts, 1273 studies were excluded due to being irrelevant, duplicated or non-English language. 57 full articles were reviewed, which resulted in a further 45 studies being excluded (see Table 3.2). The PRISMA checklist and flow chart were used as a reference point (Moher *et al.*, 2009, see Figure 3.1).

Figure 3.1: PRISMA Flow Diagram for review (Moher *et al*., 2009)

Table 3.2: Excluded studies after full article review

Reason for exclusion	Frequency
Music therapy based	12
Not learning disability focused	11
Dementia related	9
Not intervention study	9
Not adults	3
Not arts based	1
TOTAL EXCLUDED STUDIES	45

3.5.2 Results

12 studies were included in the final review, dated between 1992 and 2019. Music was the most frequently used intervention (see Figure 3.2). The articles were scrutinised for key details including: author(s); year of publication; country; intervention details; number of participants; target group; length of study; and outcome measures and outcomes (quantitative designs) or perceived outcomes (qualitative designs).

Figure 3.2: Different intervention types present in the review

There were several countries represented, with the UK producing the most research papers (see Figure 3.3).

Figure 3.3: Different countries represented in the review

The majority of the studies were small-to-medium scale (see Figure 3.4) and only one study had <100 participants (Moceviciene and Prudnikova, 2015, with 123 participants).

Figure 3.4: Number of participants per study

Five quantitative measures, six qualitative measures, and one mixed-methods approach were identified (see Table 3.3).

Table 3.3: Summary of studies included in review

	NAME	DATE	COUNTRY	TYPE OF DESIGN	INTERVEN-TION DETAILS	NO. OF P'S	TARGET GROUP	LENGTH OF STUDY	OUTCOMES
1	Hooper and Lindsay	1992	UK	Case study (cont.)	Live music listening	1 +3 cont	Female with LD	10 daily sessions (8 mins)	Increased QoL on Lindsay and Baty (1986) Behaviour Rating Scale; decreased anxiety.
2	Hooper	2002	UK	Quant. (cont.)	Musical games and activities	2	LDs	10 weekly sessions	Increased positive social interactions and decreased negative social interactions.
3	Boso, Emanuele, Minazzi, Abbamo-nte and Politi	2007	Italy	Quant. (non-cont.)	Active group music sessions	8	Autism	52 weeks	Significant imp. on Clinical Global Impression Scale and Brief Psychiatric Rating Scale.
4	Mocevic-iene	2014	Lithuania	Mixed-method	Group music workshops	54	Mod/ profound LDs	6 months	Themes of improved quality of life: self-confidence; self-esteem and self-realisation.
5	Dinold	2014	Austria	Qual.	Inclusive dance workshops	N/A	All disab-ilities	3 years +	Themes of improved self-confidence; openness; social interactions and autonomy.

6	Ward and Parkes	2015	UK	Qual.	Singing workshops in care settings	N/A	LD and/or dementia	Ongoing	Themes of high levels of enjoyment; improved mood; memory; choice and social engage-ment.
7	Mocevicie-ne and Prudnikova	2015	Lithuania	Qual.	Group music workshops	123	Moderate /profoun d LDs	One-off	Themes of improved self-awareness; self-esteem; self-realisation and integration.
8	Jaschke and Scherder	2015	Netherlands	Quant. (non-cont.)	Music listening (active vs. passive)	90	IQ range 54-85	4 weeks	Low levels on Cohen-Mansfield Agitation Index and Repetitive Behaviour Quotient 2; high levels on Intellectual Disability Quality of Life 16.
9	Barnet-Lopez, Perez-Testor, Cabedo-Sanroma, Oviedo and Guerra-Balic	2016	Spain	Quant. (cont.)	Dance/ movement sessions	22 + 20 cont	LDs	26 sessions	Significant imp. in The Koppitz Human Figure Drawing Test.
10	Hassan	2017	UK	Qual.	Choir participation	N/A	LDs	6 months	Themes of improved self-identity and confidence.

11	Whelan	2018	UK	Qual.	Dev. of digital music program for young people with autism	N/A	Autism	Ongoing	Themes of improved social interaction and inclusion.
12	Aujla and Needham-Beck	2019	UK	Quant. (non-cont.)	Dance program	13	LDs and physical disabilities	1 academic year	No significant change identified on Personal Well-being Index over time.

Quantitative outcome measures: four of the five quantitative studies reported improvements in various aspects of WB (with the exception of Aujla and Needham-Beck, 2019). For example, Boso *et al*. (2007) found significant improvement in mental health and decreased anxiety (using the Clinical Global Impression and Brief Psychiatric Rating scales), over a 52 week intervention. They concluded that active music sessions could help to improve autistic symptoms, alongside musical skills in young adults with severe autism. Jaschke and Scherder (2015) found high levels of quality of life (using the Intellectual Disability Quality of Life 16), over 26 music sessions. They suggested both passive and active music sessions were an important aspect in the lives of people with a LD, but concluded more research was needed to provide clearer and more definitive results. Hooper (2002) found improved social interaction (through video recorded observations), over 10 weekly sessions, using musical games and activities. He commented on how non-verbal interactions such as music participation encouraged social interactions and provided insight into relationships between people with severe LDs. Barnet-Lopez *et al*. (2016) found significant improvemnts in the

results of the Koppitz Human Figure Drawing test (1968), which indicated improved emotional WB after dance sessions.

Qualitative measures: all six qualitative studies reported improvements in various aspects of WB. These supported the findings from the quantitative studies by showing themes of improved social interactions (Dinold, 2014). Dinold found participants reported enhanced experience and quality of life through the meeting and making of new friends. Reduced anxiety was also evident (Hooper and Lindsay, 1992). Hooper and Lindsay reported how using relaxing music can serve to enhance quality of life in the short term and potentially the longer term also. However, several further benefits were noted. For example, Dinold (2014), found improved levels of self-consciousness, openness and autonomy, and Ward and Parkes (2015) found themes of improved mood and enjoyment, focussing on anecdotal reports. A need for further evidence was suggested in order to fully understand the realtionship between the impact of the intervention and the WB of the participant. Hassan (2017) identified themes of improved self-identitiy through choir participation and performance, and Whelan (2018) found themes of improved social inclusion and interaction facilitated through a digital music platform. The mixed-methods study (Moceviciene, 2014) identified reported themes of improved quality of life, self-confidence, self-esteem and self-realisation, following group music workshops.

3.5.3 Conclusion

The aim of this review was to evaluate research studies carried out concerning WB, adults with a LD and the effect of arts-based interventions. Due to the relatively small number of studies reported and the highly varied nature of these studies, the aggregation of results via

meta-analysis or meta-synthesis was not possible. However, a narrative review was undertaken.

Regarding the focus on WB, although the majority of these studies have all reported positive findings on the benefits of arts interventions for adults with LDs, they have focused on a variety of related concepts that are linked to WB, for instance social interaction (Hooper, 2002), self-confidence (Moceviciene, 2014) and autonomy (Dinold, 2014), rather than specifically measuring WB as a whole concept in its own right. One exception to this is the study carried out by Jaschke and Scherder (2015) which used the Intellectual Disability Quality of Life Scale (IDQOL-16, Hoekman *et al.*, 2001), along with two other measures of agitation and repetitive behaviour. In addition, Aujla and Needham-Beck (2019) used the Personal Well-being Index for people with intellectual disabilities, although this failed to identify any perceived changes to WB over time. Although it can be argued that these different concepts all contribute to the complex nature of WB as described by the PERMA model (Seligman, 2011), it would appear that the real crux (i.e. the concept of WB as a whole) has been largely side-stepped.

Concerning the target population, it is interesting to note how all of these studies (with the exceptions of Boso *et al.* (2007) and Whelan (2018) which both focused on autism) used a target population including all types of LDs rather than seeking to identify findings that relate to more specific target groups. The disadvantage of having a broad inclusion criteria of all LDs is that the effect of the complex nature of the LD itself is difficult to isolate. In refining the target population to one particular LD, it would be possible to manage this variable to a certain extent, keeping in mind the varied differences within that specific LD.

Regarding the intervention type, when examining the impact of music specifically (nine studies) as compared with other art forms (three studies), this review suggests that music interventions have produced the most research papers in the field. In addition there have been other significant literature reviews completed (for example, Savarimuthu and Bunnell, 2002; Hooper *et al*., 2008a, 2008b) providing additional support for the benefits of music for people with LDs but without the focus on the overall impact on WB. In consideration of these findings it would appear that musical participation is a likely effective intervention for this target group. It is interesting to note that the three studies that did not use music as an intervention used dance instead. It can be argued that dance incorporates the use of music, thus it is impossible to identify whether it was the dance or the musical element that produced the beneficial WB effect. Future research could address the issue of whether music is specifically beneficial for WB in people with LDs, in comparison to other arts-based interventions.

Despite the limitations of this review, largely concerning a lack of studies available and the broad variety of methods reported in the selected articles, it highlights the state of research in the field. Although music and other arts-based interventions and the LD population have been studied, there are few relevant articles and the impact on WB rather than another related outcome is new and research is still in its infancy. This study provides an up-to-date review of the impact of arts-based interventions on WB for adults with LDs. The findings suggest that arts-based interventions, particularly music, have the potential to improve WB for people with LDs. The studies reported in this review all identified components of WB, although only four actually mentioned WB (or indeed, quality of life) as a whole construct, highlighting the need for more research adopting this holistic approach to WB. More specific target groups (specific LDs such as DS) would help to identify which individuals would be

most likely to benefit, and in addition, an understanding of using music interventions as a contrast to other art forms, would also be highly beneficial.

3.5.4 Strengths and limitations

Strengths of this review include the extensive search strategy and the use of broad and inclusive search terms. However, a study of this nature is not without limitations that require acknowledgement. For example, only English language papers were reviewed, which could have resulted in the omission of relevant work. Also, the extensive variety in terminology associated with LDs and the arts could again have resulted in missing relevant papers. As discussed in the conclusion (see Section 3.5.3), the identified studies were limited in terms of the methods used. For example, sample sizes were very small, and only one study had over 100 participants. Some studies did not actually report the number of participants in attendance, particularly where larger scale workshops were being run over a longer period of time. To recap on the measures used (see Table 3.3; section 3.5.2 and section 3.5.3), the majority of these were focussed on aspects of WB, rather than assessing WB as a construct in its own right.

To conclude, this review has provided an understanding of the current state of research, and has identified the potential significance of using the arts, in particular music, as a valuable support mechanism of WB for people with LDs. The following section will bring the focus onto DS and the WB benefits of music participation, highlighting the limited number of studies to date.

3.6 HONING THE FOCUS: WELL-BEING, DOWN'S SYNDROME AND MUSIC

Professor Sue Buckley OBE (Director of Science and Research, Down Syndrome Education International) has questioned the role of music and whether full use of music in all its forms is being made in the lives of individuals with DS. She concluded that far more use of music could be made for the DS population, with benefits for self-expression and behaviour, along with pure enjoyment itself (Buckley, 2006). Despite a lack of the full recognition of the potential WB benefits of music participation for people with DS, anecdotal evidence has long supported the involvement of musical activities as being advantageous. In addition, the advancements of music therapy, within the clinical therapeutic setting, have provided further support for the anticipated benefits from other musical interventions. One (stereotypical) feature of DS which is referred to with great frequency is an innate musicality and enjoyment of music:

> It would be difficult to find literature, both popular and professional, on Down's syndrome children which did not make reference to their musical ability in some form or another, yet the scientific literature is surprisingly short on experimental evidence. (Stratford and Ching, 1983, p. 23)

Many of the historical papers reporting on DS mention an appreciation of, or ability in, music. One of the earliest recorded references to the musicality of people with DS came from a ground breaking report by Fraser and Mitchell (1876) on the characteristics of the syndrome. They spoke of a young female adult with DS as being very fond of music. Shuttleworth (1900) restated these findings when talking about individuals with DS and commented that they have 'a great love of music, their idea of time as well as tune being remarkably able' (Shuttleworth, 1900, p. 705). Lapage (1911) mentioned only two remarks

on the characteristics of children with DS in his general book of LDs in children, saying they were 'very difficult to teach. They have very good powers of mimicry…Another curious point is that they are very fond of music, more so than other children' (Lapage, 1911, p. 105). However, by the 1950s, the popular stereotype of the person with DS who was loving and fond of music was being challenged. Blacketer-Simmonds (1953) found no significant differences in musical ability when comparing a group of 42 individuals with DS, with a matched control group with other LDs.

Although this stereotype still does persist even today within certain environments, it is important to remember that people with DS have a wide range of abilities, strengths, challenges and preferences. Their individual personality profile is as unique as that of the general population and the only certain feature all people with DS share is an extra copy of chromosome 21. There is very little current literature investigating the musical abilities of people with DS but in reality their musicality in irrelevant – the real point here is the potential WB benefits that music participation might offer, whatever the level of musical appreciation or ability. Notably the musical talents of people with DS testify to the lack of any significant relationship between IQ and artistic ability (Warren, Richard and Brimbal, 2005). Warren *et al.* (2005) suggest that all adults with DS should have access to opportunities for creative expression, including musical activities. They argued it was the belief of the teachers who saw beyond the usual expectations and provided the chance for these individuals to succeed and experience life-transforming outcomes.

There are increasing opportunities for people with DS to participate in musical activities. One such opportunity is provided by a Southend Mencap-funded charity 'The Music Man

Project UK' (MMP), originally based in Essex but now spreading nationally and internationally as a result of a recent development initiative. MMP was founded by the former deputy head teacher David Stanley, who has a passion to access the innate musicality in everybody, irrespective of their additional needs. This is the UK's first full-time, ongoing music education service specifically for children and adults with LDs. MMP 'provides education, enjoyment and access to inspirational performances which raise awareness and challenge misconceptions' (Stanley, 2015). Approximately 50% of MMP students (both adults and children) have DS.

In 2015, MMP made its West End debut at the London Palladium with their 'Music is Magic' show (see Photograph 1), which included the premiere of a musical 'From the asylum to the Palladium', (written and composed by David Stanley) which told the story of 'mental hospitals' where people with LDs were treated as patients, alongside single mothers, the mentally ill, homosexuals, and poorly behaved children. The journey from this shocking past to the current 'care in the community' approach and the relative opportunities available today was presented by the MMP students themselves in an inspirational performance (see Photograph 2). MMP has been described as 'outstanding' by OFSTED, has been the recipient of many awards and received praise from the Prime Minister. The author was responsible for establishing the first satellite centre in Maldon, Essex in 2015 (MMP Maldon).

Photograph 1: 'Music is Magic' show with David Stanley at the London Palladium (Paul Carpenter Films, 2015)

Photograph 2: 'Music is Magic in Space' show at the Royal Albert Hall (Paul Carpenter Films, 2019)

Despite the efforts and reports of organisations such as MMP (along with carers, parents, teachers and other professionals), there is still an absence of research literature to support the growing anecdotal basis of the benefits of active music participation for individuals with DS. There is an even greater gap when looking at the complex construct of WB, particularly concerning adults. The specific benefits of active music participation for the DS population are not yet fully understood or identified and require further investigation to determine which musical interventions are most beneficial for which specific area of WB. Music and other creative activities are often regarded as merely recreation for people with LDs and are seldom mentioned with regard to WB in its entirety. It is essential to provide equal access opportunities to music-making and its associated WB benefits to people with DS (and indeed other LDs), to allow them to realise their optimal functioning potential and lead rich and fulfilling lives, comparable to the non-LD community.

This thesis therefore aims to investigate these gaps in the literature and seeks to explore the benefits of active music participation on WB for individuals with DS. The research will focus on adults with DS, as the majority of research to date has centred on children and young people. Therefore the overarching research question for this thesis is:

 'What is the effect of active music participation on well-being among adults with Down's syndrome?'

In Chapter 4, the methodology and methods used to answer this research question (and sub-divided research questions) are presented.

CHAPTER 4: METHODOLOGY AND METHODS

Following on from the introduction and literature review presented in Chapters 1, 2 and 3, this thesis concerns how active music participation can potentially benefit the WB of adults with DS. This chapter restates the research question(s) and research aims. Epistemology is presented, along with justification for the most appropriate perspective for this investigation (pragmatism); methodology and the selected research design (multiple methods); the particular research methods selected to obtain the necessary data (interviews; observations; online survey; pre and post-intervention measures); followed by the analysis procedure (thematic analysis; statistical analysis). After presentation of a general methodological outline, the complex issue of reliability and validity when measuring WB, particularly for people with LDs, is discussed. Finally, each individual study is presented in chronological order.

4.1 RESEARCH QUESTION(S) AND SPECIFIC RESEARCH AIMS

Overarching research question:

1) What is the effect of active music participation on well-being among adults with Down's syndrome?

This overarching research question can be further sub-divided into the following individual research questions:

2) What is the most appropriate method for assessing well-being among adults with Down's syndrome? (See research aim (i))

3) What counts as effective active music participation for adults with Down's syndrome? (See research aims (ii), (iv), (v) and (vi))

4) To what extent does the PERMA model fit the emerging data from the participants? (See research aim (iii))

In consideration of the above research question(s), the following specific aims (linked to individual studies) are examined:

(i) To scrutinise potential tools to measure WB among adults with LDs, recognising a lack of validated measures for this target group (see Chapter 4, Section 4.5.1, Pilot study).

(ii) To obtain an in-depth understanding of what taking part in regular active music sessions means for four adults with DS, and their families (see Chapter 4, Section 4.5.2, Study 1; Chapter 5).

(iii) To explore how well the PERMA model fits the data from the participants (see Chapter 4, Section 4.5.2, Study 1; Chapter 5).

(iv) To investigate the prevalence of music participation as an activity within the Mencap organisation and to provide an insight into their view of music-making on WB for their adult members (see Chapter 4, Section 4.5.3, Study 2; Chapter 6).

(v) To investigate the impact of a one-off music intervention on WB among adults with DS (see Chapter 4, Section 4.5.4, Study 3; Chapter 7).

(vi) To investigate the impact of a 10 week programme of music-making on the WB of adults with DS (see Chapter 4, Section 4.5.4, Study 3; Chapter 7).

4.2 EPISTEMOLOGY

Epistemology is a branch of philosophy related to the nature of knowledge and justified belief. The significance of epistemology is highlighted by Maynard (1994): 'Epistemology is concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure they are both adequate and legitimate' (Maynard, 1994, cited in Crotty, 1998, p. 8). According to Crotty (1998), research epistemology is a philosophical worldview and is 'the theory of knowledge embedded in the theoretical perspective and thereby in the methodology' (Crotty, 1998, p. 3). It is the duty of the researcher to disclose their particular worldview, and the worldview implicit in the research question, in order to ensure that any assumptions are understood and thus transparency can be maintained throughout the research process.

There are many potential epistemological underpinnings, but three that are often used in social science research: post-positivism; social constructionism; and pragmatism, each with their own preferred methodological approaches. Post-positivism is frequently considered to be a more 'scientific' approach relying on objective theory testing, with reductionist empirical measurement being the focus. Social constructionism is concerned with the view that meanings are constructed by individuals as they engage with the world they are interpreting. This process is largely inductive with the researcher generating meaning from the data collected. In comparison, pragmatism is not committed to any one philosophical approach and allows the researcher to draw from both social constructionist and post-positivist methodologies (Cresswell, 2009). Given the complexities associated with working with LD participants (such as communication and comprehension), added to the subjective nature of WB, the relative freedom of choice that a problem-centred pragmatic approach

would allow seems the most appropriate choice for this type of investigation. A purely post-positivist approach would not allow for the in-depth understanding and meanings of WB for the participants, likewise, input from a purely social constructionist approach would be restrictive in terms of potential for generalisability.

4.2.1 Pragmatism

Pragmatism is a 'real-life' problem-centred approach which directly tackles the research question itself. The research question for the proposed study has evolved from the experience of working as a teacher/advisor in the LD environment for many years. A pragmatic approach allows the researcher the freedom to select the methodologies which best serve this 'real world' situation. In commenting on pragmatist philosophy, Rescher (1995) suggested: 'The characteristic idea of philosophical pragmatism is that efficacy in practical application – the issue of 'which works out most effectively' – somehow provides a standard for the determination of truth in the case of statements, rightness in the case of actions, and value in the case of appraisals' (Rescher, 1995, p. 710). Pragmatism has the advantage of making use of pluralistic approaches in seeking relevant knowledge (Cresswell, 2009), and can therefore be expected to facilitate scrutiny of the research question from multiple angles and making use of multiple techniques. This approach allows for the broadest data collection from different types of knowledge, in this relatively under-represented field of research.

4.2.2 Reflexivity of the researcher

It is the duty of the researcher to disclose their professional position and any likely influences in order to aim for transparency. It is also essential for the researcher working with (particularly) qualitative data to be aware of their own personal biases with regard to

interpretation, as they will inevitably make sense of their research findings through their own individual perspective, particularly concerning their previous social experiences (Cresswell, 2009). In this case the researcher is regularly involved with some of the participants in the pilot study and all of the participants in Study 1 (see Section 4.5.2) as one of their music teachers and has been for several years. This provides a unique opportunity to study the musical experiences of the participants as an 'insider' and accepted member of the group. This researcher-participant relationship provides many strengths to the research design, particularly the ease of interaction and effective communication between the two parties, which can be problematic when working with people with LDs.

However, this 'insider' position also raises challenges that require consideration, so as to minimise any researcher influence or bias. The expectations of the researcher for the participants to respond in a certain way requires careful management in order to avoid assumptions on the part of the researcher. In addition, the question of familiarity with the participants needs to be monitored to ensure this does not detract from the research question itself. With these challenges being noted and the researcher being aware of the possible risks, the 'insider' position of the researcher has the potential to provide rich and detailed data on the topic of interest. In addition, the researcher sought validation through supervisors with regard to all data analysis, with particular reference to Study 1 (ethnographic case study).

4.3 RESEARCH METHODOLOGIES

As discussed previously, epistemology is concerned with our philosophical approach to the world and how we understand and interpret knowledge. Methodology is concerned with the strategies of inquiry that will allow us to carry out our investigations and obtain the

knowledge we need. The epistemological perspective thus has a direct influence upon the methodological approach and how a researcher embarks upon answering their research question. Epistemology and methodology are inextricably linked and one cannot exist in isolation without the other.

4.3.1 Quantitative vs. qualitative research designs: A multiple methods approach

Historically, research designs have been categorised into two main categories: quantitative and qualitative. These two designs emerge from their differing epistemological perspectives and subsequent data collection, analysis and interpretation procedures. The quantitative approach tends to support a post-positivist epistemology and according to Cresswell (2009): 'a quantitative research is a means for testing objective theories by examining the relationship among variables' (Cresswell, 2009, p. 4). A purely quantitative approach would not allow access to the necessary in-depth personal experiences required to understand the complexities of WB. Likewise, a qualitative based research design with a focus on a social constructionist epistemology with subjective personal experience at the centre, would potentially limit larger scale conclusions and generalisations. Typically, a multiple methods approach tends to employ multiple types of qualitative and quantitative data (Cresswell, 2009).

A multiple methods approach to research can be defined as research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts, or language. A multiple methods approach recognises that both quantitative and qualitative designs are useful and equally important. The aim of multiple methods research is not to replace the traditional two approaches but rather to utilise the strengths and thus minimise the weaknesses of both in a single research paradigm. It acknowledges the use of

multiple approaches in answering research questions rather than limiting the research options for the researcher. The methodological pluralism offered by a multiple methods approach has the potential to create superior research compared to the traditional quantitative or qualitative designs (Burke Johnson and Onwuegbuzie, 2004). Philosophically speaking, multiple methods research employs a pragmatic approach that attempts to unite the information provided by quantitative and qualitative research into a practical, workable solution. Therefore, this study makes use of multiple methods, relying on a suite of quantitative and qualitative designs adopted over three main studies. The four research questions are addressed through a pragmatic methodological perspective allowing for a multiple methods approach. Table 4.1 highlights how the research questions and research aims are linked, in addition to the mapping of individual studies and methodological designs used. The multiple methods utilised include: ethnographic case study (qualitative approach); non-experimental design (quantitative approach); and, experimental design (quantitative approach).

4.3.2 Qualitative design: Ethnographic case study

An ethnographic case study was used to obtain an in-depth understanding of what taking part in regular active music sessions meant for adults with DS and their families, as described in Study 1 (see Section 4.5.2). A central feature of the ethnographic tradition involves the researcher studying people for a considerable period of time in their own natural environment. The role of the ethnographic researcher is to become fully immersed within the particular culture being studied, in order to allow a detailed description of the group and/or individuals within that group. The researcher needs to obtain an 'insider's perspective' and take part in the group whilst observing at the same time. As mentioned previously, the researcher is highly involved in the 'musical' lives of the participants. She spends much time

engaged with the group, often for extended periods. This provided unlimited access to the group and their families. Throughout this time the researcher was a fully accepted member of the group within this environment. This approach is often utilised when exploring a new (or under-represented) field of research, where the researcher has an in-depth knowledge of the topic under investigation (Robson, 2011). The research situation in this thesis is ideally placed for an ethnographic approach. The research question seeks to understand the musical experiences and the influences of music on WB for this group of people. As an existing member of the community, the researcher was in a unique position to facilitate this.

In Study 1, an ethnographic approach is linked with a case study as a strategy of inquiry. This is a well-established research strategy where the focus is on a 'case'. The main defining characteristic is a concentrated focus on this particular case, studied in its own right. There are many variations on what the case can be, for example, an individual, group or organisation, and context must be taken into account. A case study typically involves multiple methods of data collection, for example participant observation and interview.

4.3.3 Quantitative designs

Two main quantitative designs were employed throughout the research period. A summary of the research questions, research aims and methodologies used, mapped onto a pilot study and three separate studies, can be seen in Table 4.1 below.

Table 4.1: Summary of methodologies employed in the research

STUDY	RESEARCH AIMS	RESEARCH QUESTION(S)	DESIGN
Pilot	Research aim (i)	Research questions 1 and 2	Quantitative approach using: Pre/post-test experiment using specifically designed questionnaires (uncontrolled).
1	Research aims (ii) and (iii)	Research questions 1, 3 and 4	Qualitative approach using: Ethnographic case study.
2	Research aim (iv)	Research questions 1 and 3	Quantitative approach using: Non-experimental survey (online).
3	Research aims (v) and (vi)	Research questions 1 and 3	Quantitative approach using: Experimental design, repeated-measures intervention.

4.3.3.1 Non-experimental design

A non-experimental design was used to investigate the prevalence of music participation as an activity within Mencap groups and thus establish an insight into the view of this organisation on the benefits of music participation on WB for their adult members, as described in Study 2 (see Section 4.5.3). Broadly speaking, a non-experimental design does not have a manipulated variable, or as in this case, an intervention strategy. Rather, it aims to provide a large-scale description of a particular phenomenon. Both surveys and questionnaires are frequently employed in non-experimental designs. A questionnaire is defined here as a research tool that typically consists of a series of questions designed to measure a particular variable (such as WB). In

comparison, a survey is defined as a set of questions designed to obtain and evaluate the opinions or experiences of people on a specific topic of interest.

4.3.3.2 Experimental design (repeated-measures)

An experimental design was used to investigate the impact of a 10 week programme of music-making on the WB of adults with DS, as described in Study 3 (see Section 4.5.4). A quantitative experimental design examines the impact of a treatment (or intervention) on a measured outcome (WB in this case). The participant is tested in both the pre and post-test conditions (repeated-measures). All other variables, for example type of LD, require controlling as far as is possible. In the following section, the methods used within these designs are introduced, before the chapter ends with a full account of each proposed study.

4.4 METHODS: MEASURING WELL-BEING: Research questions 1 and 2

Overarching research question 1: What is the effect of active music participation on WB among adults with DS?

Research question 2: What is the most appropriate method for assessing WB among adults with DS?

Research aim (i): To scrutinise potential tools to measure WB among adults with LDs, recognising a lack of validated measures for this target group.

The vast array of research undertaken up to this point in time demonstrates a desire by social scientists and psychologists to understand the factors that affect WB. What makes people

happy? What makes for a contented society? These are difficult questions to answer but

their importance continues to drive research forward at a significant pace. These difficulties

are partly due to the problems associated with accurately measuring WB. This can only be

fully understood by asking individuals how they feel about their lives which can lead to

problems in itself, such as reliability, validity and terminology (Kreuger and Schkade, 2008).

Data have predominantly been collected from individuals through self-reported measures

such as questionnaires or surveys, often referred to as 'global' measures. This has led to a

much greater understanding of the correlates between WB and influential factors, such as

friendship, marriage, heredity, employment, health and physical disability (Diener *et al.*,

1999; Lyubomirsky, King and Diener, 2005). Although WB research methods used up to this

point have been successful to a degree, there are still improvements to be made concerning

reliability and validity of the data collected and subsequent interpretation.

There have been countless attempts by researchers to develop reliable and valid scales that

measure the 'full picture' of the WB of an individual. Many of these scales have relied

heavily on one aspect of WB – either positive affect; negative affect or life satisfaction

(Diener, 1984) but due to the multidimensional nature of WB these have only produced a

partial answer. In response to this dilemma, the development of the Satisfaction With Life

Scale (SWLS) attempted to incorporate the multi-faceted nature of WB and measure this as a

cognitive-judgemental process (Diener, 1984). Results suggested that scores on the SWLS

correlated with other measures of WB and support findings that specific personality

characteristics are linked to WB (Diener, Oishi and Lucas, 2003).

Despite advancements in the assessing and understanding of WB, research has continued to come under scrutiny at both the conceptual and empirical level (Pavot, 2013). At the conceptual level the philosophical assumptions have been challenged by alternative WB constructs, thus the validity and use of measures designed to assess WB are questioned. At an empirical level, shortcomings concerning the potential effect of memory failures, individual biases and the influence of cognitive context at the time are now being scrutinised. Newer methods offered as an alternative to traditional global reports have included the Experiential Sampling Method (ESM; Csikszentmihalyi and Larson, 1987), which led to the concept of the 'flow' state (Csikszentmihalyi, 1990). The 'flow' state is a mental state of mind where the individual is fully immersed in an activity and experiences an energised focus, full enjoyment and enjoyment in the process itself, often referred to as being in the 'zone'. The ESM method utilises frequent experiential reports on current emotional experience. However, a significant drawback with this approach concerns the fact that participants may become bored of the required commitment to complete the reports. Also, vast amounts of highly complex data are created from each participant.

The Day Reconstruction Method (DRM; Kahneman *et al.,* 2004) falls somewhere in between the ESM and traditional global reports. This approach moved away from the need to provide random responses throughout the day to a more predictable diary entry at the end of each day. This is a less intrusive method although it does still require a considerable amount of time at the end of each day. Like ESM, the DRM method tends to focus on the temporally proximal affective experiences of the individual. Evidence suggests that data produced from both methods is distinct from the type of data obtained from global measures of WB. Emotion data from ESM and DRM tend to be more attributed to WB in social relationships, whereas

global measures tend to correlate with variables connected with material WB (Pavot, cited in Eid and Larsen, 2008).

Significant progress has more recently been made in developing reliable subjective measures of personal and social WB and the pursuit of even more reliable measures continues. The ESS (European Social Survey) Well-being Module represented one of the first main systematic government attempts to produce policy relevant national WB records (Huppert *et al.*, 2008). The ESS Well-being Module was administered to approximately 43,000 adults in 23 European Union countries. This article sought to understand and evaluate the success of European countries in promoting the personal and social WB of their citizens. WB was identified as consisting of nine components: positive feelings; absence of negative feelings; life satisfaction; vitality; resilience and self-esteem; positive functioning; supportive relationships; trust; and belonging. It recognised that in addition to a better understanding of domain-specific measures such as family situation or income, it is also essential to look deeper and focus on how well an individual functions. This shifted the emphasis from a more transient state of WB to one that is more sustainable in the longer term. Furthermore, research suggests that the reliable measurement of WB indicators should be viewed as not merely the absence of distress symptoms, which can present results that are not truly representative of the WB of an individual (Bech *et al.*, 2003).

Diener *et al.,* (2010) presented two WB measures: The Flourishing Scale, which is a brief eight item measure of the respondent's perceived success in various areas, for example, self-esteem and optimism; and The Scale of Positive and Negative Experiences, which produces a score for positive and negative feelings combined. Diener *et al.* (2010) commented that

although these new measures are promising, more validity work is required before they can

be extended to communities other than the student population they worked with. A major

difficulty with these existing WB measures is the inappropriateness of design for the LD

population. They require a certain level of cognitive functioning, for example, the ESM and

DRM require the participant to be capable of reading and writing fluently, which is beyond

the ability of many people with LDs.

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS) has been widely used and

validated in recent years (Tennant *et al.*, 2007, see Appendix 1). It was originally funded by

NHS Health Scotland and developed via a collaboration between the University of Warwick

and the University of Edinburgh. The aim was to monitor the mental WB of the general

population. It also was designed to provide a means of evaluating the impact of various

projects and programmes on WB. It comprises 14 items that relate to an individual's mental

WB and responses are made using a five point Likert scale rating. Each item is positively

worded and uses simple language and sentence structure (e.g. I've been feeling useful; I've

been feeling relaxed). In addition, there is a shortened seven item version available, which

demonstrates a strong outcome correlation with the full length version (Stewart-Brown *et al.,*

2009). The shortened version (SWEMWBS) is suitable for use with people with LDs due to

its straightforward design and ease of application - although it has not yet been validated for

use in this population.

The UCL Museum Wellbeing Measures Toolkit is a recent development of a set of scales of

measurement of WB resulting from participation in museum and gallery activities (Thomson

and Chatterjee, 2014, see Appendix 1). The toolkit was designed to help those running either

in-house or outreach museum programmes to evaluate the impact of their work on the WB of the participants. The toolkit is highly flexible and allows the researcher the freedom to 'pick and mix' the particular tools used (e.g. a generic well-being questionnaire; or, a positive well-being younger adult version). It is also suitable for either a one-off activity or a longer programme of activities. Although this measure was not specifically designed for the LD population, it has been used with success among individuals with cognitive impairment, such as sufferers of dementia (Devine and Lloyd, 2015).

Although this current research has adopted the PERMA model of WB (Seligman, 2011) as the model of choice, the corresponding PERMA Profiler scale for measuring WB (Butler and Kern, 2015) is not suitable for this target population. The wording used is too complicated and would not be appropriate for people with LDs. Although there has been an adaptation of PERMA for adolescents, to date there is not an LD version available. This further demonstrates the real absence, particularly in the UK, of WB measures specifically validated for use with people with LDs. The measurement of WB within the LD population is a topic which requires careful planning and an empathetic understanding of the particular needs and abilities of the individuals.

4.4.1 Measuring well-being in people with learning disabilities

The accurate assessment of the WB of people with LDs is highly problematic but is nevertheless essential to allow people with LDs access to a quality of life comparable to the non-disabled community, along with the freedom to have some degree of control over their own lives. In seeking to obtain accurate and meaningful data, there are many methodological issues when working with the LD community. Two of the traditional methods used to assess

WB – questionnaires and interviews – have reported difficulties with this population (Finlay and Lyons, 2001). Problems with language and communication are well documented (Nind, 2008). These include lack of understanding; complexity of phrasing; difficulties with expressive speech; and speech clarity. Vocabulary should be as simple as possible to obtain the relevant information, and abstract concepts are often more difficult to comprehend for people with LDs (Smyley and Elsworth, 1997). An appropriate means of accurately responding must be sourced. Particular care must be taken to provide questions that can be understood and be responded to without confusion. Many standardised questionnaires are inappropriate for this population, not only due to the language and comprehension difficulties, but also due to the psychometric properties not being applicable to the group in question (Finlay and Lyons, 2001). Resulting from these concerns, the validity of questionnaires and interviews has been challenged, in particular the question content, phrasing, response format and psychometric properties.

The LD population is extremely heterogeneous and there appears to be no easy solution to overcoming these concerns – the population for a particular measure needs to be clearly defined and this is a significant problem when dealing with a broad variety of LDs, all with their own particular challenges. A variety of strategies have been suggested in the literature to increase the content validity of these measures, such as reviews by multiple judges to ensure that all facets are covered, and thorough pilot work (Finlay and Lyons, 2001). There has been some effort on the part of researchers to draw together and review WB measures for people with LDs (Schalock *et al.,* 2002; Van Loon *et al.*, 2010; Townsend-White, Pham and Vassos, 2012; Verdugo *et al.*, 2013). Nevertheless, there is still little consensus on the application of WB measures for the LD community. Townsend-White *et al.* (2012) suggested that a greater number and variety of instruments would enable researchers and

clinicians to select appropriate instruments based on their specific needs. The researchers

commented that the concept of measuring WB for individuals with LDs is still in its infancy

and there is a modest amount of literature in the field. Verdugo *et al.* (2013) noted that there

are even less measures available for people with profound and complex disabilities. In a

systematic review of self-reported quality of life measures the researchers concluded that the

majority of measures were not well validated nor were they related to any theory of quality of

life. In fact, only six were viewed as psychometrically sound and these were only suitable for

people with mild LDs. The review reported in Chapter 3 (see Section 3.5) identified the

methods used to date in existing research and these provided a useful insight into the ongoing

challenges experienced when dealing with this population.

4.4.2 Analysis of methods identified in the review

From the findings of the review presented in Chapter 3, it can be seen that there appears to be

no one singular approach that has tended to be favoured when measuring WB among the LD

community. A wide variety of methods were employed in the reviewed studies and all except

one (Aujla and Needham-Beck, 2019) consistently led to positive findings in support of the

various arts-based interventions (see Table 4.2). The studies that reported outcome measure

statistics (Hooper and Lindsay, 1992; Hooper, 2002; Boso *et al.,* 2007; Jaschke and Scherder,

2015; and Barnet-Lopez *et al.*, 2016) all showed significant improvements after the

intervention had taken place (and not significant results in the control group where the

experimental design was controlled), except for the Personal Well-being Index: Intellectual

Disability (Cummins and Lau, 2005). Likewise, the studies that reported via qualitative

methods (Moceviciene, 2014; Dinold, 2014; Ward and Parkes, 2015; Moceviciene and

Prudnikova, 2015; Hassan, 2017; Whelan, 2018; Aujla and Needham-Beck, 2019) also

reported improvements following the period of intervention, with the exception of the study

mentioned above. However, it should be born in mind that these studies were relatively small

scale with regard to participant numbers (see Chapter 3, Section 3.5.2, Figure 3.4) and this

should be taken into account when drawing conclusions and/or making generalisations from

the findings. Also, as can be seen, these measures do not acknowledge WB as a single

construct (with the exception of IDQOL-16, Hoekman *et al.*, 2001, which is non-English

language, and Personal Well-being Index: Intellectual Disability, Cummins and Lau, 2005),

but rather they assess fragments of WB. Furthermore, for example, the Koppitz Human

Figure Drawing Test (Koppitz, 1968) and the Repetitive Behaviour Quotient-2 (Leekam *et*

al., 2007), require a certain level of drawing or writing ability, which is beyond the capability

of many people with LDs. For these reasons, the measures identified in the review were

deemed unsuitable for use with the target population of this research.

Table 4.2: Summary of measures identified in review

MEASURE	DATE	AUTHOR(S)	AIM OF MEASURE	LIMITATIONS OF MEASURE FOR THIS RESEARCH
Brief Psychiatric Rating Scale	1962	Overall and Gorham	A measure of psychiatric symptoms e.g. anxiety.	Not a full WB measure - a rating of psychiatric distress.
The Koppitz Human Figure Drawing Test	1968	Koppitz	An assessment/indicator of emotionality.	Not a full WB measure - seeks indicators of emotional disturbance; requires drawing ability.
Clinical Global Impression Scale	1976	Guy	A measure of global functioning following treatment/medication.	Not a full WB measure - a rating of psychiatric illness severity, improvement and response to treatment e.g. medication.
Behaviour Rating Scale	1986	Lindsay and Baty	A measure of relaxation following behaviour relaxation therapy.	Not a full WB measure - a means of managing anxiety through relaxation techniques.
Cohen-Mansfield Agitation Inventory	1986	Cohen-Mansfield and Billig	A systematic assessment of agitation.	Not a full WB measure – records frequency of aggressive (agitated) behaviours e.g. for dementia sufferers.
Intellectual Disability Quality of Life-16	2001	Hoekman, Douma, Kersten, Schuurman and Koopman	Quality of life scale for people with LDs.	Non-English language.

Personal Well-being Index – Intellectual disability	2005	Cummins and Lau	Subjective well-being scale for people with LDs.	Designed for mild/moderate LDs – no option for severe/profound measurement.
Repetitive Behaviour Quotient-2	2007	Leekam, Tandos, McConachie, Meins, Parkinson, Wright, Turner, Arnott, Vittorini and Le Couteur	A self-report questionnaire concerning repetitive behaviours e.g. in people with ASD.	Not full WB measure – records routines or repeated behaviour via self-report; requires fluency in reading/writing e.g. adults with ASD.

4.4.3 Questionnaire and interview development for people with learning disabilities

It should be noted that the difficulties highlighted above do not apply to all people with LDs, particularly those with borderline or mild LDs. In these cases it would be wrong to oversimplify questions and standardised questionnaires may be appropriate, although this should not be assumed. It should also be recognised that some constructs may just be too difficult to assess for people with LDs, particularly more abstract concepts and those concerning judgements of time. According to Finlay and Lyons (2001), the following suggestions would help to increase inclusiveness and validity in using questionnaires and interviews with people with LDs, although they note that not all suggestions should be used with all participants and a degree of flexibility must be maintained:

(i) A minimum number of words should be used and ambiguous or complex phrases avoided.

(ii) Researchers need to be aware that participants may respond to the topic, rather than the question itself.

(iii) Comparisons should be split into two separate and distinct parts.

(iv) Significant events can be used as markers when referring to time periods.

(v) Check that a question has been understood by asking for examples, or by using alternative phrasing.

(vi) Make sure if probes or rephrasing is used, the participant does not think their original answer was wrong.

(vii) Allow plenty of time for interviews, with the possibility of gaps or uncodeable answers.

(viii) Any difference between receptive and expressive speech needs to be identified - researchers often over-estimate the comprehension of people who have good expressive language skills.

(ix) Make sure the participant knows that it is ok to not know an answer.

(x) Be aware of acquiescence in answering questions, along with suggestibility and the desire to please (Finlay and Lyons, 2001, pp. 319-335).

In light of these potential pitfalls when researching with participants with LDs, it is clearly an area that requires careful planning and specialist knowledge in the field. Based on the information presented here, the following section describes how WB was accessed for the LD population involved in the current research.

4.4.4 Well-being measures selected for this thesis (Research question 2)

4.4.4.1 Quantitative measures

With regard to Research question 2 (research aim (i)), the following points have emerged and contributed to the WB measures selected for this target group. A main concern when selecting WB measures is the lack of validation of the majority of existing scales of WB for a

target group with LDs. For this reason it was necessary to seek out measures that had been used within similar groups (e.g. dementia sufferers), or measures that were easily accessible for this target group. The two scales selected were: the shortened version of Warwick-Edinburgh Mental Well-being Scale (SWEMWBS, Tennant *et al.,* 2007); and the UCL Museum Wellbeing Measures Toolkit (Thomson and Chatterjee, 2014, see Section 4.5.4, Study 3). These two measures were selected for a variety of reasons including:

1) Both measures are designed to provide both an overall measure of WB, and a measure of WB following the impact of a project. Therefore they were particularly suitable for a project of this type.

2) Both use a simple and basic vocabulary in comparison to other WB measures, e.g. the PERMA Profiler.

3) Both have a simple sentence structure with few words.

4) They are quick to complete (with just 6 or 7 questions depending on the specific measure).

5) The UCL Museums Wellbeing Measures Toolkit uses brightly coloured umbrellas which are visually appealing.

6) The UCL Museums Wellbeing Measures Toolkit has been used with other cognitively impaired participants (dementia sufferers; Thomson and Chatterjee, 2014) – although not validated for LDs.

For these reasons the researcher felt that these two measures were a suitable option for participants with DS. With the additional pictorial response option (smiley faces) this seemed a likely successful method from which to obtain valid WB scores.

Therefore, a combination of SWEMWBS and the UCL Museum Wellbeing Measures Toolkit provided a solid foundation upon which to investigate the impact of music participation on WB for this population, and full versions of each scale are available in Appendix 1. A specifically designed questionnaire was used in the pilot study, however this proved difficult for a number of reasons, such as the pictorial scales for participants to respond with were not suitable for the target group (see Section 4.5.1, Pilot Study, Appendix 2). A specifically-designed online survey was also used for Study 2 (see Section 4.5.3).

4.4.4.2 Qualitative methods

Two qualitative methods were selected as appropriate means of data collection.

The *interview* is a qualitative research technique that involves the researcher asking the participant(s) detailed questions and engaging in dialogue. A semi-structured format is often favoured in social research (as opposed to structured or unstructured), which allows a certain degree of flexibility whilst ensuring the interaction remains 'on track' through having some questions predetermined on the area of interest. The interviewer usually has a checklist of topics to be covered, but the exact wording and order are often decided while the interview is actually taking place. Additional questions can easily be added for clarification or further information (Robson, 2011). Interviews were used in this research to gain an in-depth knowledge of what taking part in regular active music sessions meant for the students and their families. Bearing in mind the necessary points to consider when interviewing people with LDs (see Section 4.4.3), the interview technique can be a highly effective method for this cohort when carried out with empathy and an understanding of the individual needs of each participant (see Section 4.5.2, Study 1).

Participant observation is when the researcher is part of the group being observed. It is essential for there to be a good rapport between the observer and the participants, as is the case in this research. Observations can be described, analysed and interpreted, and reported data can be either thematic or narrative (Robson, 2011). Participant observation allows the observer considerable freedom in the gathering of data, for example note taking and journal keeping. Participant observation was used in this research to record detailed behaviours seen during the music sessions. This method is particularly suitable for participants with LDs as it is entirely non-invasive and is not reliant on the participants' involvement or their participation in any way (see Section 4.5.2, Study 1).

The following section provides details of each of the four studies which form this thesis. The multiple methods employed allow a triangulation of strategies for data collection, thus providing the most effective means of answering the overarching research question.

4.5 INDIVIDUAL STUDIES

As developed throughout this chapter, four separate studies combined to form this research (see Table 4.3). Each is presented in turn below.

Table 4.3: Summary of studies

OVERARCHING RQ: What is the effect of active music participation on WB among adults with DS?				
STUDY	**AIM**	**DESIGN AND METHODS**	**PARTICIPANTS**	**ANALYSIS**
PILOT STUDY	(i) To scrutinise potential tools for measuring WB among adults with LDs.	Pre/post-test design (uncontrolled) using questionnaires.	15 adults (mixed LDs).	Statistical analysis.
STUDY 1	(ii) To obtain an in-depth understanding of what taking part in regular active music sessions means for 4 adults with DS and their families. (iii) To explore how well the PERMA model fits the data from the participants.	Ethnographic case study using observations, interviews and audio/video materials.	4 adults with DS and their families.	Thematic/narrative analysis.
STUDY 2	(iv) To investigate the prevalence of music participation as an activity, within the Mencap organisation.	A specifically designed online survey administered via email.	Mencap groups based in the UK.	Statistical analysis.
STUDY 3	(v) To investigate the impact of a one-off music intervention on WB among adults with DS. (vi) To investigate the impact of a 10 week programme of music-making on the WB of adults with DS.	A repeated-measures design measuring change over a 10 week programme of weekly music interventions, and within individual sessions, using UCL Museum Wellbeing Measures Toolkit and SWEMWBS.	24 adults with DS.	Statistical analysis.

4.5.1 Pilot study: Research question 2

Research question 2: What is the most appropriate method for assessing WB among adults with DS?

Aim: (i) To scrutinise potential tools for measuring WB among adults with LDs, recognising the lack of standardised measures for this population.

Design and methods: This was an uncontrolled pre and post-test design, measuring change over a two hour music intervention, using questionnaires.

Questionnaires: WB was measured through two specifically designed questionnaires. Each participant was asked to complete Student Questionnaire 1 (SQ1) and Student Questionnaire 2 (SQ2). SQ1 was completed on arrival and before the music session took place (pre-test) and SQ2 was completed immediately after the session had finished (post-test). SQ1 included some general introductory questions regarding personal details (date of birth, gender and living arrangements) and some additional open and closed-ended questions concerning WB. SQ2 contained further questions concerning WB in relation to SQ1. Responses were made either verbally, through the use of pictorial scales, or with the help of a carer or support worker. Response options included the Wong-Baker Faces pain rating scale (Wong-Baker FACES Foundation, 2016); the Self-Assessment Manikin scale (Bradley and Lang, 1994); and a five point smiley face scale similar to those used in government surveys for people with LDs. The questionnaires were in paper format and the questions were read aloud to the

participants. Anonymity was maintained throughout. Both questionnaires and scales can be seen in Appendix 2.

Participants: 25 adults with LDs were invited to participate in this research project, 15 of whom accepted (nine females, six males) representing a 60% response rate.[5] This sample included participants with all types of LDs. The participants were selected from two sources: (1) a Music Man Project workshop which took place at the Royal College of Music on 26 June 2016, and (2) during a Music Man Project daily session which took place in the Southend area on 19 July 2016. Sample selection was made on the basis of an invitation to be part of the research project, whilst attending the workshop or session. The sample covered a wide variety of ages ranging between 20 and 57 years (overall mean age = 32 years, standard deviation (S.D.) = 10.47; female mean age = 30 years, S.D. = 7.27; male mean age = 34 years, S.D. = 14.42). All participants except for one (who resided in a care facility), lived with family members. Ethical consent was obtained for all participants prior to the session commencing via participant information sheets and consent forms (adapted where required).

Analysis: These findings helped to identify some of the specific challenges that need consideration when working with this population. These included allowing plenty of time for questioning, without the participants feeling rushed or pressured in any way. In addition, completing the questionnaires in the same room as the instruments already set up for the session proved a distraction for some of the participants. Therefore, a quiet space was

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[5] It should be noted that a group of ten participants was cancelled two days prior to the study taking place. The support manager responsible decided that his service users would not enjoy the genre of music being used. This is somewhat typical of the experiences of people with LDs, with others making life choices on their behalf.

proposed for the subsequent studies, in order to allow the participants to concentrate on answering the questions to the best of their ability and without distraction. The use of these scales with participants with LDs proved to be difficult, particularly the complex faces and figures used in the Wong-Baker scale and Self-assessment Manikin scale. Therefore, alternative measures were sought for the remaining studies below, as these were not deemed suitable for this population.

4.5.2 Study 1 (see Chapter 5): Research questions 3 and 4

Research question 3: What counts as effective active music participation for adults with DS?

Research question 4: To what extent does the PERMA model fit the emerging data from the participants?

Aims: (ii) To obtain an in-depth understanding of what taking part in regular active music sessions means for four adults with DS and their families.

(iii) To explore how well the PERMA model fits the data from the participants.

Design and methods: An ethnographic case study of the Music Man Project UK (MMP), which provides music education to adults and children with LDs. The participants were all part of the Music Man community, based in Essex. The researcher was already an accepted member ('insider') of the group, spending much time with the participants and their families on a regular ongoing basis. Data was collected via three methods: (1) Participant observations during the regular daily sessions – some predetermined areas of interest were identified, bearing in mind the PERMA model (Seligman, 2011) of WB. A journal was used

to record all information as it happened; (2) Semi-structured interviews with music learners; their families; and Music Man staff. This explored the impact of the music sessions, including musical and social features, with the participant being given the freedom to express their thoughts on the subject. Interviews were face-to-face, one-on-one. Informal interviews were also undertaken as appropriate; (3) Audio and visual materials (for example, videos and photographs of concerts) were collected throughout the period of fieldwork. This study ran for a 12 month period from February 2017 – February 2018.

Participants: Four nested case study participants were selected, all of whom had DS and were part of the Music Man community, attending different daily sessions for a minimum of one session per week. The focus was centred on the participant and extended to other relevant individuals (family/tutors). Three males and three females were initially selected to provide a gender-balanced targeted sample, although one female and three males actually took part. An invitation to be part of the case study was sent to selected participants. Ethical consent was obtained from all participants (including family/tutors where included in the study) using adapted participant information sheets and consent forms where appropriate (see Appendix 3).

Analysis: Data collected was largely qualitative. A holistic approach was adopted to create a highly detailed and descriptive narrative; Interpretative Phenomenological Analysis (IPA) was employed to link common themes between participants.

4.5.3 Study 2 (see Chapter 6): Research question 3

Research question 3: What counts as effective active music participation for adults with DS?

Aim: (iv) To investigate the prevalence of music participation as an activity within the Mencap organisation and to provide an insight into their view of music-making on WB for their adult members.

Design and methods: A specifically designed online survey was distributed to all the UK Mencap groups. This sought to identify: (i) whether music participation (in comparison to other activities) was used as an activity for adults, and if so, (ii) why it is used, (iii) in what capacity is it used, (iv) how it is funded, (v) and why it is not used more (if appropriate). This study ran June – December 2017.

Participants: Approximately 400 Mencap groups throughout the UK. Ethical consent was obtained online.

Analysis: Quantitative statistical analysis procedures were applied to the returned data. Common themes were sought in responses to gain an insight into the current use of music participation for people with LDs, within the UK Mencap organisation.

4.5.4 Study 3 (see Chapter 7): Research question 3

Research question 3: What counts as effective active music participation for adults with DS?

Aims: (v) To investigate the impact of a one-off music intervention on perceived WB among adults with DS.

(vi) To investigate the impact of a 10 week programme of music-making on the WB of adults with DS.

Design and methods: A within-subjects design, measuring change over a 10 week programme of weekly music interventions. WB was measured by the UCL Museum Wellbeing Measures Toolkit (adapted via using a pictorial scale for responses). This relatively new (2014) scale is freely available online and is suitable for pre-test/post-test comparisons. With minimal adaptation this was suitable for people with LDs. In addition, SWEMWBS was employed to increase validity, again using a pictorial scale for responses (see Appendix 1). These measures were applied to monitor the overall impact of the longer 10 week programme (Study 3a: data collected at week -10 (baseline), week 1, week 6 and week 10) and also on the effect of the individual sessions (Study 3b: pre and post-test week 1, week 6, week 10 and non-music week). This study ran April – December 2018 (see Chapter 7).

Participants: 24 adults with DS, recruited through Music Man Project; Mencap; RCM Sparks team; and DS support groups, were invited to participate in the 10 week music intervention programme. Ethical consent was obtained as per in the pilot study.

Analysis: Quantitative statistical analysis procedures (repeated-measures) were applied to the data to identify significant changes between the pre and post-test responses (per individual sessions and across the whole intervention).

4.6 ETHICAL CONSIDERATIONS

This research was reviewed and approved by members of the Conservatoires UK Research Ethics Committee (CUK REC) and no significant ethical difficulties were highlighted to date. The British Psychological Society's (BPS) code of human research ethics describes four main principles: respect for the autonomy and dignity of persons; scientific value; social responsibility; and maximising benefit and minimising harm (BPS, 2010). These four principles have been strictly adhered to throughout this research. For example, participants were regularly asked if they were happy to continue, whether they needed a break or if they were unsure about anything. Each participant (or legal representative) gave their informed consent to take part and was given a participant information sheet (adapted where needed for LDs) which outlined the aim of the research and informed them of their right to discontinue at any time should they wish to do so. All participants provided consent for photographs to be taken and included in the research. All photographs of performances are freely available in the public domain. Strict anonymity was maintained at all times and participants were fully debriefed after the sessions had taken place.

4.7 CONCLUSION

In summary, the research question of this thesis required a pragmatic methodological approach to tackle this 'real life' issue, in order to manage the complexities of WB and LDs. A combination of quantitative and qualitative methodologies were used in a multiple methods design, which allowed the flexibility to use the strategies most suited to this under-researched field of study. The measuring of WB in the LD population is highly problematic and there is a real lack of validated scales available. The four studies which combined to

produce this thesis used a variety of carefully selected methods in order to answer the

overarching research question.

CHAPTER 5: STUDY 1

5.1 INTRODUCTION

Study 1 is an ethnographic case study of MMP UK (see Photograph 3). The study followed four adult music students with DS and their families for a period of 12 months (February 2017 – February 2018). The researcher is a music tutor and regional director of this Mencap-funded charitable organisation and is experienced in the field of LD. During the year of fieldwork she spent between 14 - 30 hours per week with each of the students and their families in a variety of musically-related environments and situations. These included regular weekly music classes; concert rehearsals; Christmas concerts; local fundraising concerts; concerts at care homes; weekends away performing; workshops for new centres; and at a sell-out show at the London Palladium in October 2017 (DVD available). Ethical approval was granted by the CUK REC (June, 2016).

The researcher had unlimited access to the students and the musical activities they undertook, with the families giving generously with their time and effort. The unique position of the researcher as an established member of the group (see Chapter 4, Section 4.2.2) facilitated the collection of rich and varied data, offering a detailed insight into the real life musical experiences of the participants and any perceived benefits (or disadvantages) to WB as a result. This holistic approach, based on descriptive and inductive data, aimed to produce the fullest picture possible of the participants as part of the MMP community. This chapter provides background information regarding MMP UK; details on the ethnographic case study of MMP UK; data collection methods; participants; and analysis of data and findings.

5.2 BACKGROUND TO THE MUSIC MAN PROJECT UK (MMP UK)

Photograph 3: The Music Man Project UK (Photograph courtesy of Paul Carpenter Films)

MMP UK is the UK's first full-time music education service specifically for children and adults with LDs (see Section 3.6). It is a not-for-profit franchise model, supported by local charity Southend Mencap. The programme originated in South Essex (Southend) and was the innovative 'vision' of former deputy head teacher and musician, David Stanley. MMP developed as a result of a growing demand from parents and families for musical opportunities for people with LDs. A weekly Saturday music school was originally established in 2001 for a small group of young adults with LDs. It quickly became apparent that this was not sufficient to meet the high demand for musical opportunities for people with LDs. The sessions grew in popularity and before long it was clear that there was not enough space for everybody who wanted to attend the Saturday morning sessions. Therefore in 2012 the Saturday music school expanded to running six days a week and this was the start of the

specialist full-time music education service that is in place today

(https://themusicmanproject.com/).

The main MMP ethos states that there is innate musicality in everyone irrespective of their LD and through accessing this much can be achieved on a variety of different levels. This includes not just musical progress but also improvements in social skills, physical and mental health and many other aspects of WB. MMP's aims are focussed around education, performance and fun in a highly supportive environment that is open to anybody with a LD. This is through the teaching of originally composed repertoire at: special schools and colleges; care homes; weekly Saturday music school; adult daily group lessons; and workshops in various locations, including at the Royal College of Music.

The term 'active' is an important criterion for MMP teaching strategies. Students are very much actively involved in music throughout the sessions. This is a participatory activity and encouragement and support are offered to this effect. Participation is guided by the students themselves and their level of involvement provides them with a sense of agency and control in this aspect of their lives. They are free to make decisions about their degree of participation e.g. solo performances, and this is an important aspect of the group.

Musical content is varied and written to suits the highly varied needs of these musicians with LDs. The founder of MMP (David Stanley) is an experienced and established composer. He produces the MMP repertoire, often with lyrics from the students or other member of MMP, and these are published in MMP songbooks. The songbooks contain sheet music, lyrics, instrumental parts, teaching instructions and the educational background to the piece. Each

session uses a selection of familiar songs, while introducing new repertoire to keep challenging the students appropriately. All music includes signs and actions based around Makaton sign language, to ensure non-verbal students can participate. There is often the inclusion of instruments (e.g. glockenspiel, djembe, small percussion), with instrumental parts adapted to suit the needs of the students. This ensures the most able students are challenged, while also allowing less able students to take part on simpler arrangements. MMP tutors are experienced musicians, predominantly with music/performance qualifications and expertise. They all have special needs experience alongside their musical skills. Musical pedagogy is specialised with an emphasis on both education and fun. Learning tends to take place in a subtle manner through the music participation itself. For example, song lyrics can utilise musical terminology, or address emotional expression, through the topics covered. Sessions are varied and the overall feeling is positive and upbeat. Teaching pace is sufficient to prevent either a loss of concentration, or boredom and/or frustration becoming an issue. Termly reports are available for those students who request them.

Since its expansion in 2012, MMP groups have been established in Essex, Kent, Suffolk, East Sussex, Hampshire, Lincolnshire, Bristol and Scotland, as well as overseas centres operating in South Africa (Sizanani), India (Bangalore), Nepal (Kathmandu) and the Philippines (Iloilo) (see Photographs 4 and 5).

Photograph 4: Workshop in South African township (2016) (Photograph taken by author)

Photograph 5: Workshop in Bangalore, India (2018) (Photograph courtesy of Sarah Mann, MMP staff)

Additionally, workshops or concerts have been given in West Sussex, Surrey, Gloucestershire, Tyne and Wear, Cheshire, Lancashire and Northern Ireland. At the time of writing there were also several more in the pipeline to be visited as time permits with current

teaching commitments (and now Covid 19 restrictions). These visits are often undertaken at weekends to ensure the continuous running of the existing weekday MMP groups. MMP provides ongoing training such as the provision of a MMP teaching handbook, MMP sheet music and songbooks, further staff visits, additional workshops, mentoring for staff, online teaching resources and fund raising ideas or support for any new group wishing to join the MMP community. MMP aims to provide the same musical opportunities to those with LDs as those experienced by aspiring musicians without LDs – although teaching styles and time frames may differ to suit the needs of the individual. High level tuition is provided by highly qualified musicians, additionally with special educational needs teaching experience. A variety of musical instruments (including drum kit, percussion, African drums, ukuleles, glockenspiels, hand bells and singing), originally-composed repertoire and performance opportunities form a standard part of the MMP curriculum (see Photograph 6).

Photograph 6: Group adult weekly lesson in Maldon (Essex) (Photograph courtesy of Paul Carpenter Films)

Performances can be seen at a variety of prestigious venues across London and further afield. In 2015 MMP had their debut major performance - 'Music is Magic' - at the London Palladium (see Photograph 7). This included over 200 students with LDs from around the UK and a successful Guinness World Record attempt for the largest ever triangle ensemble! The second half of the show included a musical 'From the Asylum to the Palladium'. This followed the historical LD journey from the harrowing days of the institution to where society has progressed to today – and how far there is still to go along this difficult path. 2017 saw the production of the next London Palladium performance - 'The Label' (see Photograph 8). This was another musical challenging how people with LDs are assigned 'a label', rather than being seen for who they really are. In April 2019 MMP had their largest production to date at the Royal Albert Hall (see Photograph 9), reaching a large audience in excess of 3000 people. MMP performances, whether they be at the Royal Albert Hall or a local nursing home, aim to educate the wider society about the journey towards equality of opportunity for people with LDs. Through performances, MMP aims to challenge popular misconceptions about what people with LDs can or cannot do and the staff have the highest aspirations for what can be achieved by their students. First and foremost the students are musicians and performers – not a person identified by their LD.

Photograph 7: 'Music is Magic' at the London Palladium (2015) (Photograph courtesy of Paul Carpenter Films)

Photograph 8: 'Music is Magic' at the London Palladium (2017) (Photograph courtesy of Paul Carpenter Films)

MMP has won many awards for its unique work with the LD community and has been described as 'outstanding' by OFSTED, who commented on exceptional opportunities for

pupils (MMP, 2018). The Royal College of Music described the work as 'truly

inspiring…the power of music to bring everyone together was very apparent'. It has been

praised by the previous and current Prime Ministers for its pioneering work in the field.

MMP has been in the final of the 'Music Teachers Award for Excellence' twice in the last

three years and won the 2016 'Kids Count Inspiration Best Creative Contribution' award

(MMP, 2018).

Photograph 9: Royal Albert Hall debut performance (2019) (Poster courtesy of Trudi Crumley)

5.3 ETHNOGRAPHIC CASE STUDY

Study 1 used MMP UK as the basis for an ethnographic case study. The period of study ran from February 2017 to February 2018 inclusive. The initial plan for a field study period of 6 months was extended to 12 months to enable coverage of further significant events taking place later in the year, including the show in 2017 at the London Palladium. This was such a significant event for the participants (and their families) that it would have been detrimental to the research not to have it covered in the period of fieldwork.

Throughout the year of fieldwork the researcher spent many hours with the participants, their families, friends and MMP staff. The amount of hours varied according to the events taking place. As a minimum this was two days per week during term time (14 hours per week), and on occasions this would include weekend days and trips away to other centres (up to 30 hours per week). This provided insight into the unique experiences of the participants as they participated in a variety of musical events. This included local weekly music classes through to performing at the London Palladium – with a highly varied schedule of events in between. Ethical approval was received through the CUK REC (June 2016). Participants gave informed consent via a participant information sheet (adapted where necessary for LDs) alongside discussions with the researcher to ensure each participant understood the project as it developed (see Section 4.5.2).

5.4 DATA COLLECTION METHODS

Three data collection methods were utilised in order to provide as broad a picture of the experiences, as well as triangulation of the data obtained:

1) Semi-structured interviews with participants and their families.

2) Researcher observation (recorded in a journal of field notes).

3) Video/photographic documents.

5.4.1 Semi-structured interviews

Semi-structured interviews were conducted with both the participants and their families. The semi-structured design ensured that relevant topics of interest were covered whilst allowing the interviewees sufficient freedom to talk in a relatively relaxed manner with the interviewer. The interviews were of a predominantly qualitative nature – seeking to understand each individual's subjective experience. The questions were intentionally broad i.e. 'How…?' and 'Can you tell me…?' style of questions, designed to encourage detailed responses. An interview schedule was used as a prompt to ensure that sufficiently detailed and relevant information was obtained from each interviewee and that important information was not omitted (see Appendix 3).

All interviews were recorded and additional consent was obtained for this from each participant at the time of interview. The researcher ensured that all participants understood that they did not have to talk about a particular topic if they did not feel happy doing so and all were thoroughly debriefed after each interview session. All participants appeared relaxed throughout the process with no issues of concern arising from any individual. Particular care was taken with the interviewees with LDs (in accordance with the guidelines highlighted in Chapter 4, Section 4.4.3). The researcher is aware of the individual needs and levels of

cognitive understanding of each participant and this was made full use of in order to facilitate the most effective interview technique possible.

Interviews for the participants with LDs took place over three separate sessions so as to minimise fatigue or loss of concentration and thus maximising the quality of their responses. These took place during their MMP weekly sessions at the relevant venue for the regular group that they were a part of. Interviews with family members took place in a single session and within their own home environment. This provided a familiar and comfortable environment in which to conduct the interview and minimise any stress which may influence the discussion. These individuals gave of their time generously and appeared to be open and honest in their discussions. The researcher felt the interviews were an accurate reflection of their experiences and the information provided was rich in detail and highly relevant to the research topic. The four participants included in the final write up all produced interviews of a similar depth and quality of detail. Table 5.1 provides a summary of the interview duration times for each participant, along with the additional individual family members who participated.

Table 5.1: Interview duration times

PARTICIPANT NUMBER	INTERVIEW 1	INTERVIEW 2	INTERVIEW 3	TOTAL INTERVIEW TIME	FAMILY MEMBER	INTERVIEW TIME
1	7 mins 57s	13 mins 11s	5 mins 25s	26 mins 33s	Father	40 mins 56s
2	4 mins 50s	7 mins 21s	4 mins 34s	16 mins 45s	Mother	37 mins 13s
3	3 mins 7s	4 mins 54s	3 mins 26s	11 mins 27s	Father	40 mins 46s
4	5 mins 57s	13 mins 9s	5 mins 59s	25 mins 5s	Sister	26 mins 45s

5.4.2 Journal of field notes

The researcher maintained a highly detailed written journal throughout the period of field work (see Appendix 4). The participants were visited two or three times per week in a variety of music-related environments. Observations included:

1) Daily MMP music sessions – the participants attended once or twice per week at their regular venue. These gave a clear indication of what the participants experienced on an ongoing basis. Typical behaviours reported included, for example: settling down at the start of the session; volunteering for tasks; helping others; interacting with friends; participation within the class and focus/engagement levels.

2) Workshops – helping establish new MMP groups around the country, for example, Liverpool and the Royal College of Music (see Photograph 10). These have become quite a regular event with an increasingly high demand for visits from the MMP students and staff.

These provided an ideal opportunity to witness the participants in a new environment that was unfamiliar to them. Typical behaviours reported included, for example: the journey to and from the venue; setting up on arrival; interacting with unknown people; performing and encouraging others to participate.

Photograph 10: Attending a recent workshop held at the Royal College of Music (Photograph taken by author)

3) Local concerts – within the immediate geographical area such as at local mainstream schools or nursing homes for the elderly. These are both for educational purposes and entertainment. Typical behaviours reported included, for example: the performance itself; interacting with the public; and preparing and tidying the performance space (see Photographs 11 and 12)

Photographs 11 and 12: Smaller-scale MMP UK performances (Photographs taken by author)

4) Fund raising concerts – a couple of times each year the MMP students and staff organise fund raising events where students and staff perform together in a joint concert. These give the participants the opportunity to talk with the public about their charity and to perform alongside the staff. Typical behaviours reported included, for example: public speaking; performing and serving the public.

5) External social events – for example, performances at birthday parties, weddings and funerals. Opportunities sometimes arise to perform at social or personal events. For example, at a recent funeral of a fellow MMP student, the participants gave a highly sensitive performance of a requested song, demonstrating empathy and respect.

6) Christmas concerts – these are quite significant events (usually c400+ in the audience) and are held in large churches on two consecutive evenings at the end of the winter term. These are joyous events with audience participation. Typical behaviours reported included, for

example: interacting with the audience; helping others; performance and ability to cope in a busy environment.

7) Significant events – MMP students often attend and perform at major national events such as the London marathon and the Royal Mencap Christmas service held at the Barbican centre. These can be quite a challenge due to crowds, limited space etc. so provided the opportunity to observe the participants in a stressful and unfamiliar situation.

8) The 'Music is Magic' show at the London Palladium (2017) – MMP students perform at a major London theatre on a bi-annual basis (the most recent of these events took place during April 2019 - DVD available). These are the most significant event of the MMP year and demand a lot from the students. Years are spent in preparation and the day itself is very long and exhausting for everybody. Typical behaviours reported included, for example: emotional responses; ability to remain focussed; stamina; consideration of others; performance in a London theatre and ability to manage in a highly stressful environment.

For all observations, the researcher used three main approaches to recording data:

1) Participants were observed for set periods of time, usually fifteen minute blocks throughout the day, where a running commentary of behaviour was written down and photographed where appropriate.

2) Participants were observed when interesting behaviours were seen outside of these set periods of time, and this behaviour was written down and photographed where appropriate.

3) Participants were observed at particular events, for example performances, where a running commentary of behaviour was recorded as appropriate for the event. For example, performances were videoed and/or photographed.

5.4.3 Video/photographic documents

During the period of fieldwork the researcher also maintained a detailed photographic diary of events. Photographs were taken at all of the above reported events to provide additional visual/audio documents to support to the findings. Video recordings were also used and detailed DVDs (mentioned above) are available of both the 2015 and 2017 'Music is Magic' shows held at the London Palladium.

5.5 PARTICIPANTS

Six participants originally consented to take part in this case study. One participant (P6, female) withdrew at the start for personal and health reasons, leaving five individuals to be included for data collection. After careful consideration it was decided to exclude P5 (female) from the final write up. It was felt that the interview with her support staff was not of the same depth and quality as the other four participants - who all have a close supportive family network. P5 does not have any immediate family and has little or no contact with her extended family members, and for this reason the interview had to take place with the support worker on duty on that particular day. Although they claimed to have known and worked with P5 for a number of years, they did not provide a level of understanding of her needs comparable to the family members of the other participants. This was unfortunate but the researcher felt this would not provide an accurate representation of the individual concerned and thus this participant was omitted from the final analysis. It should be noted that no data were collected for this participant and the decision to remove P5 was made early on at the outset of the study. Therefore, four participants (3 males/1 female) of varied ages (26-54 years) and with differing levels of cognitive functioning, were included in the final analysis.

These four participants were selected keeping the following points in mind:

1. Established MMP attendees – to provide an insight into the long-term aspects of being part of this community.

2. Age – varied ages so as not to exclude a particular age range.

3. Cognitive functioning – varied levels of cognitive ability to provide the broadest picture.

4. Geographical location – for ease of researcher contact with participant and family members.

5. Family support – to provide differing perspectives in addition to the participant.

Due to the withdrawal and omission of two female participants, this sample was not gender-balanced.

There are some health-related conditions associated with Down's syndrome to acknowledge but these were not reported as having a significant detrimental impact on quality of life of any of the participants during the period of study. One of the participants (P3) is known to have the mosaic form of DS although it is unknown what type of DS the other participants have. Table 5.2 provides a summary of the participants' personal details, and each participant is then introduced in more detail.

Table 5.2: Personal details of Study 1 participants

PARTICIPANT NUMBER	GENDER	AGE	*MAJOR HEALTH CONCERNS	LIVING ARRANGEMENTS
1	Male	26	Congenital heart defect	With father and stepmother
2	Female	30	Congenital heart defect; Hypothyroidism	With adoptive mother and foster baby
3	Male	27	Mild irritable bowel syndrome	With father
4	Male	54	Memory impairment (dementia)	Supported living (flat)

* See Chapter 3, Table 3.1

5.5.1. Participant 1

Background – Male; age 26.

P1 was born in Essex and still lives there today. He lives with his father who is very supportive and is the youngest of three siblings (update: sadly the father of P1 passed away unexpectedly in December 2020). His two sisters are considerably older than him (44 and 43 years) and he has a step-mother (although not actually married to his father) who lives across the road and with whom he has a very close relationship. He has a small hole in his heart which causes no problems and he has no other significant health issues. P1 presents as a

happy and helpful young man who enjoys life and goes out of his was to help others. He is quiet and thoughtful and appears confident in his approach to life.

5.5.2. Participant 2

Background – Female; age 30.

P2 was born in Essex and was put up for adoption at birth, as her biological mother did not feel that she could cope with the challenges of raising a disabled child. She was fostered from birth by a family who then went on to adopt her permanently at around 12 months of age. She has no real contact with her biological family, although her maternal grandmother has kept in touch to a certain degree. P2's adoptive father died from cancer when she was 10 years old and her mother said she coped well with this and indeed kept the rest of the family in a positive frame of mind. She lives with her adoptive mother and a regular stream of new-born foster babies waiting for adoption (around 40 babies in the last 30 years). She also has an adoptive brother and sister (adult biological children of her adoptive mother) who live nearby with their families, with whom she spends much time. P2 had major heart surgery at the age of 11 which was highly successful – a contentious issue as the medical team had been reluctant to operate previously as they felt it unlikely she would survive past childhood. She still has regular check-ups with her cardiologist and also has an underactive thyroid gland for which she takes Thyroxin medication. P2 is a very happy and confident young lady who certainly lives life to the full and will happily tell you how much she loves her life.

5.5.3. Participant 3

Background – Male; age 27.

P3 was born in Essex and still lives there today. He lives with his father - his mother passed away from cancer a couple of years previously. His father has since taken early retirement to be able to take over his son's full time care, as this was a role that the mother had largely fulfilled until her passing. P3 is the younger of two brothers and he has a good relationship both with his father and brother. He suffers from IBS (irritable bowel syndrome) from time to time and has no other significant health issues. P3 presents as a cheerful and cheeky young man who likes to make people laugh. The death of his mother has had a profound effect on the whole family and particularly the confidence of P3. After a lengthy period of depression, recovery seems to be happening - largely due to the immense dedication of P3's father.

5.5.4. Participant 4

Background – Male; age 54.

P4 was born in London and now lives in Essex. He lives in supported living accommodation with the help of support staff, which enables him to live a semi-independent life. Both parents have passed away some time ago and P4 is the youngest of four siblings. One of his brothers died in his twenties from cancer, another brother also has LDs (but not DS) and the oldest is his sister, with whom he has a very close bond. P4 has no health issues but according to his sister she feels that his memory is beginning to deteriorate (P4 has since been diagnosed with dementia). He is a quiet man who always has a smile on his face. He clearly enjoys life and is a keen football supporter.

5.6 ANALYSIS

5.6.1 Interpretative Phenomenological Analysis

The data were analysed using Interpretative Phenomenological Analysis (IPA), which is a detailed investigation into how individuals make sense of their social and personal world. It aims to understand experiences from the point of view of the participants themselves – to take on their perspective. It has an idiographic focus which aims to provide an insight into what particular experiences or events mean for the participants. The approach is phenomenological which allows a detailed examination into the lived experiences of the individual (Smith (Ed.), 2008). This interpretative approach has strong links with hermeneutics – the theory and methodology of text interpretation. This needs careful consideration as IPA involves not only the interpretation by the participants of their world, but also of the researcher trying to interpret that participant's perception through their own particular lens (Smith (Ed.), 2008). The interviews, field notes and photographic/video evidence were analysed using this approach through the following seven stages:

1. Initial transcription of audio recordings of interviews, reading of field notes and organisation of photographic evidence.

2. Thorough reading and re-reading of transcribed interviews, field notes and photographic evidence.

3. Points of interest were noted and underlined for each participant.

4. Emerging sub-sub themes were recorded for each participant – grouped from the above points of interest.

5. Emerging sub-themes were recorded for each participant – grouped from the above sub-sub-themes.

6. Emerging themes were identified from the sub-themes for each participant, presented in terms of a table of themes (see Appendix 5).

7. Finally, individual tables were combined into one final table of overarching themes across the four participants (see Table 5.3).

Table 5.3: Summary table for case study participants

*OVERARCHING THEMES	**SUB-THEME	***SUB-SUB-THEME
1. POSITIVE EMOTIONS (5.7.1)	1.1 Pleasure providing (5.7.1.1)	*Enjoyment* *Positive experience*
	1.2 Sense of anticipation (5.7.1.2)	*Looking forward/forward planning* *Anticipating performances and concerts*
	1.3 Emotion management and support (5.7.1.3)	*Emotional expression and support* *Positive attitude of staff*
2. EDUCATIONAL DEVELOPMENT (5.7.2)	2.1 Learning through music (5.7.2.1)	*Musical education* *Role modelling* *Additional learning opportunities*
	2.2 Focus development (5.7.2.2)	*Concentration encouragement*
	2.3 Social development (5.7.2.3)	*Friendships* *Relationships with staff* *Social skill development* *Social activities and opportunities*
3. MEANING (5.7.3)	3.1 Significant to life (5.7.3.1)	*Importance of MMP* *Life changing experiences and opportunities*
	3.2 Significant to family (5.7.3.2)	*Positive impact on family* *Negative impact on family*
4. ACCOMPLISHMENT (5.7.4)	4.1 Sense of achievement (5.7.4.1)	*Satisfaction and pride* *Parental and family pride*
	4.2 Sense of self-confidence (5.7.4.2)	*Self-confidence*
	4.3 Practical support (5.7.4.3)	*Support given to MMP students* *Support given to MMP staff*

*Overarching themes: present in all 4 participants in all 3 data categories
**Sub-themes: present in all 4 participants in at least 1 data category
***Sub-sub-themes: present in at least 2 participants in at least 1 data category

5.7 RESULTS

Four overarching themes were identified: Positive Emotions; Educational Development; Meaning; and Accomplishment. These themes are closely linked with the key concepts of WB (see Chapter 2, Section 2.1.2) and music participation (see Chapter 2, Section 2.2.4). Clusters of sub-themes were noted within each overarching theme and these will be reported in turn. The themes and sub-themes are supported by verbatim quotations from each participant and notes and photographic evidence from the researcher field journal.

5.7.1

Overarching theme 1: Positive Emotions

The overarching theme of Positive Emotions was present for all four participants, across the three categories of data collection (participant interview, family interview and journal of field notes). Three related sub-themes combined to generate the overarching theme, including: (1) pleasure providing, (2) sense of anticipation, and (3) emotion management.

5.7.1.1 Pleasure providing

Pleasure is a feeling of happiness or enjoyment; the activity of doing things in order to enjoy oneself, rather than doing what has to be done. Thus this sub-theme was primarily concerned with *enjoyment* and, with relevance to the activity under investigation, a *positive experience* including a love of music and the associated pleasurable outcomes.

Enjoyment

Enjoyment concerned the participants taking pleasure from an activity they were participating in at MMP. The ability to experience enjoyment and take pleasure from things is regarded as a central feature of WB (Ryan and Deci, 2001; Seligman, 2002, 2011; NEF, 2008) and the resulting positive emotions serve to help create a fulfilling life experience. When talking with P1, the following comments demonstrated the enjoyment this activity provided for him: 'I do really love my music' and 'I just love music'. The unprompted use of the word 'love' indicated a high level of pleasure and P1's father added that his son had always enjoyed music:

He's always liked music, erm, he spends a lot of time upstairs with his headphones on listening to music and conducting to it…and in the car he has always been subjected to Radio 2…so he's had a broad background in music. (P1's father, interview)

P1 further demonstrated enjoyment both in response to direct questions and with responses of his own volition. For example, when asked to look back and think about whether he had a good day or a bad day (at MMP), he replied 'it is a brilliant day' (P1, interview). This gave a sense of the degree of pleasure received during P1's time spent at MMP. P1 had gone beyond the confines of the original question to express his level of pleasure, in that he replaced the phrase 'good day' with 'a brilliant day' of his own accord. This type of comment was typical for this participant when he was discussing his time spent at MMP. Indeed, MMP and taking part in music was a major factor in P1's life. The interview with P1's father supported this interpretation:

> That is the atmosphere that is created with all the kids. You know I go in there on a Saturday morning and stand outside and watch and everybody in that room is enjoying it. Whatever their ability level is and whatever their difficulty is. No, they are all enjoying it… (P1's father, interview)

From the perspective of the parent looking in, all those participating were experiencing pleasure at their own unique individual level. Everybody was being included and having a happy time making music.

As the interview progressed, it also became apparent that there was no perceived negativity connected to attending the music sessions. When the researcher asked about possible detrimental aspects of attending MMP and making music, the response was that 'I don't think there is any downside to it…no…none at all.' (P1's father, interview). P1 himself also reported that there was nothing at all that he did not like about MMP, including the activities, the other students and the staff. P1 explained how he very much enjoyed being part of the

MMP group. When asked what it felt like to be part of the group he replied: 'I would say fantastic, yes I love what it's done so far' (P1, interview).

Further evidence to support these comments were plentiful in the field notes. P1 was an enthusiastic person and his enthusiasm was passed on to those around him. He very much enjoyed dancing and the physical aspects of music participation were important to him (see Photograph 13).

Photograph 13: P1 enjoying participating in the actions (P2 in the background)

P1 chatted about his love of conducting and how this had become something that was very special for him and provided him with a great deal of enjoyment. He regularly conducted at concerts and this was a role that he had really developed for himself (see Photographs 14 - 17).

Photographs 14 - 17: P1 enjoying conducting during rehearsals for the London Palladium

He frequently said how much he 'loves' doing this and his father also mentioned how much pleasure this provided to his son. P1's conducting skills had transferred to outside of the immediate MMP realm. For example, at a recent staff birthday celebration he was invited to come up and conduct the professional band for a couple of items. This was a real highlight for P1 and something that clearly provided him with a great deal of pleasure and enjoyment – evidenced through smiles and laughter - just as such an opportunity would for any aspiring young conductor (see Photograph 18).

Photograph 18: P1 conducting a professional band

Moving to P2, this participant spent much of her time (up to 20 hours per week) and energy engaged in musically-based pursuits at MMP. P2's love of music was clear to see in the observations and she was often observed tapping along to the beat or clapping her hands. She was an enthusiastic participator and frequently mentioned how much she 'loved doing music' (see Photograph 19).

Photograph 19: P2 enthusiastically joining in the weekly MMP session

P2 was a chatty young lady who was keen to talk about her time spent at MMP. When asked about why she came along she replied 'I love it Music Man', she also told me she had a favourite song ('Note by Note') and that she kept coming back because she enjoyed being there so much: 'I like Music Man the best…I enjoyed it…Music Man is brilliant.' (P2, interview). This participant, similar to P1, expressed her enjoyment at MMP with the use of the word 'love' – demonstrating her high level of pleasure. She also commented on how MMP was her favourite activity. This was supported by P2's mother, in that she also made enthusiastic comments similar to those of her daughter:

> We went on a Friday, which is the day she had free and she loved it…she loves the
> environment…it's such a happy place. She loves it and I would know…she would love to
> do another day. (P2's mother, interview)

Field notes provided further support for evidence of the enjoyment experienced by P2 at MMP. She participated eagerly in the activities and always had a smile on her face. Her

excitement at being there was apparent with lots of 'fist pumping' and smiles (see Photographs 20 and 21).

Photographs 20 and 21: P2 'fist pumping' and looking happy at her MMP weekly session

At times P2 appeared to be almost euphoric and completely absorbed in the moment. This could be viewed as this individual's equivalent of being in 'the zone' - or 'a state of flow' (Csikszentmihalyi, 1990). This was an encouraging observation, as this participant was sharing a similar emotional experience as any musician without an LD might in a similar situation (see Photograph 22). During her time at MMP, P2 had developed into a natural and competent performer who enjoyed the sharing of her talents with others.

Photograph 22: P2 in 'a state of flow' (Csikszentmihalyi, 1990)

P2 also found that her musical talents had spread out into the 'real world', similar to the experiences of P1. She too found herself with many performing opportunities at various locations during the year of field study. One such event was at a public charity concert where she gave a performance to a large audience, who were supportive and were visibly moved by her musical talent (see Photograph 23). P2 mentioned how she felt 'very, very happy' after her performance and she had particularly enjoyed people talking to her afterwards about her singing.

Photograph 23: P2 performing at a charity concert in the public realm

For as long as his family could remember, P3 had 'loved' anything to do with music. P3 also confirmed that he 'really loved' music and indeed anything related to it. It was therefore not surprising that P3 enjoyed participating in musical activities at MMP, and his father specifically mentioned on several occasions that his son had a real passion for music:

He's always loved music. He's got, he must have between 100 -150 CDs, varying types of music. Music has always been a passion with him and his brother…he'd see a film (Disney) and he'd want the Disney CD. It was just about the music…he's always been, you know, really interested in music. Always wanted to pretend to play a guitar. (P3's father, interview)

However, since the death of his mother a couple of years ago, P3 had struggled to find pleasure in life. His father said that his son had been through a lengthy period of depression

but was now finally getting back to being himself. P3's father felt that this love of music was what kept his son's motivation going to attend MMP. He described it as a perfect environment for his son to thrive in, by doing something that was very special to him.

When P3 was asked why he came to MMP he said that it was 'really good' and that he was 'staying for good'. Similar to P1 and P2, P3 said he 'loved' music, and his enjoyment was apparent and his enthusiasm came through clearly in our conversation - this was a place where he found pleasure. This was also shown by him telling me that it made him feel 'happy…just happy' (see Photographs 24 and 25).

Photographs 24 and 25: A very happy P3!

The researcher spent a day with P3 visiting a local nursing home, where a few of the MMP students gave a performance to the elderly residents. The journey to and from the venue was travelled together in the minibus and this gave plenty of opportunity to talk in a natural (non-interview) situation. The following journal extract gave an insight into the visit:

Concert at Nazareth House on 14th March, 2017. This is the first trip out in 'Ludwig' minibus. Sat in front seat next to P3 for the journey. He is very excited about both the concert and the new minibus. P3 kept singing 'We wish you a merry Christmas.' When asked why he replied: "I am so happy it feels like Christmas today!"…For the return journey P3 and the researcher sat together again and it wasn't long before 'We wish you a merry Christmas' started up again! (Field notes, 14th March 2017, Photograph 26)

Photograph 26: P3 performing at a local nursing home

P3's pleasure and his level of joy at that moment following performance were evident

through his smile and animated appreciation of the applause. Enjoyment was being

experienced on so many levels for P3, for example, the journey, the performance, the new

minibus, etc. (see Photograph 27). These type of opportunities, created by being part of the

MMP community, appeared to provide pleasure and enjoyment to all who were involved –

the students themselves (and their families and supporters), the staff and the audience.

Photograph 27: P3 (and P1) on tour in the new minibus (both on the left)

P3 was a keen performer and again like the other participants, seemed to enjoy all

performance opportunities, from the smaller events like the one mentioned above, to the

larger and more prestigious events at London venues. He became very excited beforehand

and he said he could feel quite nervous – particularly before the London Palladium show

which was his first major performance with MMP. A feeling of immense happiness followed

his performances, described by P3's father:

He's suddenly gone from not wanting to get on stage to now he wants to be on there. He

wants, he loves it when people applaud…but he just really enjoys it. He's really up for it,

he gets so nervous beforehand and then afterwards he just doesn't stop talking about it

until he falls asleep in the car. (P3's father, interview)

These performances clearly provided P3 with much enjoyment and created a family

opportunity to spend pleasurable time together. In fact these events were talked about for

many months after and gave the performers happy memories to cherish. Field notes

confirmed P3 to be an enthusiastic performer who was always keen to volunteer when

required, for example, for solo roles or to help others (see Photograph 28).

Photograph 28: P3 performing at a smaller venue (second from left)

Finally, P4 was considerably older than the other three participants and was therefore at a

different life stage. His mobility was slightly restricted and he could be nervous of stairs and

falling. As a result of his advancing age, P4 did not have the advantage that the other three

participants had of living with parents who fully supported their MMP activities (both parents

have long since passed away). However, his sister was very committed to caring for him and she and her husband did everything they logistically could whilst both were still working in full-time employment. When talking to P4 concerning how he felt about going to MMP, he replied 'I glad I go to Music Man' and he spoke of how he 'really' enjoyed the songs in particular. He also very much enjoyed it when visiting musicians came to share their musical talents with the group, where he readily joined in and was keen to show off his own musical abilities (see Photograph 29).

Photograph 29: P4 enjoying performing and spending time with a local visiting musician

Corresponding to the previous three participants and their love of music, P4's love of music was not difficult to see. P4's sister talked about her brother's pleasure at participating in music and how much he enjoyed music: 'He just, he just loves it! There is nothing else you could, I don't think [he's] got anything else in his life that excites him more than the Music Man' (P4's sister, interview). The level of enjoyment experienced by P4 was clearly facilitated by his 'love' of music – this was an activity that suited his personal interests and abilities well. P4 enjoyed the songs and was very happy to perform them - he also added that

he liked to practise singing the songs when he was in the shower! An interesting point

emerged when P4 was asked what he particularly liked so much about the music and the

songs at MMP. He replied that he liked them so much because 'I know the actions'. It

would appear that his familiarity with the MMP repertoire added to his pleasure. There can

be comfort in doing activities that you feel confident about, without any fear of the unknown

or making mistakes.

Summary: Enjoyment

All four participants found participating in music provided *enjoyment* for them in one
form or another. This was unique and different for each participant and their musical
outcomes were a reflection of their individual experiences including age, character,
personal preferences and previous musical exposure. For example, P1 enjoyed
performing (particularly conducting) and being part of the MMP community while P2
commented how MMP was her favourite activity. P3 enjoyed 'anything to do with music'
and since joining MMP had been able to find enjoyment again after the passing of his
mother. P4 appeared to find some comfort in his familiarity with the MMP repertoire.
Being able to find enjoyment in life is central to WB and this was reported by all
participants and further supported by reports from their families and the field notes.

Positive experience

Positive experience related to the participants demonstrating how being part of MMP was a

positive (rather than neutral or negative) feature in their lives. P1 appeared relaxed whilst he

was at MMP and often went out of his way to help others experience the same. On the rare

occasions P1 was unsettled at MMP, it was usually because something had happened prior to

him coming, which had upset him. He willingly talked with the staff about issues that were

bothering him. Any problems were usually quickly resolved and then forgotten once the

session began, and he became involved in what was happening. This environment appeared

to provide a level of support way beyond the music making alone and it supported the participants in a variety of ways (see Section 5.7.1.3). During one of the visits to the weekly group, the researcher noted: 'This (MMP) is clearly a place that P1 loves and where he feels very much at home' (Field notes, 7th July, 2017).

Moreover, both P2 and her mother mentioned how MMP was a very positive experience with no associated negativity for either of them. P2 told me there was nothing that she did not like about MMP, illustrated in the following interview extract:

Researcher: 'Is there anything you don't like about it?'
P2: 'I like it here'.
Researcher: 'So is there nothing you don't like?
P2: 'No, no, no'. (P2, interview)

P2's mother reiterated the point:

> It's nothing negative at all, everything's positive…when you've got Down's syndrome and learning difficulties, life could be such a struggle, such a struggle. But her life isn't because of all this input and the different people, her life is not a struggle. Because they make it like it is so therefore she loves her life and I thank them for that. (P2's mother, interview)

P2's mother was clearly of the opinion that attending MMP and all it had to offer had had a major positive effect on her daughter. She felt that without it her life would not be 'anywhere near as enjoyable' – in fact she commented that during the long summer break she can actually see a regression taking place in her daughter's mood and general behaviour:

In the summer holidays there is nothing much going on…no Music Man. She might

watch the same video five times! And I went 'you're not having 'Oliver' on again!' 'But

I like it!' And when you look at her she will sit and she will go (demonstrates face) and

she goes into that, tongues out. (P2's mother, interview)

From these comments it was clear that MMP was certainly missed during the holiday period

and this had a detrimental effect on the WB of P2. P2's mother also felt that MMP offered

more than her daughters' other activities, with far more opportunities arising as a result:

There are opportunities that are in there, so with no Music Man she wouldn't be doing

that. Hadleigh [a day centre for adults with LDs] is a different kettle of fish. She goes to

Hadleigh three days a week, it's completely different. Drama is completely different.

Erm, but Music Man is so positive. (P2's mother, interview)

This finding was also evident for P3. During an interview, the researcher asked about any

negative aspects of attending MMP and music making. P3 replied: 'I love, I love all of it.'

(P3, interview). P3 said there was nothing at all that he did not like about MMP and his

father also described how there were no apparent detrimental aspects:

I can't think of any negative aspects, none at all. They all just love it so much and they

talk about it afterwards…so I picked him up from Hadleigh, from their Christmas carols

and I took them for a bite to eat on the way and, erm, him and D just talked nothing else

but Music Man. All the time.' (P3's father, interview)

The fact that MMP was being talked about outside of the actual sessions demonstrated that it

was having a significant impact on P3's wider life. A lack of negative aspects would further

suggest that it was providing a positive experience for P3 as well as for his father.

Finally, field notes for P4 recorded a positive individual who seemed to be very settled in the MMP environment and it was evident he wanted to be there and this was his choice. He spent much of his time smiling and laughing – particularly during the African drumming games where he always led the pulse. He was often seen sitting in the group tapping along to the beat on either his knee or arm. Although P4 was slightly more reserved and less physically able than the other three participants, this did not distract from his own positive experience and this was a place where he appeared to be contented. His weekly attendance to both the Friday group and Saturday music school were the 'highlights of his week' according to his sister, and could therefore be viewed to be a positive contributing factor to his level of WB.

Summary: Positive experience

The participants all shared a common *positive experience* at MMP in their own unique way and this was supported with accounts received from both them and their families. A lack of any negativity associated with this music participation was also described. For example, P2 shared how she liked everything about being at MMP, and the father of P3 mentioned how there were not any negative aspects of attending the group for his son. The individual positive experiences taking place at MMP could help to shape fulfilling lives for these participants and this appeared to be an encouraging environment in which to achieve this.

5.7.1.2 Sense of anticipation

Arguably anything that provides a feeling of enjoyment also has the potential to create a positive sense of anticipation – a looking forward to attending or participating in whatever is associated with the subsequent pleasurable outcome. This sub-theme concerned any aspect of music participation that created this feeling of optimistic expectation.

Looking forward/forward planning

Looking forward/forward planning was concerned with the participants having something to look forward to and/or the associated forward planning associated with this. The weekly attendance at MMP provided a goal for these participants and added considerably to their life experiences through the provision of a shared enjoyable time spent together. When P1 was asked whether he looked forward (or not) to attending his music classes, he replied that he did 'very much' and that it made him feel excited and happy, particularly on the morning before he came along. He added that he looked forward to seeing his friends and the teachers. During the music session, P1 also talked about how much he looked forward to visiting other MMP centres. P1 was a MMP student ambassador and was always very happy to talk about this and which particular roles he was responsible for as an ambassador. One of the main roles that student ambassadors undertake is visiting other MMP groups in different regions. Usually around six ambassadors will go along, with two or three members of staff. This could be either to support existing groups in their learning and preparation for forthcoming performances, or to help new groups become established at their outset. The latter role is far more challenging, as the new students can be reluctant to participate and their staff are also being trained simultaneously. P1 frequently attended these events, where his enthusiasm quickly helped new students to relax and take an active part in the workshop (see Photographs 30 and 31).

Photograph 30: P1 (far left) visiting a new group in Scotland (P2 third from right in front row, P3 front right on floor)

Photograph 31: P1 spending his birthday on tour to Liverpool with MMP

P1 talked about how much he anticipated attending these new groups and was very excited about the following day when another visit was scheduled to take place. P1 was keen to help this centre (MMP Sussex) to practise the London Palladium show repertoire - this was going to be their first major MMP performance. His enthusiasm was obvious to see and his anticipation was demonstrated through his animated body language and non-stop talking.

This was something that P1 looked forward to and he gave it much thought before the event, planning what might be required of him on the day and working this through in his mind so he could give of his best to the task. He seemed to enjoy planning ahead and this was a skill that he had certainly developed further through his role as an MMP ambassador. The ability to plan ahead is a useful transferable skill which will arguably help to support him throughout his adult life.

The father of P1 gave an insight into how much his son keenly anticipated his attendance at MMP. This was through his careful forward planning and ensuring that he was completely organised the night prior to the session: 'He gets everything ready the night before, doesn't he, and in the car early if he's going in the car, and at the bottom of the stairs when he's ready to go on the bus' (P1's father, interview). This demonstrated a good deal of foreplaning for P1. It would seem unlikely that he would commit this amount of effort and organisation to anything that he was not particularly looking forward to participating in. P1's father commented that he felt that attending MMP on a regular basis had helped his son to develop this level of organisational ability, and that this was also helping him to be more organised in other areas of his life. He felt this was a very important step for his son, and was encouraging him to mature into an independent young adult.

A comparable sense of positive anticipation came through when interviewing P2, regarding a variety of different scenarios. These included a discussion about how she felt the morning before she came along to MMP:

Researcher: And how do you feel in the morning before you are coming…?
P2: I feel, get up, get ready, go, go, go Music Man!

Researcher: And how does that make you feel?

P2: Happy! (Energetic clapping) (P2, interview)

Through her exuberant body language it was clear that there was a positive sense of looking forward to the forthcoming day to be spent at MMP. P2's mother also made the point that her daughter frequently asked when she would next be going to MMP or performing at a concert, and that it was most certainly something that she looked forward to:

Yeah because it's something to look forward to…you are going towards something. And it goes on, 'How many days before we do, erm, the Barbican? What are we doing next then?' You know what I mean? On a Friday she so looks forward to it, it's that looking forward, that loving life, isn't it? (P2's mother, interview)

In addition, field notes indicated an excited sense of anticipation taking place during the weekly classes. P2 became noticeably excited when it was her turn to do something, for example, to sing a song on her own or to demonstrate something to the class that she had mastered. There was lots of smiling, jumping up onto her feet and a general aura of happy expectation concerning what she was about to do. This was present in a range of situations, from singing the 'Hello Song' which happened at the start of every session, right through to talking about the major events such as the London shows. The significance of the musical activity itself almost seemed irrelevant and the sense of anticipation was still present, regardless of the magnitude of the event. She seemed to look forward to any musical event that was in her diary (see Photograph 32).

Photograph 32: P2 up on her feet waiting for her turn to sing solo

This expectancy was also evident in her anticipating the restarting of the group after the six weeks summer break:

> The six week holiday she goes 'tut, oh you know, when's it?' she will say like now, she will say 'erm it's my last Music Man!' I say 'yeah I know'. She goes 'when's it back, when's it back?' And I'll tell her if I remember. So she'll say 'how many weeks is that?' And I'll tell her… I said 'it's not long'. (P2's mother, interview)

Having to plan ahead and learning how to be patient is a useful life skill to possess. MMP is a safe and supportive environment in which to experiment with these kind of skills, allowing natural development at a pace suitable for the individual.

Likewise, P3 displayed excited anticipation on several occasions throughout the period of field study. He verbally expressed how much he looked forward to coming, especially to see his best friend D. He also commented that he felt 'very happy to be coming' in the morning before he came along. While he was eating his breakfast he felt excited about the MMP session he was about to participate in. P3 rarely missed a day and he said it would upset him if he could not attend – unless he was going on holiday with his father. P3's father added to this by discussing how much his son looks forward to coming: 'It's his club, he looks forward to it so much' (P3's father, interview).

P3 (along with P1 and P2) anticipated being at MMP from the evening before. He often brought related items to music class, such as CDs or books, demonstrating good forward planning and an understanding of the activities taking place. For example, when the group were focusing on music related to science fiction and space, he brought in his Star Wars book to discuss with the other members of the group. P3's father said attending MMP was a major part of his son's week. He commented that his son was always up early before him on MMP days: 'He's up before me actually, getting the lunch ready, and gets his bag ready' (P3's father, interview). This demonstrated the skill development of forward planning for this participant too – similar to P1 and P2 in this respect. This behaviour demonstrated a similar eagerness to attend by being organised and prepared in good time.

Visiting new groups was also an activity that P3 very much looked forward to and as a student ambassador this was something he was often involved with. Both P1 and P3 frequently attended the same trips away to visit the new groups, or to provide workshops or performances. A field journal extract taken from a weekend visit away to a new MMP group

in Southampton provided a meaningful insight into the level of anticipation experienced by P3:

> P3 is so excited, sat next to SM. Telling jokes – called the driver (DS) Lewis Hamilton (5, 4, 3, 2, 1 go!). The students are listening to the 'Music is Magic' CD and P3 wants it louder, singing along. P3 can be heard laughing, making jokes, teasing and chatting happily with his friends. He asks his dad how many beers he can have tonight! One bottle – as you need to be on top form in the morning…The whole group had a lovely evening meal together, talking about tomorrow's workshop and music, music, and more music! (Field notes, 3rd February 2017)

P3's father reported that his son looked forward to these weekends away for several weeks beforehand – and he too also looked forward to them very much. It enabled him to spend time with his son doing something that they both felt passionate about. He explained how important he thought it was to spread MMP to new centres so 'they can experience similar things to what had been happening back at home in Essex' (P3's father, interview). He thought his son also understood this and this was one of the reasons he liked going away on these trips. P3's father said how these trips were also something he had to plan ahead for – he had responsibility for maintaining the minibus. This was a role he enjoyed and he felt that he was giving something back to MMP. Both P3 and his father had a positive sense of anticipation in relation to spending time away with MMP, which came across strongly in both of their interviews and the field notes. For different reasons, they looked forward to different aspects of the group and the combined result was a positive life outcome for this family (see Photograph 33).

Photograph 33: P3 (on right, and P2 in front) on one of the much anticipated trips away with MMP tutor (Jenny Hitchcock)

P4 talked about how much he looked forward to Fridays when he knew he would be coming to MMP – and then his attendance at music school which followed on the Saturday morning. A strong routine was important for P4 as he liked to know what he was doing each day and where he would be travelling to. This provided him with a sense of comfort and considerably reduced his anxiety level. MMP had been a part of P4's routine for roughly ten years. P4's sister definitely felt that it was something that her brother looked forward to – particularly playing the instruments and meeting up with his friends:

> It just gives him, it just gives him something at the end of the week to look forward to if
> he's not done anything during the week. Because it's on a Friday as well, he's got the
> Friday and the Saturday. He's very stuck in his ways, P4, he can only do certain things
> during the day…he can only do one thing a day. So Monday is his going to get his money.
> Tuesday he goes bowling with some of them, erm, Wednesday evening he does the drama.

Thursday he goes to 'The Hub' – but Friday is his main one…yeah, he's there all day.

(P4's sister, interview)

P4's sister also mentioned that he really did not like to miss a session – even if he was under the weather.

Field notes suggested that P4 had developed a good level of forward planning and thinking ahead. This was apparent in his organisational skills and his ability to plan effectively during lessons:

P4 notices that his African drum is missing at the start of the afternoon session and realises that he will need it for the next song. He is thinking ahead about what he will need before it gets to the point where he actually needs it and would therefore miss his part. This shows that P4 has not only good observational skills but is also able to forward plan with regards to what is happening at that point in the class. Being part of the music group would appear to encourage the development and maintenance of these type of important life skills. (Field notes, 26th May, 2017)

P4's ability to think ahead and plan was a useful transferable skill that could be adapted to a variety of different situations and could help him to maintain his semi-independent lifestyle.

Two of the families discussed thinking forwards about future employment opportunities for their sons and this was something that worried them. P1's father remarked on how MMP had inspired his son in terms of his career ambitions. He indicated that his son often chatted about how much he would like a job that involved music in some way. P1 had undertaken a considerable amount of work experience at local theatres and their staff had seemed to be

very pleased with how he had fitted in there, and how hard he had worked. The entire family had been hopeful that this might have led to a part-time job for P1 at the theatre (unfortunately that had not been the case to date):

> Oh yeah definitely, he did some work experience at erm, what was it, Willkie's to start with wasn't it? And then he also did some work experience at the Cliff's Pavilion and err, what was the other one? (Palace Theatre) Erm, and I think he was hoping that they would have a few hours for him at Christmas but as yet nothings err…but he would of loved to of done that as a job…you know that's the sort of thing, 'cos its music again you see, you know. It's all part of it. (P1's father, interview)

On the one hand it had clearly been a big disappointment that a Christmas work position had not been offered to P1, but they still seemed to feel enthused that this was potentially an area that their son could find future employment. They felt that being part of MMP had helped P1 to generate these kind of career plans and had provided him with a positive sense of looking forward to the future, and what this might bring through his developing musical abilities and increasing confidence.

Akin to P1, P3 also talked about how he would like to work at MMP, in particular with David Stanley: 'I'm looking for work, looking for work. I'd really love to work with David (Stanley)' (P3, interview). Although P3 had not yet had any opportunities to work in this area, it was something that was on his mind and had given him an incentive to commit to working hard. It was interesting to recognise how both of these young men wanted to work within a musical environment, signifying an area of work in which they would feel confident and valued as adults within the community.

Moving away from discussing the acquisition of life skills associated with forward planning and organisational abilities, this section now focuses more on the encouragement of independent decision making about personal life choices. The fact that the participants were keen to continue participating in their music sessions was an indication of their positive anticipation of their wanting to attend on a regular ongoing basis. All of the participants had a degree of control over the activities they attended and they clearly expressed how much they wanted to attend the MMP sessions and had made up their own minds about doing so. None were being taken there on somebody else's decision. The father of P1 discussed how much his son wanted to attend the sessions and explained that he could never envisage him not being a part of the group:

> You know, erm, and I don't, obviously I don't see him waking up on a Saturday morning and saying I ain't going today…I don't think he would ask to have a day off from there, put it that way. (P1's father, interview)

P2's mother discussed how her daughter was always keen to attend MMP and how she became excited and looked forward to going. She expressed her deep gratitude for having this facility nearby:

> She never gets in the car unhappy, never, never says I don't want to go. Nothing just, just pure joy. She just, every day I think she finds quite joyous. So, very lucky to live near, and we do, to have the things we've got. (P2's mother, interview)

P3 had himself decided to start attending MMP and this was a decision that he told me he was very happy about. P3's father said that his son was so keen to attend that he was up early on

the days he went to MMP. P3's father also noted how much his son missed MMP during the summer break and how he was very keen to get back to the group (very similar to P2):

In fact he doesn't like the six weeks in the summer…He really, he really can't wait, 'oh is it next week?' I said 'no it's another two weeks to go'. 'Oh!' Then he puts it up on the calendar. (P3's father, interview)

During the interview P4 often commented that he 'really wanted to come' to music group and he talked about it frequently with his family and support staff. When asked what his motivation was for keeping on coming back each week, he simply replied: 'I want to…I'm coming every Friday' (P4, interview). P4 would certainly not attend something he did not look forward to, or did not want to be a part of. He had a fair degree of independence and travelled to the sessions on his own on public transport. P4's sister further confirmed this and said she would really like him to be able to attend more frequently than he did: 'If he had the money, I would make sure he went twice a week. Yeah, yeah but he just hasn't got it, but he would. He would love to do that' (P4's sister, interview).

It was disappointing that a lack of funds had a direct negative impact on the life experiences of P4 - but this is very much a reality for people with LDs, with an ever decreasing supply of funds available (Mencap, 2018). P4's sister also expressed her slight frustration regarding her lack of time to be able to take her brother to more events. She felt that he was missing out due to her having to work full time and not being as available as some of the parents of the younger students. However, she did make the point that P4 and his entire family very much looked forward to the bigger shows like the London Palladium and that these were an exciting experience for all of them to be involved in together.

P4 spent his birthday at MMP and organised doughnuts for the entire group. This thoughtful act was a good example of his forward planning skills, typical of this participant's behaviour at MMP (see Photographs 34 and 35).

Photographs 34 and 35: P4 celebrating his birthday at MMP with the 'birthday hat'

Summary: Looking forward/forward planning

MMP provided the participants with something to look forward to and to plan ahead for. Each participant had made up their own mind about why they wanted to attend MMP and expressed how they wanted to keep on doing so. The shared goal of music-making was an activity that created a positive sense of anticipation. For example, P1 described that he 'very much' looked forward to coming to MMP and how he looked forward to the workshops at new centres. P2's mother mentioned how her daughter frequently asked when she would next be attending MMP. P3 looked forward to weekends away with MMP which he shared with his father, and this enabled him to plan ahead for these visits. P4 talked about how he looked forward to Fridays when he knew he would be coming to MMP and explained 'I want to…I'm coming every Friday'. Two participants were also planning ahead in terms of career choices as a result of their musical involvement.

Anticipating performances and concerts

In this context*, anticipating performances and concerts* was concerned with the unique sense of anticipation created through these key events and the subsequent impact that this had on the participants and their families. The MMP ethos values performance as part of its music education programme. MMP performances are much anticipated events and the majority of students participate in one way or another – some may prefer the smaller in-house type of concert, while others relish the excitement and challenge of the larger events. These four participants were experienced and regular performers. P1 said he was very excited about the forthcoming show at the Royal Albert Hall: 'There's a big show coming up in 2019. It's the Royal Albert Hall…to build up, yes, as my skills go, very important' (P1, interview).

P2, and indeed her entire family, found performance of any sort something that was greatly anticipated. P2 told me she was very much looking forward to the London Palladium show and we also talked about the Christmas concerts that had taken place recently. When questioned about these events it became apparent that they not only provided a forward goal for P2, but they also gave her the opportunity to be able to plan ahead and learn to manage her excitement for the event. Her mother's comments also described how she counted down the days before a big concert. P2 had to learn to control her excitement and had thus inevitably acquired a degree of patience:

So I have to contain her a bit. She's so, only four more, four more days and we'll be at the Palladium. It's that anticipation you know, and that, and she goes 'where will you be sitting, where will you lot be?' And I have to name who's coming to see her. (P2's mother, interview)

P3 also talked about how he looked forward to the concerts. He said having performances to look forward to made him feel very excited and happy. He 'loved' being part of the London Palladium show, which was his first major performance. P3's father said he was already talking a lot about the Royal Albert Hall show. This was evident during a recent 'creating to music' time when P3 composed a song about the forthcoming Royal Albert Hall event (see Photograph 36):

You know…he knows that well I've done the Palladium you know. He's now thinking about the Albert Hall. I said no it's 18 months away! He can see in advance that there is something coming…It's something to look forward to. (P3's father, interview)

Photograph 36: P3's narrative about the Royal Albert Hall show

For P4, the large-scale performances were a significant source of excitement (see Photograph 37) and were looked forward to by his entire family, particularly the London concerts. P4's sister explained how her brother really benefitted from having this type of aim to focus on:

'When he does the concerts, Christmas concerts and the shows, it's just, yeah, that's what he works towards. He knows he is working towards that, and he knows.' (P4's sister, interview)

Photograph 37: Outside the London Palladium (with the author) for the long awaited 'Music is Magic' show (Photograph courtesy of David Stanley)

Having something positive to aim for provided a motivating sense of anticipation for P4 – a positive goal to work towards. Both P4's sister, her husband, and various other family members all helped out on show days. They worked tirelessly, including in the weeks running up to the show, and all talked about it together before the big day arrived. On show day they all travelled up to London together and it was a real family occasion.

Summary: Anticipating performances and concerts

Performances and concerts were all much anticipated by these participants and their families. They were planned and discussed for months before the event and provided a common aim which became the focus of the weekly sessions. Both past and future shows were at the centre of MMP life. For example, P1 was already planning ahead for the Royal Albert Hall show and P3 described how excited he had been after his first major performance at the London Palladium. P4's entire family were involved in the major productions and they also gained much from their involvement. The opportunity to perform is a key component of a musical education and these participants were experiencing this at the highest level.

5.7.1.3 Emotion management and support

Emotional support can be found in a variety of places including from a partner, family, friends, colleagues, peers and within different types of groups and communities. It comes in a variety of forms and is primarily concerned with reassurance and encouragement in times of need. Emotional support provides a degree of protection against the challenges of life and can help an individual to cope with any difficulties which may be encountered in day to day living (Oliver *et al.*, 2014). The MMP community emerged as a close and supportive environment which provided a variety of opportunities for the participants to learn emotion management skills. The opportunity to express emotions is central to maintaining emotional stability and a good level of mental health. The participants were able to *express emotions* in a way appropriate to their needs, and the *positive attitude of staff* enabled this.

Emotional expression and support

Emotional expression included any situation where the participant expressed emotion within the MMP environment, which was directly related to music participation. This also included

descriptions by the participants of how their musical experiences affected their mood or feelings. Emotional support forms a central part of authentic relationships where an individual feels unconditionally loved and cared for in a two-way friendship. *Grief support* referred to those incidences specifically involving the loss of a loved one, which was an important point for two participants.

At several points, P1 described how he experienced 'good' feelings during his time spent at MMP. For example, as discussed above, when the researcher questioned him about how he felt before coming to MMP, and whether he had good feelings or bad feelings about MMP, he extended his answer to 'I would say brilliant'. This indicated how positive he felt about being at MMP, which was a supportive and caring place where emotions could be shared with others. When asked about whether he thought that the music itself could help him to show how he was feeling, he replied 'I would say pretty happy' signifying that the music participation was also having a positive beneficial effect on P1's mood. Indeed, when interviewing P1's father, he discussed how his son always came home from MMP in a 'good mood'.

Field notes reported on several occasions where positive emotional behaviours were observed for P1. Care and empathy were evident, particularly when rehearsing the sensitive topic of the musical 'The Label'[6] from the 'Music is Magic' show at the London Palladium. This indicated a certain level of maturity and understanding were in place. For example, P1 closely followed the storyline of the play and this gave him the opportunity to have

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[6] 'The Label' told the story of a baby born with DS and how his mother was determined for him not to be seen as a label, but to be seen as a young child like any other.

expressive emotional experiences in safe surroundings with trusted friends. One afternoon during the summer months, P1 also demonstrated how both music and being part of the MMP community provided him with an appropriate emotional outlet for his grief regarding his grandfather. The subsequent effective support which took place was documented in a series of photographs (see Photographs 38 – 44). The following journal extract describes the situation:

Rosie Ladkin (professional soprano) visited MMP today for her first rehearsal with the students for 'The Label'. P1 absolutely transfixed throughout her singing. Ends up crying and very emotional. This clearly means so much to him and the message behind the play, the tune and lyrics are very powerful. I asked P1 why he was crying – what was he feeling? He replied 'memories'. Of what? 'Memories of my grandad. (Field notes, 14th July, 2017)

Photographs 38 – 44: Sequence highlighting emotional expression and support of P1

P1 used his emotional experience of the song to express his personal emotions regarding the loss of his grandfather. He seemed to find support for his grief from the music. His peers offered him comfort and as can be seen in the photographs, within a couple of minutes he looked very relaxed and contented again. It was as if a kind of emotional release had taken place. He was perfectly happy throughout the rest of the afternoon.

In general terms, P2 did not present as an overly emotional individual – she seemed to be able to manage her feelings and had a very supportive family network around her. She found it difficult to comprehend talking about her feelings and the concept of emotional support was beyond her cognitive level of understanding. However, P2 described many pleasurable feelings that she perceived when she was talking about MMP. She described having 'good feelings' about coming along and she also mentioned that she was sad if she had to miss a session, such as for a medical appointment. When questioned about how she felt while actually participating in musical activities with regard to her mood, she told me it made her feel 'happy inside'. She also said she felt very relaxed at the group – and inside her tummy it felt 'lovely'.

P2's mother commented that her daughter loved being part of the MMP group: 'She loves that feeling of all the students together with the same aim, you know what I mean?' (P2's mother, interview). This would suggest that the group provided a strong sense of belonging for P2, which is vital to feeling valued as a person. An interesting point to emerge from this discussion with P2's mother was the issue of trust:

> So at Music Man she has got it all. She is with friends, she's with adults that she
>
> trusts…she just feels so safe there. I know they are very simple things but that's what it's
>
> all about with her. (P2's mother, interview)

This demonstrated how P2's mother thought her daughter felt protected and safe. This vicariously provided her mother with a feeling of emotional security, through knowing her daughter was in an environment where she did not have to be concerned about her safety. When questioned specifically about how she thought her daughter's mood was affected by

MMP, P2's mother felt this was positive. She also added that this then helped her to feel positive and supported:

Very good 'cos it's positive from the minute she walks in there…absolutely, 'cos she's happy I'm happy. She is safe, I feel fine. I don't even think about them Friday. Jackie picks her up and I don't think about them till I go and pick them up. (P2's mother, interview)

By P2 attending MMP, this provided her mother with a stress-free day and a valuable source of respite from her full time caring role for her daughter. She felt that her daughter's friends at MMP were as important to her as her actual brother and sister:

She has met a whole new group of people that she considers friends/family. It is like a family – the Music Man family. Yes and she feels, and don't forget it's just she and I, she hasn't got a dad. Her siblings don't live far. My son's over there and my daughter's over there but they both work. Her friends at Music Man are as important as her family, they are like her family. They are, and that in turn makes her feel better about herself. 'Cos she's got people who care. She feels it, so there you go. (P2's mother, interview)

Field notes provided additional detailed information with regard to emotional experiences for P2. She was seen to experience a range of different emotions, again particularly during rehearsals for the musical 'The Label'. She demonstrated empathy and understanding towards the other performers and was keen to make sure others were okay, providing them with emotional support whenever needed.

Since the death of his mother, P3 had experienced many emotional challenges through coming to terms with his loss. He did not present as an outwardly emotional person and he often kept his feelings to himself. In fact when talking to P3's father, he commented on how his son did not like to show any emotions at home. He thought his son behaved in this way as he did not want to upset anyone, particularly his father:

Definitely helps his emotions and feelings. Erm, he's never really spoke about his mum. He does but he's never shown me any – that he's upset. He won't do it but I know he does it with some people. Erm, and again, it's a way for him to talk to others, especially some of the helpers as well. I'm sure you know, they are there to support all the students and you know, he will probably talk to them more than he will me 'cos he doesn't want to upset me. You know, so from my point of view it definitely helps. (P3's father, interview)

When P3 was asked about if he felt music could affect his mood and make him feel happy or sad, he replied that it made him feel 'really happy'. He also mentioned his mother and how being at MMP often reminded him of her. This helped him to express how he was feeling about her (see Photograph 45): 'When I sing I think of mum…mum loved, mum loved music' (P3, interview).

Photograph 45: P3 deep in private thought while singing

P3's father also added that he felt that the music sessions had a positive effect on his son's mood and this then had a lasting beneficial effect for the rest of that day:

Definitely positive with P3, definitely positive. It's just the enthusiasm to go and when he comes back he is talking about what they did – all day! 'Oh we have got a new song' and we have to go through this one. (P3's father, interview)

Despite this having been a difficult couple of years for P3, it would seem that MMP had helped to provide a great deal of positivity for not only him but for his father as well. P3's

father talked about how the students' feelings for each other were strong and they provided an additional level of emotional support for him and his son:

> I'm sure other people will say the same thing, erm, because they become very, very close friends don't they? …and he loves going and just chatting with them and I think it is a great benefit for him and others. (P3's father, interview)

P3's father expanded the point and discussed how this also helped to support his own emotions, through his son being part of MMP:

> Definitely, definitely, yeah, 'cos he is so enthusiastic, he is happy. If he is happy, I'm happy…it gives me a boost and obviously you know I enjoy helping 'cos that to me is using my brain. Obviously with the minibus, you know, I do things for that. But I also know that I am supporting P3 and that makes me feel better. (P3's father, interview)

Field notes reported similar findings in terms of grief support for P3. On one occasion, when on the way home after a local performance travelling back in the minibus, the following happened:

> A funeral car pulled up alongside the minibus. This reminded P3 about his mother who had passed away last year from cancer. He looked like he was going to get upset so I acknowledged his comment and said how pleased his mum would have been with his performance and this quickly changed his mood back to happy again. We then talked a bit about the Palladium show and who would be coming to watch him. (Field notes, 14th March, 2017)

For P3, his performance was still very much in his mind and he was able to link this with more positive emotions and thoughts about his mother – rather than remaining focussed on

the funeral car. He was able to turn a negative memory into a more positive one through his recent involvement with musical participation. Involvement in making music appeared to provide P3 with a level of emotional support which helped him to work through the grieving process in a way suitable for him. This was particularly important given his reluctance to either show his emotions, or to talk with family members about how he was feeling. It would seem that MMP was one of the few places where P3 felt comfortable enough to be able to express his feelings openly. This process resulted in creating pleasurable feelings for P3 and enabled him to remember his mother through music in a positive manner.

Turning towards P4, MMP provided emotional support to him, his sister and the extended family in a variety of interesting ways. P4 described how participating in MMP activities gave him positive feelings and that he was glad he was a part of it. When specifically asked about how coming to Music Man made him feel, he replied: 'I glad I go to Music Man…I feel, I feel it quite good…I feeling I be alright. I happy coming to Music Man' (P4 interview). P4 had happy feelings about his attendance at MMP and this was further evidenced through his sisters' comments. She felt that MMP was a significant source of positive emotional support for her and her immediate family. She commented on how well the teaching staff knew and understood their students' specific needs. As a result of this the staff were able to support the students through any sort of emotional upheaval. For example, P4 had been recently looking at moving home to another care setting and this had left him feeling extremely unsettled and anxious. David Stanley (P4's main tutor) had been able to chat this through with him and help to put his mind at ease. P4's sister felt this was a very beneficial support network, as her brother really listened to what David Stanley told him and 'took it all on board' due to their trusting relationship. This was an extra benefit aside from the music itself, but nevertheless created a positive impact in supporting this family.

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P4's sister expressed slight concern at how much time was often required to support her brother and his Music Man adventures. This was really more of a physical drain on her rather than a negative emotional impact, bearing in mind her working hours:

> Erm, I don't think it does, erm, how do I explain? If he wasn't there, then, erm, if he wasn't there it would impact on him and myself but him being there and doing everything impacts on us because we are having to do more. (P4's sister, interview)

Despite this slightly negative viewpoint, P4's sister agreed that the positive benefits far outweighed any negative points and the overall feeling was one of a highly supportive network of like-minded people. MMP provided good emotional support for P4 and his family (he has another brother with LDs who also attends MMP) and it was a considerable family commitment to ensure P4 got as much out of attending as he could with the level of support the family were able to provide. P4's sister felt it would have a serious negative impact on him if he stopped coming and for this reason she tried her utmost best to make sure that this did not happen.

Moreover, field notes for P4 provided evidence concerning emotional support and understanding. As many of the previous MMP shows have tackled highly emotive topics surrounding LDs, this has been thought provoking for the students and has allowed them to explore their own emotions on the different topics. As was seen in the other participants, during rehearsals (and in the actual show itself) of 'The Label', P4 was similarly expressive in his delivery of the songs and his acting. He demonstrated a great deal of emotional understanding of the meaning of the musical and this came across in an empathetic and considerate way. This type of emotional experience provided P4 with a safe environment in which to explore his own emotions on a subject that was very real for him. P4 presented as a

very kind individual during the sessions. He often sat next to a younger student who had mobility problems and frequently experienced physical pain and he always did whatever he could to support her. P4 showed a very good level of understanding and empathy towards the other students.

Summary: Emotional expression and support

MMP provided a safe environment for the participants to experience emotions and learn how to manage them. All participants reported a positive effect on their mood or feelings while participating in music. P1 described 'brilliant' feelings; P2's mother commented on how her daughter 'loved that feeling of all the students together'; P3 was able to express his grief for his mother through their shared love of music; and P4's sister felt that MMP was a valuable source of emotional support for her entire immediate family. The participants demonstrated empathy and understanding towards each other and in various different scenarios. For example, during the musical 'The Label' and in response to hearing particular songs. Emotional support was provided in a way to support the particular needs of the participant at that point in time. This was either through the participation in music itself, or through the wider community of MMP.

Positive attitude of staff

The *positive attitude of staff* related to the encouraging manner in which the staff taught and interacted with the students. The staff demonstrated high expectations towards the students, with a strong belief in their abilities. All participants and their families commented in one way or another about how the staff were highly positive in their attitude to teaching and this had a strong beneficial impact on their adult children. More specific comments relating to the positive attitude of staff were received from P1 and P2 and their families. P1's father felt that MMP was a place where maturity was encouraged through the positive attitude of the staff who 'treat them like adults':

He has grown up a lot since the Music Man, he has just gone on and on hasn't he? We do nag him a bit from time to time. But there isn't much I have to, you know, he's really good. He has his shower in the morning, you don't have to tell him to do anything, you know…but it's nice to get to the point where you don't have to keep on and tell him what to do. He just does it. (P1's father, interview)

P1's father felt that MMP had helped his son to develop life skills which he did not have prior to his involvement at MMP. Through high expectations from staff and the supported opportunities available at MMP, P1 had been able to become a more independent young man. This had encouraged his maturity into adulthood: 'He's certainly grown up a lot since he started there, he's a lot maturer than he was, put it that way…he can go on his own on the bus, and come home' (P1's father, interview).

P2's mother commented on how the positive attitude of the staff had encouraged her daughter to 'believe in herself more'. P2 was now sufficiently confident to try new things through the positive encouragement of her tutor David Stanley: 'She's got confidence in him so therefore she's got confidence – I can do this!' (P2's mother, interview). This kind of positive attitude was the foundation of the success of MMP – feeling encouraged in a safe environment allowed these participants to relax and flourish and reach their full functioning potential within this setting and their own wider lives (see Photograph 46).

Photograph 46: P2 and her favourite teacher David Stanley

Summary: Positive attitude of staff

The *positive attitude of staff* was mentioned by all participants' families. For example, P1's father felt that this attitude had helped his son to mature and develop new life skills. P2's mother felt her daughter was now far more willing to attempt new skills through this gentle and positive encouraging attitude. This kind of positive learning environment invariably leads to success – the participants developed a sense of belief in their own abilities through the confidence received from the teachers. Feeling a sense of worth allowed the participants to maximise their individual learning potential.

5.7.1.4 Positive Emotions conclusion

The three sub-themes which formed the overarching theme of Positive Emotions are

summarised in Table 5.4 below:

Table 5.4: Summarised sub-themes for the overarching theme of Positive Emotions

Sub-theme	Summary
Pleasure providing	
	Two sub-sub-themes (*enjoyment* and *positive experience*) formed the sub-theme of 'pleasure providing', with each adding a different perspective. For example, each participant found enjoyment in a unique way that suited their interests and abilities, such as P1 and his enjoyment of performing. A love of music was apparent in each participant, which could potentially be a significant factor in the success of MMP for these individuals. For example, P2 'loved doing music' and this was evidenced through her behaviour and body language. All four participants decided for varied reasons why they attended MMP. For example, P3 had been inspired by his best friend and was now 'staying for good'. A comparable positive experience was shared by all the participants, with each having the opportunity to create their own positive experiences for themselves. The combination of these sub-sub-themes created a varied provision of pleasure, which was able to reflect the unique characteristics of the participants. The idiosyncratic nature of these findings added to the diverse outcomes perceived by these individuals.
Sense of anticipation	
	Two sub-sub-themes (*looking forward/forward planning* and *anticipating performances and concerts*) contributed to this sub-theme. The presence of activities that were looked forward to by the participants gave them a shared positive sense of anticipation which extended out to their families. Examples included the willingness of the participants to attend extra activities such as the workshops (P1 and P3 in particular), and how they carefully planned ahead for their day at MMP. The excitement surrounding the performances and concerts served to strengthen this sense of anticipation even further. The MMP ethos of valuing performance as part of its education programme added a considerable sense of meaning to the lives of these musicians.

Emotion management and support

> Two sub-sub-themes (*emotional expression and support* and *positive attitude of staff*) contributed to the sub-theme of 'emotion management'. There was evidence to support how the participants' feelings and/or mood were improved through music participation. The participants themselves described how taking part in music at MMP made them feel, and their parents reported on how it benefitted their mood. The positive attitude of the staff was a significant factor in the positive outcomes experienced by the participants. The staff were held in high regard by both participants and their families. The presence of emotional experiences and grief support helped these individual to develop into semi-independent adults with a high level of emotional awareness. The grief support provided to two participants in particular saw the emergence of coping strategies in dealing with the loss of a loved one.

In conclusion, the overarching theme of Positive Emotions was seen at MMP in a variety of different situations and in ways to suit the needs of the individual at that time. Three sub-themes (pleasure providing, sense of anticipation and emotion management and support) all played a significant role in allowing the individuals to achieve the highest positive emotional experience as was possible. Pleasure was seen in the music-making activities; a sense of anticipation was present with regards to attending weekly sessions and the exciting opportunity to perform; and MMP provided a safe and encouraging environment where the participants could experiment with emotions and develop their emotional understanding. Emotional support was readily available at MMP when needed through either support from other members of the peer group; through relationships with staff; or indeed, through the participation in music itself. The ability to experience positive emotions on a regular basis was having a beneficial impact on the participants - bearing in mind the many challenges experienced by people with LDs, in addition to the everyday challenges of modern life.

5.7.2.

Overarching theme 2: Educational Development

The overarching theme of Educational Development was present for all four participants, across all three categories of data collection (participant interview, family interview and journal of field notes). Three related sub-themes combined to generate the overarching educational development theme, including: (1) learning through music, (2) focus development, and (3) social development.

5.7.2.1 Learning through music

Learning through music covered all aspects of acquiring knowledge of any form, which was either supported or facilitated through participation in music. This could be directly related to *musical education*, for example, instrumental progress, or alternatively indirectly as a result of music participation, for example, *role modelling* or *additional learning opportunities*.

Musical education

Musical education referred to any learning which involved the acquisition of musical skills or knowledge at MMP, for example playing musical instruments or singing. P1 was a student who was keen to develop his musical abilities and always gave of his best in this regard. He very much enjoyed playing the instruments, particularly the ukulele and glockenspiel, and practised hard to make progress. He had his own ukulele and glockenspiel and brought his instruments along to each session (see Photograph 47). The fact that he remembered to bring these along demonstrated a commitment to his learning. Field notes mentioned how musically aware P1 was, particularly during show rehearsals. He only had to hear the first couple of notes of a song and he could immediately identify the piece. An enthusiastic approach to learning was evident, which contributed to his musical success.

Photograph 47: P1 with his ukulele

P1 felt that learning to play the musical instruments was one of his main motivating influences for his continued attendance at MMP (conducting being his favourite). When asked why he came along, he replied: 'Why I came here to Music Man to learn music…playing all different instruments. We learn, all do music, erm, we learn all do skills. That's why you're here, to learn and have fun' (P1, interview).

Learning new musical skills was important for P1 and he was an ambitious musician. He linked 'learning' and 'having fun' together in the same sentence, which implied that these two processes coexisted in some way for him. P1 expected to learn at MMP, which could be a contributing factor to his success there. This conscientious approach was typical of P1's character and the MMP environment was allowing this aspect of his personality to flourish.

P1 carefully followed the tutors for guidance (see Photograph 48). P1 explained how he liked to learn by 'looking at the tutors':

> To learn what instruments come along and follow Jenny Hitchcock, what's coming up…Like erm, what sang today, I can't remember what the song's called. Right, there are some letters coming up and Jenny points at the letters and remember my aim to focus on the letters on the glockenspiel and watch Jenny at the same time. (P1, interview)

This observational method of learning is ideal for students with LDs, particularly where reading and writing skills may not be in line with the accompanying level of cognitive understanding (Werts, Caldwell and Wolery, 1996). This can serve to reduce the kind of frustration which may be experienced in a more traditional type of learning environment. This highlighted the need for constant adaptability and adjustment in teaching methods for students with LDs – even more so than when teaching students without LDs.

Photograph 48: P1 closely following David Stanley while demonstrating African drumming

Participating in music had also provided many interesting opportunities for other forms of learning for P1. For example, P1's father discussed how MMP supported his sons' varied interests and kept him feeling enthusiastic about life. He felt that MMP was a stimulating environment in which his son could thrive. P1 had an inquisitive nature and benefitted from being stimulated at an appropriate level:

> Well yeah because he's the sort of person that needs an interest. Yes, he needs something to nurture that brightness and he's getting that from music…with the potential of starting keyboard lessons as well. That will be a whole other interest, won't it? (P1's father, interview)

From this response it would appear that P1 was being given every opportunity to further his musical journey and this was satisfying an underlying human need for him to feel a sense of achievement. P1's father was very thankful that his son was part of something that not only challenged him but also actually recognised and valued his achievements.

A further interesting point made by P1's father was regarding an appreciation of concepts such as musical genre, and how this might help to encourage the development of skills such as decision making:

> Yes because it, it helps you to appreciate things. And it also, there is such a wide variety of musical styles. It helps you to make decisions. I mean you could be listening to three people singing and you can say "oh that one's got a very good voice; that's not bad; and I wish she'd go away! (P1's father, interview)

This suggested that P1's father believed that musical participation could potentially help his son to develop the necessary skills required to be able to make up his own mind about choices that he may have to make, and therefore learn to develop his own viewpoint on

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different matters. This skill could prove beneficial in other areas of life requiring a similar decision making approach.

Similar to P1, P2 was a keen participator who enjoyed learning new musical skills. She was also happy to practise, particularly for the shows, and she understood how this was the means through which she would further develop her musical ability. She too had her own instruments. Learning new songs was something that P2 particularly liked and she willingly took on the challenge of tackling new repertoire during her weekly classes. Again, similar to P1, she commented on how she followed the lead of the staff: 'I like the instruments and singing…I like practising a lot, and practices for the London Palladium…Erm do, to learn, and learn, listen the staff' (P2, interview).

P2's mother spoke very highly of how she felt her daughter was learning and continually making progress and being inspired to participate: '…they are making music there and she loves 'what are we doing next?' You know what I mean?' (P2's mother, interview). She was delighted that as an adult, her daughter still had the opportunity to continue learning through music-making at MMP:

> She's actually doing it. With the dancing she is doing it in a big crowd and they do exams and stuff, so it's just not…but with the music. It's a newish thing to her don't forget, she's not been doing it all her life. And she's learning, she's you know, she's her age and she's still learning and she's loving it, absolutely loving it... She's learning at Music Man. (P2's mother, interview)

It was interesting to hear how P2's mother showed surprise that her daughter was still learning at 'her age'. This could indicate that maybe she did not expect her daughter to continue to learn into her adult years. Nevertheless, from these comments it was apparent that P2's mother felt that the music itself was facilitating the learning process, more so than some of the other activities P2 attended on a regular weekly basis. She mentioned that although her dancing involved an element of music, she thought it was not the same as actually 'doing' music and therefore the learning experience had less of an impact for P2. Music-making enabled P2 to continue achieving regardless of her age – in a similar way to any individual continuing to learn throughout adulthood should they seek to do so.

P2's mother added that although the students were learning, this happened in a very stress-free and non-judgemental manner:

> There's no pressure. He [teacher] doesn't put any pressure on them does he? Yeah, all the staff seem very nice and approachable and he lets them have a go. 'Cos I crack up when she tries to sing, she's got the most funniest voice in the world…but it's aspiring [*sic*]. And David gives it, I mean, the surprise for me, she said 'I've got a surprise but I'm not telling'. So I said right. Then when I saw them lining up and I saw that mic! Ann's videoing it and you can hear me going 'oh no!'...and that was her surprise. And I thought, he doesn't pick the best singers, obviously. He lets them have a go, you know, he doesn't put the best in and he does what's right…anyone can have a go. That is the beauty of it and it does them all good and I think of their well-being. (P2's mother, interview)

Field notes for P2 described a confident musician who was organised and attentive and confirmed her willingness to approach new things with a good attitude:

Great African style dancing…P2 is really trying hard to learn the difficult African names and rhythms and this is paying off as there is definite progress apparent in comparison to the last time I saw her practise this song. (Field notes, 26th May, 2017)

P2's determination to achieve was a great personal attribute and this will support her learning in all spheres of life. Being able to experiment within a safe environment will nurture this positive attitude, combined with her ability to ask sensible questions (see Photograph 49) when appropriate: 'P2 doesn't chat when she is supposed to be listening and asks sensible questions when she is unsure about something' (Field notes, 19th May 2017).

Photograph 49: P2 asking a question during MMP session

MMP provided a positive learning experience for P2 and this was evident not only in her musical progress but also in her willingness to approach new tasks and to take instruction wherever needed. There was much learning through music taking place for this participant and this was adding considerably to her life outcomes.

P3 had a passion for everything musical and this was an important feature in his life. For this reason he was keen to learn new musical skills and worked very hard to achieve this, showing a similarly determined attitude to P1 and P2. P3's father described how his other son was a good musician and guitarist, and how he had encouraged P3 as well. However, he felt that once P3 joined MMP, his musical education had really been able to progress:

> …his brother is a good guitarist and would let him strum on his guitar and try and do that sort of thing but it's not until he actually went to Music Man – and then he got heavily involved in trying to understand beats and how the music is formed. (P3's father, interview)

MMP had provided an opportunity to satisfy an interest in understanding the basics of music theory for P3 and his father felt that this had helped his overall ability in music. P3 was now able to count the beats and this had improved his performance skills and ability to confidently participate in the group performances. It was encouraging to see how MMP could accommodate these widely varied musical interests – whether it be conducting, percussion playing or indeed music theory. An all-round musical education was available to suit the individual needs of these participants and at a pace that was progressive but without unnecessary pressure.

P3's father commented that he thought his son would struggle to learn to actually play an instrument like the guitar, but the instruments at MMP were far more approachable for his son's level of musical understanding and dexterity (see Photograph 50). This allowed P3 to make noticeable progressive steps rather than feeling defeated by something that was beyond his reach. The degree of concentration on P3's face in Photograph 50 is clear to see. The glockenspiel was a favourite instrument for P3. His father described how he practised at

home with determination and much perseverance, and he too had his own instruments: 'But glockenspiel, great, he sits there at night you know, 'cos he's given E, C, D, D, E, E, and he does that you know' (P3's father, interview).

Photograph 50: P3 concentrating hard

Despite P4's sister's concern about his deteriorating memory, P4 still enjoyed the experience of learning. He was able to remember musical activities, as well as absorbing new information such as songs or instrumental parts. P4's sister mentioned that she thought his favourite activity was playing the instruments – in fact a favourite activity for three out of four participants (P1's favourite activity being conducting – although he did mention that he too liked the instruments). P4 had a notebook listing the different tasks he needed to practise at home. His sister said she felt that coming to MMP helped to keep her brother healthy and

'on board with everything'. Remaining physically and mentally active in this way on a regular basis could help P4's brain remain alert, and able to respond to learning in the positive way that he did.

P4 also had some of his own instruments (glockenspiel and ukulele) and was keen to show off his musical skills to other people (see Photograph 51). For example, on a recent holiday he entered a talent show and performed an MMP song to a large audience with his ukulele: 'Well, something I doing, right, is ukulele. Right and erm, guess what? I went on holiday, right, I went to Skegness. I was singing 'Ukularmy'…yeah I was' (P4, interview).

Photograph 51: P4 with his ukulele

The eagerness of P4 to demonstrate his skills to others outside the immediate MMP circle was a good indication of how he felt about his musical ability. The fact that he was willing to perform to an unfamiliar audience revealed a confidence in his achievements and he wanted others to share in his delight. To be able to do this was a very different experience to performing alongside his MMP friends in a known environment, demonstrating the impact that music was having on P4's outlook on life. P1 also was keen to perform in a similar way and had been known to entertain guests with his singing on cruise holidays, which he often travelled on with his father. These participants were serving to educating the wider audience about the talents of people with LDs. P4's sister also talked about how vital it was to educate the audience and how an important two-way learning process was taking place during these MMP performances.

Summary: Musical education

All participants were receiving and valuing a musical education as part of MMP. They all enjoyed learning new musical skills and were keen to demonstrate these. For example, the participants entered talent shows while on vacation and had opportunities to perform to the public, outside of the immediate MMP circle. P2's mother expressed her delight in her daughter having the opportunity to continue learning as an adult. P3 worked hard to achieve his musical ambitions and good progress was being made. The level of challenge provided for these students was enough to satisfy their desire to learn new skills but never pushed them beyond their capabilities. No student felt excluded due to their LD and every effort was being made to provide a safe and happy environment for these students to achieve to the very best of their individual abilities. Learning in this way is pleasurable and the learner can perceive progress is taking place.

Role modelling

Role modelling is a key feature of the MMP approach to teaching – including both staff and other students acting as role models. A role model is a person whose behaviour, example or

ability is copied by others. Role modelling was evident for all four participants in a variety of different scenarios. As seen previously, particularly with P1, learning in a 'visual' style through the observation of others is often favoured by people with LDs. Role modelling was directly responsible for P1 being able to pursue his passion to become a conductor. This was through him initially observing Jenny Hitchcock (MMP tutor) conduct the students, and then progressing to being able to conduct the music himself: 'I watched Jenny Hitchcock, she was the first conductor. I keep an eye all the time, then I want to become a conductor' (P1 interview). P1's father confirmed that Jenny Hitchcock was the inspirational role model behind his son wanting to become a musical conductor. P1's father also mentioned how this positive role modelling had allowed his son to continue even further with his musical education and to satisfy his inquisitive nature: 'This idea of him doing the conducting – it's taken things a stage further…I mean, he certainly practises the conducting bit' (P1's father, interview).

As a result of successful role modelling, P1 conducted at the London Palladium (see Photograph 52), such was his level of expertise now, and he conducted at the Royal Albert Hall in April 2019:

I am waiting to see what happens at the Royal Albert Hall show 'cos it's not only gonna be, from what I understand, he's not gonna be just conducting the students, you're gonna be conducting the entire orchestra as well! (P1's father, interview)

Photograph 52: P1 conducting at the 'Music is Magic' show at the London Palladium

Field notes added further details on the benefits of having significant role models involved in the musical education of P1, as can be seen in the following journal entry reporting on a local fund raising concert:

P1 really rises to the challenge of being conductor…did a very good job of conducting the 'March Medley'. This time with audience participation too. This was a real step up for P1 in that he involved the audience members and not just his MMP friends. Very clear guidance given to all the instrumentalists at exactly the right time. (Field notes, 7th July, 2017)

Musical participation and the opportunity to perform were key components of the MMP ethos, and for P1 could be viewed as a direct result of the observation of a role model tutor. In addition to this, the ability to learn to manage the stress of performing on stage was a valuable life skill that had the potential to teach these participants about how to manage their

stress and emotions in the broadest sense (see Section 5.7.1.3). Being able to cope with the everyday stresses of life is a major contributing factor to sustaining positive WB (Howard, 2008).

In a similar fashion to P1's father, P2's mother also spoke about role models but added how it was not just the staff who were significant, but the other more able students too:

> It's with friends who are always welcome, learning from them as well. Absolutely, like S, S is so lovely, she is her hero – heroine I should say...that's why she does all this jigging about, because she, S does it. (P2's mother, interview)

This provided a benefit to both individuals involved. The observer was acquiring new skills through this process, and the observed was then placed in a position of respect and empowerment. It emerged from the data that being able to teach another student was highly beneficial with regards to developing a sense of confidence in one's own abilities as a musician (see Photograph 53).

Photograph 53: P2 looking over her shoulder to watch her 'heroine' S

Role modelling was responsible for P3's initial interest in MMP. P3's father explained how P3 watched one of his best friends perform in the first MMP London Palladium show in 2015, and this inspired his son to want to try out MMP for himself:

> Then he decided after we had seen the Palladium show, that it was something that he really wanted to get involved with…And then he saw his friends on stage and went 'wow that's what I want to do'. So we followed that up and when it started again in the September after the summer holidays, he's never looked back. (P3's father, interview)

Within a different context, this was another example of a student acting as the role model for another student. This provided a sense of approval and recognition for the individual who was the source of this role modelling. This is especially important for people with LDs who rarely find themselves in such positions of empowerment. They can become so accustomed to being constantly given direction and not being able to make decisions about their own

lives, that a feeling of powerlessness can be the norm (Wallace, 2017). In turn, P3 was now able to act as a role model himself through the acquisition of the relevant musical skills at MMP. Fieldnotes reported him frequently helping others through demonstrating musical techniques to other less experienced students (see Photographs 54 and 55).

Photograph 54: P3 acting as a role model for P2, using his keyboard skills

Photograph 55: P3 leading another student and her two support workers in drum technique

P4 has known David Stanley in excess of 15 years, and he appeared to be a significant role model for this individual. P4 could often be seen watching him during the sessions, paying attention and closely observing everything he did. Field notes reported P4's close attention to David Stanley on several occasions:

Following instructions well. Coordination good between drumming and clapping. Loud and rhythmic singing, tapping on leg in time with the music…arms folded and watching David to follow what is happening. Rubbing hand on chin and looking thoughtful and expectant. (Field notes, 26th May, 2017)

Even through unconscious behaviours such as preparing for the session, or informal talking over lunch, the staff were continuously acting as role models for the students.

Summary: Role modelling

Role modelling was present for all the participants and could be seen to be an influential factor in their learning and behaviour patterns. Both the staff and students acted as role models on various occasions. For example, David Stanley was observed not only while teaching the students but also during times of non-teaching. Other students acted as role models, in both conscious and sub-conscious ways, resulting in positive learning outcomes.

Additional learning opportunities

There were frequent *additional learning opportunities* within MMP where the students could enhance other skills, such as story or song writing. A 'creative to music' time included listening to background music played on the piano. Being creative whilst listening to music allowed freedom of expression for the students in whichever way they deemed appropriate – sometimes a student sat quietly and became lost in their thoughts; others were more pro-active and produced a piece of work to share with the group. P1 made good use of this time and often wrote a story involving his friends at MMP (Appendix 4 shows an example of P1's creative writing work), demonstrating an indirect form of learning through the music (see Photograph 56). P2 also enjoyed being 'creative to music' and produced drawings about how the music made her feel (see Photograph 57). These two individuals were using music as their inspiration for creativity and were able to extend their skills beyond the realm of music-making into creative written work.

Photographs 56 and 57: P1 and P2 during 'creative to music' time

P3 used this activity to express how he was feeling about events that were happening in his life at that time. He did this through song writing, usually a few lines in length. Sometimes his words were full of emotion and were a good representation of what he was currently experiencing emotionally. He then liked David Stanley to set his words to a melody on the piano, which P3 very much enjoyed listening to and sharing with the rest of the group. Knowing how P3 could struggle to express his emotions, the use of song writing could provide a very important emotional outlet for P3 in a way that he felt at ease with (see Photograph 58).

Photograph 58: P3 during 'creative to music' time

P4 used this time to draw pictures, usually with a musically-inspired idea behind them (see Photograph 59) and often with a short piece of accompanying narrative. As can be seen in Photograph 59, P4 wrote 'Music is Magic' to accompany his picture of David Stanley. The inclusion of David Stanley could be interpreted as an indication of his significance to this participant, combined with his expressive words on his thoughts about being at MMP.

Photograph 59: P4's 'Music is Magic' drawing from 'creative to music' time

Summary: Additional learning opportunities

All four participants appeared to benefit from and enjoy the *additional learning opportunities* experienced at MMP. This was a time that allowed each individual a free time of expression through music listening. Each participant expressed themselves in their own individual way, at that particular moment in time. For example, P1 created imaginative stories. P3 used the time to express through words how he was feeling about certain events in his life. This activity provided a useful alternative means of communication for the participants, along with the opportunity to develop skills not directly linked to music.

<u>5.7.2.2 Focus development</u>

Focus development involved developing the ability to remain engaged on a task, or with instructions given, without losing concentration. This ability enables the individual to pay attention, and the ability to focus is a key component of the learning process. This is a skill that can be enhanced and improved upon over time through various means. Improved focus can be achieved through engaging in activities which are enjoyable to the individual, as in the case of music-making for these participants (Klemm, 2011; Howard, 2016).

Concentration encouragement

Concentration encouragement concerned participation in activities that supported learning how to remain focussed on a task without distraction. Activities that encourage concentration have the potential to develop an increased focusing ability (Klemm, 2011; Howard, 2016). Through music participation, particularly when rehearsing for significant events, these four individuals displayed a sustained level of concentration and ability to focus on the task being undertaken. P1 described how he tried to focus on both the tutor and the glockenspiel at the same time:

> …I can't remember what the song's called. Right there are some letters that come up. And Jenny points at the letters and remember my aim to focus on the letters on the glockenspiel and watch Jenny at the same time…yes it is very hard yes…if I done well I be really pleased. (P1, interview)

It was encouraging to hear P1 talking about focussing on both of these aspects of music and learning how to manage multiple tasks. This could be a very useful skill to hone and thus make more complex daily tasks achievable, for example following the sequence of a cooking recipe, which P1 enjoyed doing at home. P1 added further information on the topic when

prompted and mentioned how he felt that being at MMP had helped him to learn to focus on new non-musical skills too: 'Yes I would say all new things' (P1, interview).

Students are willing to learn when they feel they can succeed and the outcome is valued (Brophy, 2004). A willingness to tackle new tasks is highly beneficial in terms of acquiring new knowledge and continuing to make cognitive progress throughout adulthood. P1 himself had noticed the improvement in his concentration level and this was supported by additional evidence from his father. P1's father talked in particular about how his son still struggled to focus on certain things but that he could now concentrate with ease on anything musically related, and how this skill has developed over the time of his son attending MMP classes:

> There are some things that he gets a bit…there are still certain thing that he has a job to concentrate on but nothing at all where music is concerned. That now just seems to be second nature to him. (P1's father, interview)

Field notes for P1 recorded an attentive participator with frequent reports of 'fully attentive' or 'engaged' during the sessions. A noteworthy point to emerge demonstrated how P1 was still able to remain focussed, even when he was beginning to become tired during the lengthy London Palladium rehearsals:

> …fully attentive and enjoying the planning of the show…singing throughout, starting to look tired towards the end of the day but still joining in and communicating with the person sitting next to him…aware of others around and when they might need help. (Field notes, 21st April, 2017)

Possessing sufficient stamina to see a task through to completion even when tired would

indicate a certain degree of maturity had been established in P1's approach to learning. This

type of determination was valuable for P1 in so many areas, such as memorisation of lyrics or

music, and helped to reinforce the type of positive attitude that supported acquiring new

skills. This determined ability to persevere at a task also appeared to be linked with a

resilience to accepting challenges that were initially demanding for the participant (see

Photograph 60).

Photograph 60: P1 demonstrating his ability to focus during his weekly music session

P1 demonstrated a good capacity to remain focussed on a task even when there were

considerable distractions taking place around him. For example, in 'creative to music' time

(see Section 5.7.2.1, *Additional learning opportunities*, Photograph 56) there were many

noisy distractions in the room. P1 was completely absorbed in his story writing and was not unsettled by the other students around him:

> Today has been a long, hot day at St Laurence church hall, so as the afternoon progresses a time is spent 'creating to music'. David Stanley is playing the piano for this – Les Miserables. This is an opportunity to practise writing skills (or whatever the students feel like doing) while listening to music in a relaxed environment. P1 is writing a story about David and the lovely weather – he tells me it is a 'happy story about the beautiful sunny day'. P1 shows great concentration on his writing – even when there are lots of noisy distractions around him. He seems to be able to remain focussed on his writing and is being creative with his imagination. (Field notes, 26th May, 2017)

This extract again demonstrated a mature attitude with regards to learning and remaining engaged on a task. It would appear that the ability to focus on music was potentially spreading outwards to other tasks such as being creative with written tasks. The transferable nature of keeping focussed is a useful life skill to possess and this is a cognitive skill that is often absent or insufficient in people with LDs.

When talking to P2 about concentration and focus, this was a topic that she found difficult to comprehend. However she did express how she enjoyed learning at MMP, so this would indicate that concentration levels were sufficient for learning to occur. However, P2's mother strongly felt that being part of MMP had helped her daughter to be able to focus for longer on activities:

> I absolutely think it does… the music, she wasn't particularly musical but she does play the bells…Yes and I like that and I hope she'll do other bits, and she does the woodblocks and she does, and great, look at that! And I think, oh there was an old adage years ago that

once they get to sixteen they don't learn anymore…Rubbish…she's learning all the time. And she wants to, and she wants to and she's engaging and she's concentrating and she's listening. All stuff that she needs to keep doing… (P2's mother, interview)

P2's mother considered music participation at MMP to be a contributing factor to her daughter having developed an improved ability to concentrate. The fact that her daughter was still learning was a source of great satisfaction to her – and proved the historical negative attitudes towards the learning abilities of people with DS to be inaccurate. Given the high level of engagement required, particularly during rehearsals and performances, it was not surprising that music-making encouraged the improvement of such skills over a period of time. MMP was a key activity for both mother and daughter to engage in together. With P2's mother being a single parent, she explained how she felt it was very important for her to have something to focus on too, and she felt it helped to keep her feeling younger and remaining alert. Having a keen interest such as this served to bond this family, focussed around a common goal.

Field notes for P2, in a comparable way to P1, reported P2 as a fully engaged and focussed member of the group. She presented as an excellent student who remained attentive at all times and put a significant amount of effort into her work:

P2 is very good at paying attention throughout and never misses her cue. She is ready with the correct instrument at the correct time, sitting and standing as required. She doesn't chat when she is supposed to be listening. (Field notes, 19th May, 2017)

This corresponded with the reports from her mother regarding her daughter's improved ability to concentrate on more demanding tasks. P2 was being provided with every opportunity to practise this during her music sessions, and with her positive attitude towards learning she was making good progress which then served to further encourage her to keep on persevering. Through this ongoing process, P2's ability to concentrate was indirectly improved as a result (see Photograph 61).

Photograph 61: P2 (behind) and P3, demonstrating good concentration towards the end of the day

P2 paid careful attention when introduced to new repertoire. Likewise, P1 had also mentioned that he felt that MMP helped him to focus on 'all new things'. This is an area that people with LDs frequently struggle with, and they can quickly move off task and onto a less challenging situation. P2 was equally attentive whether singing or playing the instruments and even chose to play the drum kit during break time. P2 was the most physically

expressive participant and this came across clearly through the observations. She came across as demonstrating a high level of physical focus and energy and used her body to express her interpretation of the music:

> After break time P2 is back up on her feet dancing along to 'Note by Note' (her favourite song). Singing at the top of her voice. Overcome with excitement – twirling and dancing, waving her arms above her head and encouraging others to join in. Twirling round and round in complete euphoria. P2 returns to her seat to catch her breath, looks tired and totally content. Soon back up dancing again and seems to be experiencing almost a kind of full body commitment, where she is completely focussed on the movement to the music. (Field notes, 3rd March, 2017)

P2 was very capable at expressing herself through her body. She could concentrate on what her body was physically experiencing during musical participation. This was something that was not really evident in the other three participants. This may be as a result of her having regular dance lessons, which had taught her to express herself through movement. However, two of the other participants also had dance lessons.

P3 was an academically capable young man having attended main stream school (with support) and had achieved some GCSEs. Despite this, it was apparent that his ability to remain focussed was an area that could be improved upon when he initially joined MMP. Bearing in mind the recent loss of his mother, this was not a happy time for the family and many adjustments were having to be made at home. This was a very unsettled time for P3, which was no doubt having a negative influence on his behaviour. On first joining MMP, David Stanley described P3 as a young man who was often slightly inattentive and could be

thought of as the 'class joker'. He was often cheeky, unfocused and made jokes during class time.

P3's father described how music-making had helped his son to engage more with what he was doing and that the process of learning musical skills had encouraged the development of P3 being able to concentrate on more complicated tasks requiring sequencing or ordering, which he had previously found difficult (Photograph 61):

> Whilst you know, and it was unusual that he has a good left foot on him but he couldn't grasp the team play bit. Whereas here he, he can understand that he is playing the bells and he has to follow a sequence, which is team play! (P3's father, interview)

A newly acquired ability to follow a sequence of instructions had allowed P3's concentration level to progress and his father felt this improvement had extended out into other areas of his life, such as being generally more able to organise himself or, for example, being able to arrange an evening meal for guests. By using a different approach to the one used in sport through playing team football, P3 had found an effective way to further his learning capacity through music-making.

Furthermore, P3's father was enthusiastic about how determined his son now was to fully focus and engage at MMP. He described how he could often see his son really struggling to learn a new piece of music, for weeks and weeks, and then suddenly it started 'to click'. The ability to remain engaged and not give up allowed this process of memorising new repertoire to happen over a period of time. Typically speaking people with LDs learn at a slower pace than those without LDs and an ability to remain focussed is central to their successful

learning. This keen determination was indeed something that was seen in all four participants

in a variety of different scenarios.

Field notes for P3 outlined a mature and attentive student who fitted in well with the other

members of the group. It was hard to believe that this was the same person that had joined

MMP just a couple of years previously:

> In terms of concentration levels, P3 has improved considerably even during the time of
>
> field study. He is now fully attentive and has stepped up to the role of student ambassador
>
> – he is no longer mucking about or being cheeky. His sensible attitude is a delight to
>
> watch and he is going from strength to strength. His concentration levels are now
>
> comparable with the other MMP students who have been coming for many years. (Field
>
> notes, 12th December 2017)

P3's maturity had improved beyond all recognition and he was now a respected member of

the group and a valued student ambassador for MMP. This dramatic change in attitude

probably came about for a variety of reasons, including his learning how to behave in the

MMP environment and through understanding what was expected of him in this new

situation. Also, his appointment as an ambassador provided him with a role to be fulfilled

and encouraged P3 to step up to this responsibility. The grieving process for him and his

father had now progressed to a different stage. P3 demonstrated how music participation

encouraged concentration to improve over a relatively short period of time and without any

perceived stress (see Photograph 62). Through the learning processes involved, P3 had been

able to achieve his musical potential and furthermore to transfer this focussing ability to other

areas of his life outside of music.

Photograph 62: P3 looking organised and fully focussed

With regards to P4, being the oldest of the participants, his attendance at MMP helped to keep him physically and mentally active. This was particularly important with his sister's concerns about his declining memory function. Although he was the most reserved of the four participants, he paid good attention during the sessions and remained engaged for the majority of the time. P4's sister explained how she thought that P4's active involvement at MMP helped to maintain his concentration level: 'definitely…Yeah definitely…And keeping it, keeping his mind active' (P4's sister, interview). P4's familiarity with the MMP environment ensured that a regular routine was kept and this helped to reduce any anxiety related to uncertainty. The fact that P4 was very settled helped him to concentrate to his best ability and obtain the most out of his musical involvement. The repetitive nature of MMP with familiar repertoire, and new ideas introduced very gradually, was the type of supportive environment conducive to boosting focus for this participant.

Field notes described P4 as an engaged member of the group in a variety of different situations. For example, during African drumming, P4 never once forgot that he started the pulse for each drumming session and proudly chanted '1, 2, 3, 4' to get the beat started. This activity particularly suited P4 as it was done seated rather than standing. Although he did join in with the more physical activities, he did seem to be happier when sitting down. He seemed to feel slightly vulnerable when he was up on his feet. He was not as mobile as he used to be and often struggled with uneven floor surfaces.

P4 focussed carefully when David Stanley spoke to the group and he demonstrated a mature and respectful attitude towards the staff (see Photograph 63):

> P4 is good at listening to verbal instructions given to the group. Whereas some of the group members require a second or two to settle down, with P4 this is not the case. Maybe because he is a much quieter person so this comes more easily to him. He is a good listener and he always takes on board what he is being told - his actions show that he has understood the instructions given. (Field notes, 14th July, 2017)

Photograph 63: P4 listening carefully to instruction

During one of the London Palladium rehearsals when Rosie Ladkin (see Section 5.7.1.3, *Emotion management and support*) visited the group, P4 showed a particularly high level of engagement for an extended period of time during the afternoon. Whilst the singer was rehearsing with the group, P4 was totally captivated by her singing:

Today we have a visit from Rosie Ladkin – the actor/singer who is playing the narrator at the Palladium show 'The Label'. Rosie worked with the students before at the previous Palladium show in 2015. Session started with the first song and P4 sat very still and paying full attention to the acting. This is a powerful play about a child with DS. P4 was absolutely mesmerised by Rosie's singing – staring intently at her and sat completely

motionless. Mouth open and looking very thoughtful. Quiet and starting to look tired by late afternoon but still attentive. (Field notes, 14th July, 2017)

Similar to P1, P4 was able to remain engaged even when weary at the end of the day. An increased level of stamina is a useful tool for supporting the learning process. Likewise, this attentive attitude could help P4 to remain focussed on other pursuits outside of MMP. If opportunities to practise listening skills and receive direction are freely available in a non-threatening situation such as MMP, this could help P4 to maintain his memory function for as long as possible and help him to follow the semi-independent life style that he is accustomed to (see Photograph 64).

Photograph 64: P4 remaining focussed at the end of the day

Summary: Concentration encouragement

The participants all clearly demonstrated an ability to focus and remain engaged whilst at MMP. The various musical activities encouraged different types of concentration and each individual experienced this in a unique way according to their personalities and the given situation at the time. Regular participation in music has the potential to maintain and even enhance this focussing skill, which is central to living a purposeful life and upholding WB.

5.7.2.3 Social development

Social development is the ongoing process whereby an individual acquires the skills necessary to successfully interact with others and is therefore able to function effectively within their own community (Ryan and Deci, 2000; Kids Matter, 2019). Typically the majority of this development occurs during infancy and childhood. However, for people with LDs this process can often be challenging and may require additional support or encouragement to allow the individual to reach their maximum social potential and become their own unique person (Reiff, 2019). The ability to create and maintain valued *friendships* and to develop positive *relationships with staff* that are encountered on a regular basis, are both central components to successful *social skill development.* The availability of regular *social activities and opportunities* can support this developmental process.

Friendships

The ability to create and maintain *friendships* is a key element to an individual's social functioning (Diener and Seligman, 2002; Leach, 2016; Kids Matter, 2019). A few close friends can have enormous benefits to WB including decreasing anxiety, avoiding loneliness and providing a valuable source of emotional support (Diener and Seligman, 2002; Leach, 2016). This is equally important for those with and without LDs. All four participants and

their families talked positively about the friendship opportunities created not just by making friends through attending MMP but also about the wider network of friends created through the music participation itself. Like-minded musicians were able to forge new friendships through a shared musical passion (see Photograph 65).

Photograph 65: P1, P2 and P3 (with fellow student) enjoying time spent with friends at MMP

When P1 was asked for his reasons for attending MMP he answered 'meeting new people, making new friends' (P1, interview), which was second in importance to him after 'learning music'. He talked about his friends at MMP with enthusiasm. When asked about how he got along with the other students at MMP he replied: 'Yes I would say I love my friends…I love see my friends, I love see my friends, erm, I love them. I think that's it really!' (P1,

interview). It was clear from P1's response how important his friendships at MMP were to

him – he volunteered the word 'love' when asked about how he got along with them which

signified a strong bond was present. Further evidence was provided from P1's father when

he discussed the depth of the friendships his son had with his MMP friends: 'I mean he's got

lots of friends there. Erm, from my point of view they seem to be more than acquaintances, if

you know what I mean. They all love each other, yeah' (P1's father, interview). P1's father

also thought the relationships were strong and referred to how they 'love' each other – this

may be partly due to the longevity of some of the friendships which pre-date their MMP

involvement. Some of the students met at special needs nurseries or schools and possibly

MMP has helped to sustain these relationships and facilitate regular social interactions

between the friendship groups. P1's father added a further interesting point in that through

his experience he felt that there was no conflict or animosity present between any of the

students or within different friendship groups: 'I don't think, I don't think there's any friction

between any of them actually. Erm, there are obviously, the range of closeness if you like, it

varies. But there's no little cliques' (P1's father, interview).

P1's father found the friendships were positive experiences for his son and without any

perceived negativity, providing an opportunity to develop closer bonds for those who so

wanted. Field notes backed this with several references to P1 interacting with those around

him in a variety of situations – not just with his close knit friendship group but with other

students in the wider group:

> P1 is interacting with those around him, he is confident socially and is keen to talk to the
>
> others. He spent his lunch time talking to his closer friends and eating their packed
>
> lunches together. Lots of laughing and generally having fun. This afternoon he is

communicating with his peers sitting either side of him, making sure they are OK. He appears very mature in this situation and likes to be in the middle of everything that is happening. (Field notes, 3rd March 2017)

P2 was equally effusive about her friends at MMP and similarly listed this as one of her main reasons she enjoyed the sessions so much: 'I love being here with my friends…and I love my mates here…I happy seeing my mates' (P2, interview). Again the use of the word 'love' was used to describe being with her friends indicating a strong bond as in the case of P1. When asked what her relationship was like with the other students at MMP in general, P2 simply replied 'ah lovely'. She also added that she had made new friends by joining MMP and these were people she had not known previously. There was nobody she could think of that had caused her any memorable problems, so once again this was another positive social experience (see Photograph 66).

Photograph 66: P2 and P3 enjoying their time together

P2's mother talked about the 'camaraderie' and how all the students 'have all got something in common' which united them together. She mentioned that on the odd occasion when her daughter had to miss a session, how she was still thinking about her friends and how they would be missing her - although this may have actually been more of a reflection of how she was missing them: 'If she does have a day off, which I don't think she has this year yet, but if she does she goes 'oh I bet all my friends are missing me!'...her heart is still there' (P2's mother, interview). P2 appeared to miss being at the group and being with her friends when she could not attend, and they too noticed when somebody was absent. These relationships were a significant positive feature of their lives and were missed when they were disrupted for whatever reason, even for a relatively short space of time. P2's mother spoke fondly of the opportunity to meet new people and for her daughter to forge new friendships: 'It's with friends who are always welcoming – she's made a whole new bunch…because she has met a

whole new group of people that she considers friends/family – the Music Man family' (P2's mother, interview).

P2's mother spoke affectionately of her daughter's special closeness with her friends at MMP and this came across as a significant contribution to her daughter's life, and indeed to hers as well. She mentioned again the fact that she was a single parent having lost her husband to cancer and how her life could have turned out to be very isolated:

> As I say with all the mums and dads, it's all smiley all round. It's another little
> community…and when you are on your own like I am, it could have been so different.
> Yes…I know all the mums and dads, with Music Man we do this together, it's a lot more
> community. But it does a lot for everyone…you know we can email each other and it's
> very equal. There's no, I do like the fact that it doesn't seem to be, not in my eyes anyway,
> any competition. (P2's mother, interview)

In a similar way to P3's father after the loss of his wife, MMP had provided P2's mother with a valuable social network for her family - not just for the individual who actively participated in the group. MMP provided opportunities for all family members to commit as much time and commitment to the group as they deemed appropriate. This was always welcomed and was a valuable benefit to their own son or daughter and to the group as a whole.

Field notes for P2 described a highly sociable individual with a real zest for life:

> P2 is chatting with everybody from the moment she walks through the door! She is
> always in the thick of anything that is happening and likes to be active and up on her feet.

Her enthusiasm is apparent and she is not shy in talking about what she has been doing and what is going on in her life. She particularly likes to go and see musicals and regularly attends shows with her mother. Anything musical seems to grab her attention. (Field notes, 3rd March, 2017)

Even though P2 had not been a member of the group for as long as some of the other participants, this was not visible when observing her interacting with the group and talking among her friends.

P3's relationship with his best friend was his inspiration for joining MMP (see Photograph 67). He had watched him performing at the 2015 London Palladium show and this had been the catalyst for him wanting to become a part of MMP (see Section 5.7.2.1, *Role modelling*). The strength of this friendship was apparent and had resulted in a whole new range of musical experiences for P3. P3's father also confirmed this:

Whenever I said to him before 'do you want to go to a drama school?', 'cos he's very outgoing…'no, no, I could never get on stage, I'd never, no way'…very shrinking violet unless he is in a social situation like this. And then he saw his friends on stage and went 'wow, that's what I want to do!' (P3's father, interview)

Photograph 67: P3 with his best friend and inspiration for joining MMP

Comparable with P1 and P2, P3 and his father listed friends as being the second most important influence for his son's participation at MMP:

> There's two things…one is the music, second is the other students, yet whilst he obviously really loves David and Jenny. But it's the other students, he's made friends with others like X, Y and Z. He's made friends with them…The other students, it's the social thing. Well that's quite funny actually 'cos he's made a couple of friends of people he's not met before despite him knowing extensively and going to two colleges on special needs courses. There's still one or two he's not met before…yeah he gets on very well with X 'cos they often get off the bus together. (P3's father, interview)

Again there was evidence for not just strengthening existing friendship bonds but also the opportunity to establish new ones. P3 also referred to the fact that he enjoyed meeting new friends at MMP. Arguably, the fact that music making was the prime consideration for these participants attending MMP was encouraging, as this would indicate that MMP was

providing more than a social gathering for these people. Music participation was the key factor involved in facilitating these relationships.

Both the fathers of P1 and P3 remarked on how MMP had provided dating opportunities for their sons, which they felt was an important aspect of 'growing up' and fitting into society as young adults:

> There's been one or two, 'cos P3's a bit of a ladies man! And there's been one or two who really, in fact there's three now, who go to Music Man, that all want to be his girlfriend. Yeah and he will go 'yeah, yeah', 'cos he doesn't want to turn anyone away. I don't mean it in anyway but you know, he wants everyone to be his friends. And then I mean there was one girl who goes to Tuesday, erm, they agreed that they were gonna be boyfriend and girlfriend – not that they go anywhere, they don't do anything. (P3's father, interview)

The opportunity to experiment with romantic encounters in a safe environment is a very useful tool for helping to develop meaningful relationships (Mencap, 2016). As people with DS are now experiencing a much increased longevity, many go on to have long term partners or marriage. In this respect, P3's father was very concerned about the problems that social media, particularly Facebook, can create for people with LDs:

> It's happened before with another girl who does go to Music Man. Erm, she got very possessive. Very possessive, and it got, we had to end up taking people off Facebook and all that sort of thing. I mean Facebook is a nightmare for anyone with special needs. It's an absolute nightmare! (P3's father, interview)

As can be seen from the above explanation, social media is a potentially hazardous platform for people with LDs to communicate through – misunderstandings are commonplace for those without LDs so for those with, the consequences could be even more worrying. The

ability to actually meet others in a face-to-face situation is more appropriate and could further enhance social functioning.

Field notes revealed that P4 spoke less about his friendships than the others. He did, however talk about a 'best, best, best, best, best friend' that he had at MMP. Maybe he felt happier having just one or two closer friends, which would suit his quiet temperament, as opposed to having a larger friendship circle. Interestingly, P4's sister also considered that the friendships were an important motivating factor for her brother's continued attendance at the group:

> It adds, like the friendships. Definitely the friendships because he sees some of them again on a Saturday. There is such a big friendship circle there…you know, if he hadn't got that, gradually, 'cos a lot of Down's syndrome, erm, people, they sort of, the same as P4, he will go back. If you didn't put a rocket up his backside! He would gradually slip back and then all of a sudden, no P4, no, and they need that all the time on a regular basis, otherwise he would. (P4's sister, interview)

P4's sister thought that the social interactions that her brother experienced at MMP served to keep him in contact with his friends, when otherwise he might not actually make the effort if left to his own devices. The reduction of loneliness and isolation is an important problem to be mindful about when people are living semi-independently within the community. She also listed the learning and playing of instruments to be what she thought was the most important consideration for her brother (after friendships).

Summary: Friendships

All four participants and their families felt strongly about the importance of friendships. Suitable opportunities to meet new friends and maintain and strengthen existing relationships were considered important. There was a degree of fondness between the students mentioned, indicating the presence of meaningful social encounters. It would appear that MMP was providing a valuable source of developing authentic relationships with others, aside from the primary benefits of the music-making process.

Relationships with staff

Relationships with staff was concerned with how the staff and students interacted at MMP, in the learning environment and within a social context. The relationship between key staff members and their students was paramount to the group functioning efficiently. As can be seen in a previous section on *role modelling* (see Section 5.7.2.1), the influence of the tutors was highly significant on the students. Not only from the standpoint of a valuable teacher, but the tutors were held in high regard by the students and were frequently seen as a trusted 'friend' who could provide support when sought. This sense of closeness with others fulfils a basic human need to feel a sense of belongingness (Maslow, 1943).

All four participants talked about their relationship with David Stanley and he clearly was a pivotal figure in their lives. P1 mentioned that seeing David Stanley was one of his main reasons for coming to MMP (see Photograph 68).

Photograph 68: P1 and David Stanley sharing happy times

Likewise, P2 referred to David Stanley as 'lovely and smiley' and his warm and positive nature seemed to have a direct impact on those he worked alongside.

When P3 was asked about how he thought of David Stanley, either as a friend or as a teacher, he replied: 'He is like a brother I never had, like a brother' (P3, interview). P3 had a particularly good relationship with David Stanley and was frequently seen chatting with him during break or at lunch time: 'He tends to want to go and tell David everything…you know,

and but that's great. I mean David is so good, he doesn't push anyone away' (P3's father, interview). P3 voluntarily referred to David Stanley as a 'brother', indicating a perceived degree of closeness and trust comparable to that normally experienced among family members (see Photograph 69). This level of trust is rarely seen outside of the immediate family and although beneficial for the student, could potentially become a significant encumbrance for the teacher concerned. Staff also need to be mindful and ensure that students do not develop too close a bond or dependency on them, which then has the potential for them to become overly attached.

When P4 was asked why he wanted to keep on coming back to MMP after all these years, he replied: 'I want to – I like David and Jenny' (P4, interview). This participant was freely choosing to attend MMP and one of the main reasons he enjoyed it so much was his positive relationships with his tutors. It was clear from these responses that the tutor/student relationship was central to the success of MMP.

Photograph 69: P3 and David Stanley

Interviews with the parents of the participants provided an equally positive account of staff relationships with their family members. P1's father spoke of his son's relationship with David Stanley as being a positive addition to his life:

Very good, yeah very good. I would be very hard pushed to come up with anything negative, really, no, nothing. All positive, well I think David is always encouraging. Not just to P1, to everyone…he treats them like adults. (P1's father, interview)

Again there was reference to David Stanley's warm and encouraging nature. The very fact that he treated the students as equal adults and not children was a critical factor in the development of a solid foundation upon which to create a trusting, workable partnership.

P2's mother commented: 'She loves him, well they all do don't they? Well she trusts him, completely trusts him and he leads her doesn't he? He leads them all' (P2's mother, interview). The theme of trust was repeated by this mother, and can be an ongoing concern for these families bearing in mind the particularly vulnerable nature of people with LDs.

P3's father spoke of his son's relationship with David Stanley as:

> …almost hero worship, I'm sure a lot are. It's the same with Jenny, he loves, loves, loves Jenny. And her mum Janice, 'cos we see her at night sometimes in the British Legion here 'cos she goes and plays cards there. (P3's father, interview)

Similarly, P4's sister responded in a like-minded way and described her brother's relationship with David Stanley as:

> It's someone he can confide in and erm, with P4, trying to persuade P4 to move and things like that, David has also helped with that situation…I would say that David has a way, he has a certain way with him. (P4's sister, interview)

Field notes recorded many happy interactions between the staff and students at MMP both when having regular weekly music sessions and when out and about performing. A most interesting observation was the ability of David Stanley to carefully maintain this relationship with his students:

> On arrival at the MMP group many of the students are wanting DS's undivided attention to tell him their news or just to chat. He seems to have the knack of making them all feel heard but not allowing any one particular individual to dominate his attention. This is a

real skill that is so valuable in this situation – everybody wants to feel they are the most important person in the room! (Field notes, 3rd April, 2017)

Relationships with other tutors and volunteers also appeared to play an important role in creating a positive learning environment (see Photographs 70 and 71).

Photographs 70: P2 with MMP tutor Jenny Hitchcock

Photograph 71: P4 with volunteer helper Jon Webber

Summary: Relationships with staff

The staff were key figures in these participants' lives. They had the potential to make a significant positive impact through their long term relationships with the students at MMP. All staff members, not just David Stanley, were mentioned by students and their families, alongside volunteers, visiting musicians and any other significant personnel who had direct contact at MMP – these people were all in a position of power and therefore must be considerate of how this power is utilised. The type of relationship the students had with David Stanley enabled an informal teaching approach where everybody was relaxed but still sufficiently engaged and ready to learn. The atmosphere was highly conducive to learning and it was therefore not surprising that much was achieved during these sessions. The staff at MMP had an excellent rapport with their students and a deep understanding of their individual needs, which was clearly visible to an observer watching the group.

Social skill development

Social skill development is the process whereby effective social skills are learnt and

maintained. Effective social skills are essential if an individual is going to lead the most

fulfilling life possible. The ability to understand others and be understood in social situations is something the majority of people take for granted. MMP was a highly sociable environment with many opportunities to practise social encounters in a setting that was familiar and safe.

All four participants commented on how they enjoyed talking with their friends at MMP and that they felt they had found talking to others easier compared to before they came to the group. This was discussed in more detail with the family members of the participants. For example, P1's father spoke about how his son was now more able to socialise with people his own age:

> It's obviously helped his social skills because he's you know, more confident now. So he can talk to people, erm, I mean initially he was very confident with adults but not with his own age group. And that is back in history because being in the yacht club he's been around adults all the time…he mixes with a lot of younger people which I like. (P1's father, interview)

Being able to mix with peers of your own age is an essential life skill. Although this was previously an aspect of growing up that P1 had struggled with, his father felt that MMP had encouraged the development of his social confidence through being able to meet up with musically like-minded people with LDs.

P3's father felt his son also had really benefitted from the social interactions at MMP and how it seemed to encourage communication: 'It's a social thing as well. Whilst in between the tracks they are talking aren't they and they are enjoying the things, and they will have a bit of lunch together you know' (P3's father, interview, see Photograph 72).

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Photograph 72: P3 and P2 enjoying lunch together

P3's father then elaborated and explained how MMP was a topic that was much discussed outside of the classroom:

> We all went out yesterday and erm, I had to take P1 because his dad couldn't take
> him…and we had a bite to eat on the way and erm, him and P3 just talked nothing else but
> music. All the time. (P3's father, interview)

These two students shared a passion for music and having this shared interest encouraged their discussion and expressive language development.

P4's sister thought her brother particularly enjoyed the social experience of having a full day with his friends:

Yeah the talking to the other students and interacting with the other students, like the friends he has got on a Friday. When he's there, erm, especially when he goes all day. I think the ones that go all day, its lovely 'cos I've been there a couple of times when I don't work on Friday, when they all sit down and have lunch. They are all together…well I think that's nice if you are going all day to have that as well. (P4's sister, interview)

Again, lunchtime was mentioned as being a popular time for socialising between the students (see Photograph 73). P4's sister also remarked on how MMP gave her and her brother something in common to talk about together: 'Yeah he will talk about it. Non-stop! He will talk, he will talk about it non-stop. He will keep phoning me and everything like that, and bits and pieces' (P4's sister, interview).

Photograph 73: P4 and MMP friend socialising over lunch

A shared family interest is a useful tool for maintaining relationships and keeping dialogue fresh between family members. It can provide a central point for discussion, which is particularly valuable for those who predominantly fulfil a caring role, when conversation can often be restricted to more mundane issues such as living arrangements and medical appointments.

A noteworthy point emerged from field notes for two of the four participants. Both P1 and P3 had been able to develop their public speaking skills. For example, P1 recently gave an impromptu speech for a member of staff's birthday celebration (see Photograph 74).

Photograph 74: P1 giving a birthday speech to a member of staff

P1 was also invited to perform alongside some of the tutors at a fundraising summer concert:

> Summer concert at St Laurence Church, Leigh on Sea – P1 is one of about eight MMP
> ambassadors invited to perform at this event. P1 is given the role of welcoming guests and
> showing them to their seats. He is taking this job very seriously and chatting away to the
> members of the public as they arrive. (Field notes, 17th June 2017)

The willingness to talk with people that are unfamiliar to you is a highly advantageous skill
that can be used is so many different ways. P3 showed a similar willingness to talk with
members of the public albeit in a different situation:

> On the bus, we go on the bus to Southend. It takes twenty minutes and a couple of times
> he started talking to, you know, I have to be careful because if people don't want to talk.
> But generally they will have a chat with him and he will tell them all about it. (P3's father,
> interview)

Summary: Social skill development

The many social interactions that took place through MMP appeared to provide these
participants with opportunities to further improve their social skills. For example, lunch
time provided a chance to catch up with friends, as did the many trips away to
performances or workshops. The music itself was a valuable discussion point for families
and friends alike, and the many new people that were encountered through the varied
activities added considerably to the social exposure of these individuals.

Social activities and opportunities

The social aspects of participating in musical activities can be broad ranging both for the musician who was taking part and their close support network. MMP allowed families to share quality time together, participating in something enjoyable. With many additional tasks requiring attention, individual families could decide on how much of their available time to dedicate to MMP, aside from the music itself. For example, joining the parents committee; marketing opportunities; maintenance of vehicles and instruments; and, the never ending challenge of fund raising. However, there was no pressure to do anything and many opted for a less active role. One of the major advantages of being more actively involved was the resulting social opportunities that arose from these regular encounters (see Photograph 75).

Photograph 75: P2 and P3 (on the right) at a MMP related social event

Two of the participants (P2 and P3) have parents that had lost their partners to cancer and these families both felt that their involvement with MMP had helped to fill this void. P2's mother lost her husband about twenty years ago and she had kept herself very busy with caring for her adopted daughter with DS and fostering new born babies who were awaiting adoption. When talking about MMP, she felt her involvement was a significant part of her social life:

> For me, I so enjoy it. I enjoy watching them do it. I enjoy being involved because don't forget I'm a single parent. So it's another, it's another added thing for me. I've met new people. We all get on, we went to lunch at the Barbican with C's mum, she joined us, and who else's mum, A's mum. For me, at my age, I'm meeting new people. I'm experiencing new things and I think it's keeping me young. Do you know what I mean? I think it's not only her Music Man, it's mine because I like to know what's going on. I like to go to the concerts, I like to join in…it's another little community. And when you're on your own like I am, it could have been so different. (P2's mother, interview)

It was clear from this discussion that P2's mother was socially benefitting from her daughters' involvement in music participation. It had provided her with a variety of social opportunities through the activities themselves and through the friendships created. The core of MMP is a highly sociable and tight knit community with the members sharing in varied social experiences, including annual holidays and shared birthday parties (see Photograph 76).

Photograph 76: P3 and P2 (with P2's mother behind) on a weekend away socialising and performing

Preventing isolation and loneliness is a key factor in reducing stress and supporting WB (NEF, 2008; Department of Health, 2011). P4's sister also pointed out how the social aspects of being part of MMP had helped to prevent her brother from becoming isolated:

> This is the other thing, when you are not living at home, you can't get to
> anywhere…where he lives now, where they have taken a lot of the community bit away
> and he is isolated so he needs to have that. (P4's sister, interview)

The loss of P3's mother was a more recent loss and the grieving process was still very much taking place for this family. P3's father described how MMP had helped him to come to

terms with his loss by providing him with a sense of purpose and providing a sociable activity that both he and his son very much enjoyed being part of together:

> But now my week is full and like everyone says I don't know how I had time before…you see now I'm fully involved in lots of things and I love going there with him. Meeting the other parents, as we do, we have a natter about things, you know. (P3's father, interview)

Further support regarding P3's social involvement at MMP was received during interview with P2's mother:

> P3's father, he was, before P3's mother died, we hardly saw him. Very quiet, very serious man. Very quiet…God! He really has, he even dances sometimes when we go to places. And he comes to Hayling as well because he was going to and B died. I think he was just [shrugs shoulders] but he couldn't because he had P3. So he came on a Friday, I didn't say too much 'cos we were B's friends, we didn't really know P3's father. He never came to Little Dragons when we all met when they were babies. And I knew he had a tough time when P3 was born as well, 'cos by what B had said. So I mean, I did think when B, if, when B died, I thought P3's gonna be going somewhere. That's what I thought. I did't think he could cope but he has coped brilliantly. He's on, he's on that bus, he's chatting away about Music Man, and he's going out there and telling people. Amazing! (P2's mother, interview)

Here P2's mother's account described the complete turnaround of P3's father from a full-time worker to P3's primary carer. P3's father attributed this at least in part to his involvement with MMP.

Field notes observed many social interactions taking place between the students and their families. These appeared to provide a feeling of belonging and unity and MMP clearly created an abundance of social opportunities which were both directly linked to music, for example days spent away performing, or indirectly, for example through birthday parties, holidays and talent shows.

Summary: Social activities and opportunities

There were many *social activities and opportunities* that arose as a result of being part of the MMP community. The impact of this was significant and extended beyond the reach of the participants and onto their families. For two of the families, the effect was even more valuable as it had provided them with a worthwhile social outlet after the loss of their partners. MMP encouraged families to spend quality time together following a shared goal of music-making.

<u>5.7.2.4 Educational Development conclusion</u>

The three sub-themes which formed the overarching theme of Educational Development are summarised in Table 5.5 below:

Table 5.5: Summarised sub-themes for the overarching theme of Educational Development

Sub-theme	Summary

Learning through music

Three sub-sub themes combined to form this sub-theme of 'learning through music' (*musical education, role modelling* and *additional learning opportunities).* Learning through music was observable in all four participants in their own individual approach. Although a positive learning outcome was present for each one, the means by which this was achieved was highly idiosyncratic. For example, P1 had been able to develop his conducting skills; P2 demonstrated a willingness to tackle new tasks; P3 was determined to progress and regularly practised at home; and, P4 was keen to show off his musical talents through performance. Each had their own strengths and challenges to manage and it was through identification of these that successful learning was achieved. Different abilities and learning styles; different perceived experiences; and, different interpretations all combined to produce the varied positive outcomes identified for these individuals.

Focus development

One final sub-sub theme contributed to the sub-theme of 'focus development' (*concentration encouragement).* Focus development was noticeable for the participants, with each able to utilise their unique skills and interests to support this area of personal development. There was plenty of evidence to suggest this musical environment encouraged engagement at the highest level, for example during long sessions spent in rehearsal for major London performances. This opportunity to enhance focussing skills was a beneficial skill to acquire, which would prove useful in many additional areas of life for these individuals.

Social development

> Four sub-sub themes contributed to the sub-theme of 'social development' (*friendships, relationships with staff, social skill development* and *social activities and opportunities).* Social development was taking place for the participants, with the necessary freedom required to reflect their individual personalities. New friendships were formed and existing ones strengthened, all within the relatively safe confines of the MMP environment. The relationships between students and staff were positive and created an encouraging environment in which to learn. The participants were provided with many opportunities to enhance their social skills – from relaxed chatting over lunch to public speaking. The social aspects of MMP created a community atmosphere and allowed families to share a common interest.

In conclusion, Educational Development was apparent for all four participants through participating in music and the varied opportunities that arose from this. Appropriate learning was taking place and the students were able to remain focussed and engaged during the sessions. Social skills were given every opportunity to progress, and all participants presented as socially well-adjusted individuals. These results indicated that participation in music at MMP had the potential to support this aspect of WB.

Overarching theme 3: Meaning

The overarching theme of Meaning was present for all four participants, across three categories of data collection (participant interview, family interview and journal of field notes). Two related sub-themes combined to generate the overarching theme, including: (1) significant to life, and (2) significant to life of family.

5.7.3.1 Significant to life

This sub-theme was concerned with the impact of MMP on the lives of the participants, and how they individually perceived this. This could include how *important* an activity the participants felt MMP was, or the opportunity to experience *life changing* events.

Importance of MMP

The *importance of MMP* was related to how much importance each participant placed on MMP, either directly related to music participation or in the broader sense. P1 frequently mentioned how important an activity MMP was for him. He also commented that it was his favourite activity and that having the opportunity to learn conducting was his 'favourite thing ever'. As seen in the previous sections *enjoyment* (see Section 5.7.1.1) and *role modelling* (see Section 5.7.2.1), conducting for P1 was a highly significant addition to his musical pleasure and would seem to be having a beneficial impact on his life: music was helping him to create a sense of meaning and identity. P1 thought of himself as an assistant conductor to the staff, and for him this was an important part of who he had become as a person. He

practised at home and every week at his MMP sessions, demonstrating a high level of

determination to succeed (see Photograph 77):

Photograph 77: P1 practising his conducting skills during his weekly MMP class

P1's father also described the importance of MMP as an activity for his son. He felt it was

the highlight of his son's week: 'I would say it's very important to him' (P1's father,

interview). P1 discussed how he tried not to miss any MMP sessions, which provided further

evidence for how important MMP was to him. His father also mentioned how P1 only ever

missed a session if it was unavoidable, such as if they were away on holiday or if he was

unwell.

Field notes reported P1 as taking his music very seriously and always giving of his best to

whichever task he was taking part in. He viewed his role as a student ambassador as

particularly important to him and this appeared to provide him with a sense of value and

identity:

P1 can be very serious at MMP and is always fully committed to anything he is asked to

do. This appears to be a reflection of the importance he places on his time spent there. He

is a key person within the group and he is an excellent example of a student ambassador.

This for him is like a defining feature of his MMP presence, and in fact his sense of who

he is as a person – he appears to understand the importance of his role and talks about it

often. (P1, interview)

P1's father also reported that his son spoke about his 'jobs' that he had to undertake as part of

his role as an ambassador, for example, helping to set up and pack away at each session. His

father felt that by P1 being given this responsibility he had risen to the challenge and had

greatly benefitted as a result. MMP had now become even more of a key focus for P1 since

this appointment. As an activity, MMP was clearly important to P1 who thrived within this

musical environment (see Photograph 78).

Photograph 78: P1 carrying out his 'jobs'

P2 was equally enthusiastic about the importance of MMP to her and how it added considerably to her life. When talking specifically about how important an activity it was for her she replied: 'Music Man is brilliant, I would say it's the best. My life, I love it here' (P2, interview). From this response it would seem that P2 loved her life through her 'brilliant' experience at MMP. She also commented on how MMP was her 'best' activity. Through her use of words such as 'brilliant' and 'love', this demonstrated the level of importance that P2 placed on her involvement with being part of the MMP community. So from this perspective provided by P2, it would seem that MMP had the potential to add a significant level of meaning to her life.

P2's mother provided an in depth account of what she felt the importance of MMP was to her daughter. She talked about her daughter's life with DS, and the many challenges that this brought to their family. However, for P2, she felt that her life had been improved considerably through music and the efforts of all involved with this. P2's mother was extremely grateful for this and felt sad that not every person with a LD had these musical opportunities available to them:

When you have got Down's syndrome life can be really hard. There is often not much going on, particularly when you're an adult. Most of the stuff round here is for the kids. Of course there are centres to go to but they don't really do a lot there and they cost so much. But with the music, she just loves it. This is an unbelievable turnaround for her…and I thank them for that…they make her feel valued. You know for her life is so gifted. (P2's mother, interview)

P2's mother also mentioned that she had friends that were having significant behavioural concerns with their young adults with DS. She had not experienced anything like this with her daughter and she thought that MMP was at least partially responsible for this:

> There are people I know with youngsters of her age that are having a damn awful time with their kids. I have never had it with her because there's always been something to focus and concentrate on with this music. (P2's mother, interview)

P2's mother finished by commenting on what a negative impact would be felt if her daughter stopped attending: 'It would make a huge difference to her if she stopped…she couldn't not go' (P2's mother, interview). This account gave a clear indication of the importance of MMP through the eyes of a parent. MMP was having a considerable impact on P2 and for this reason could be viewed as a major factor contributing to her life experiences. MMP was important to P2 as an activity, and was adding to her development of meaning in life through the music and the many related elements this included.

MMP had become P3's equal favourite activity (shared with watching his football team). As mentioned previously, P3 was a very passionate football supporter, as was his father, indicating how important MMP was for him. P3's father also mentioned what a key feature MMP had become in his son's week. He too equated it with football: 'It's a big part of his week, massive actually…I'd say it is probably equal, maybe fractionally second, no, equal with football…it's probably higher than most other things I think' (P3's father, interview).

P3's father was keen to share his thoughts about music and DS in more general terms. He felt that people with DS seemed to respond in a positive way to music and it was something

that they all appeared to benefit from through his personal experience. He thought other families that he knew with members with DS had seen similar positive responses to music:

> I know a lot of people with children with Down's syndrome (I keep calling them children but they are adults now!) erm, and music is high up for all of them. It's very important to people, I think people with Down's syndrome do really relate to music, very well. So I think it's, that's definitely important. (P3's father, interview)

This was an interesting point to hear as P3's father was the only family member to specifically mention DS and an appreciation of music. Bearing in mind the historical references on this subject (see Chapter 3, Section 3.6), P3's father felt there was a connection between music and DS.

P3's father described how his son was keen to tell people about MMP, particularly when they were travelling together on train or bus journeys. He felt this was because it was something that was very central to his life and he wanted to share this news with others:

> Everyone he sees, he tells them about Music Man. Every person, on the bus he will be talking about it – on the bus! Yeah, it means that much to him. So they can see and he will try and encourage them as well. But even local people, you know, the majority of people don't even know about Music Man. (P3's father, interview)

P3 wanted to share his MMP experience – such was its level of importance for him. This willingness to share his MMP experience with strangers was attestation to the significance of this activity for him.

P3's father specifically mentioned how it would have a huge negative impact on his son if he could not attend MMP. He recounted again how P3 and his MMP friends talked about music non-stop, and how he missed it during the six week summer break: 'If it wasn't there, if it stopped, they would be devastated. Absolutely devastated…their faces just light up, don't they?' (P3's father, interview). P3's father was clearly concerned about this hypothetical scenario. His concerns were based on the importance of MMP to his son and a reflection of the valuable benefits it was providing. This concern regarding MMP no longer being available was similar to the worries expressed by the mother of P2. Thus it would appear for these two families that the thought of no longer having MMP available was almost too much to consider (the Covid 19 pandemic is currently a very difficult ongoing period for the participants and their LD colleagues).

P4 found the stability and predictable nature of MMP to be important for him. Routine was essential for P4 and the structured nature of the MMP environment suited his needs in this respect (see Section 5.7.2.2, *Concentration encouragement*). He also rated MMP as his 'best activity'. For P4, MMP provided a unique feature which was not seen in the other three participants. P4's sister explained how MMP provided a means of being able to get P4 and his brother together on a weekly basis. P4's sister felt it was very important for them to be able to meet regularly and maintain their close bond as brothers.

Summary: Importance of MMP

The *importance of MMP* for each of the participants varied in accordance to their specific needs at that point in time. There were individual reports of MMP as being a 'favourite activity' for all four of the participants, and P4's sister mentioned that she thought it was definitely the 'highlight' of P4's week. Aside from the benefits gained through the direct impact of music participation, other important factors were evident. For example, as a means of getting a family together on a regular basis (P4), and by helping families through challenging times (P3). The participants and their families described MMP as being central to their lives and an important adaptable focus which served a variety of individual needs.

Life changing experiences and opportunities

Life changing experiences and opportunities were events that had a strong positive impact on the life outcome of the participant. These were seen in a variety of different situations, such as at performances at major London venues, or as a result of music-making itself. P1 described how he felt while he was waiting to go on stage and conduct at the London Palladium (see Photograph 79):

> I be happy, happy, yes, yes. Oh I'm so excited…oh and then all calm and sit back down and watch the show. Erm, I would say, my point of view, the Music Man Project is the best community…loads of people came, and come and support, to support their children. And they be proud of their children as well. (P1, interview)

Photograph 79: P1 conducting on the West End stage

This gave an insight into the experience of P1 at the London Palladium. His reference to MMP as being the 'best community' demonstrated its significance to him. The students appeared to give each other encouragement and this created a sense of contentment which spread throughout the group (see Photograph 80).

Photograph 80: P1 performing with one of his friends

In addition to these life changing performance opportunities, P1's father felt many of the changes he had witnessed in his son since joining MMP were also having a life changing impact. For example, the increased circle of musically-minded friends created through MMP. In particular, friends within P1's own age group, which he had previously been rather reluctant to socialise or interact with (see Section 5.7.2.3, *Social Skill Development*). The ability to form friendships with his own peer group had been an important step in social development for P1 and could therefore enhance his WB for the future. It would appear for P1 that MMP had made a life changing positive difference directly through the music-making process, and indirectly through its related outcomes.

From the enthusiastic manner in which P2 described her time at MMP, particularly with regard to performances, it would be reasonable to assume from this that the impact for her was life changing. P2's mother described how grateful she was for these 'wonderful opportunities' for her daughter and as a result of these P2 'simply loves her life'. P2's

mother never thought her daughter would experience these life changing opportunities through music:

> I can't believe, I can't believe it. I don't think she's even that musical but that doesn't seem to matter. How many people with DS like her can turn round and say 'I've performed at the London Palladium?' Erm, and hopefully shows like this will just be the start of showing people, that these lot can actually have a great life. (P2's mother, interview)

P2's mother mentioned again how she had battled for life saving heart surgery for her daughter as a young child, and how none of the hospitals had wanted to perform the surgery on her. She remembered how only twenty years ago attitudes had been very different towards DS and LDs in general. As can be witnessed through the forward thinking approach of MMP, these type of ground breaking projects have the potential to change the lives of people with LDs.   Music had opened up a whole range of life affirming events for P2, and her mother felt this had changed her life completely. P2 now led an exciting life full of opportunities and with much to look forward to in the future (see Photograph 81).

Photograph 81: P2 performing at the London Palladium 2017

P2 had also been invited to perform at several charitable events, alongside her MMP colleagues. Through these she had been able to meet several celebrities, whom she very much enjoyed talking to, particularly about her musical endeavours (see Photograph 82). These were very exciting occasions for P2 and would appear to have had a significant impact on her life outcome and on her level of WB.

Photograph 82: P2 and Paul O'Grady at a charity concert

P3 also had the pleasure of performing at the London Palladium show and this was something that he still talked about frequently. This had been the first major performance for P3 and it had been a great success, providing plenty of happy memories to be cherished (see Photograph 83).

Photograph 83: P3 on stage at the London Palladium with David Stanley

P3 had started at MMP just a couple of years ago as a shy and slightly unfocused individual. He had now developed into a confident young man who was able to perform on a West End stage to an audience of over 2000. P3 was even asked to sign autographs after his West End debut performance (see Photograph 84):

Photograph 84: P3 signing his autograph on the Palladium programme for audience members

The regular participation in music had provided P3 with the space and skill set to develop into the musician that he had always wanted to become. It was interesting to note that during quieter times at MMP, such as 'creative to music' time, both the London Palladium and Royal Albert Hall shows were foremost in P3's mind. This provided him with one significant event to remember and one to look forward to in the future, in equal measures (see Photograph 85 and 86).

Photograph 85: P3's drawing of the London Palladium show 2017

my Story

There was a man calld Graeme he is with a band calld music man We are going to the Royl Abblet Hall next Year in 2019 and the tickts are now out on Seal. I Would Like for everyone to come along It is in 2019 of April 15th I am ask

manager → David Stanely
Jenny Hitchcook
Graeme Shaw

my Wife Sam Hyter →
Tummy Jones
Dan Camdro drumer

Photograph 86: P3's drawing of the Royal Albert Hall show 2019

Like P2's encounters with celebrities, P3 had also been able to meet a couple of his favourite actors at a Mencap Christmas concert at the Barbican Centre. P3 commented that this was 'amazing' and he could not wait to tell his friends all about his experience. P3's father had found that 'joy' had returned into his son's life through the music, and this he considered to be a life changing effect for both of them (see Photographs 87 and 88).

Photograph 87: P3 with one of his television heroes – Matthew Horne of 'Gavin and Stacey' fame, at the

Barbican Centre

Photograph 88: P3 with comedian Hugh Dennis, at the Barbican Centre

Although P4 did not take part in as many external events as the other three participants, he did have the opportunity to participate in a celebrity calendar photo shoot. This was a fund raising event for Mencap and twelve MMP students were invited to be photographed alongside celebrities, one for each month of the year. P4 was paired with the former politician Ann Widdecombe (see Photograph 89).

Photograph 89: P4 and Ann Widdecombe together for the celebrity calendar photo shoot

This was a memorable day for P4 and he had been thrilled to be selected to take part. These type of experiences appeared to provide P4 with a boost to his enthusiasm for life and energy, which his sister felt was long lasting and noticeable for a period of weeks after.

Summary: Life changing experiences and opportunities

Through involvement at MMP the participants had been able to participate in a wide range of *life changing experiences*. These included a variety of performances at top London venues, such as the London Palladium and the Barbican Centre. The participants had met actors, comedians and politicians all through their involvement with music. These provided an abundance of treasured memories for each of them and their families, which added a significant degree of meaning to their individual life outcomes.

5.7.3.2. Significant to family

This sub-theme was concerned with the impact of MMP on the lives of the participants' families, and how they individually perceived this. This could include how they valued their family members' participation at MMP; the overall family benefits of participating in music; or, how this involvement directly impacted on the family in the broader sense.

Positive impact on family

Positive impact on family referred to any advantages or benefits experienced by the family as a whole, rather than those specifically linked to the participant. For example, bringing a family closer together through music, or through providing valuable shared family experiences. P1's father felt that the impact of MMP on his son and their family had been massive and had made a noticeable difference to their life experience. He described his immense pleasure at watching his son conducting on the London Palladium stage and commented: 'That is something that I will never forget all my life, seeing him walk across that stage to conduct at the Palladium' (P1's father, interview). These opportunities were creating lifetime memories for this family. This was a 'once in a lifetime' experience for P1, and his father and stepmother appreciated this opportunity greatly. There was also the

possibility of similar opportunities becoming available at future major events. The Royal Albert Hall show (April, 2019) was another occasion for P1 to further fulfil his conducting passion. P1's father also commented on the 'fantastic opportunities to travel' that MMP had opened up for him and his son. With advancing mobility problems, P1's father was very grateful to be able to undertake these trips in a supported way. This was something that he would not have been able to do on his own, so this was an added benefit for their family (see Photograph 90).

Photograph 90: P1's father in front, P3 and P1 behind, at the airport on MMP tour to Scotland (P2 and her mother in the background)

P2's mother was very aware of the substantial difference that MMP had made to her own life. She felt that she could relax and enjoy her time more as a result of her daughter's attendance at MMP and this was a considerable positive benefit for her in her role as a parent and carer (see Section 5.7.1.3, *Emotion expression and support*). As a single parent time was precious to her and she was grateful for any support in this way. Another major factor for P2's mother

was how full their lives were now (see Photograph 90). She explained how she was never lonely and there was always something happening through MMP, whether that be a concert, workshop, tour, or social gathering:

> Living on my own without a partner I could be so very lonely but because of all the stuff P2 does with music I'm not. Yeah, I'm never lonely, never, not a week goes by without something turning up. We even all go on holiday together you know, they all love it and so do we. P2 enjoys that more than any five star holiday abroad, 'cos she is with her music friends. They all join in with everything and they just love it. (P2's mother, interview)

The ability to reduce loneliness and isolation is a major component in supporting WB (NEF, 2008; Seligman, 2011). MMP and music were supporting the WB of this family through creating a wide range of social interactions, not just through the participation in music, but also through the social connections that had been forged as a result.

P3's father considered MMP to have been a major influence in helping them to manage their grief and the subsequent changes that had to be made to their lives (see Section 5.7.1.3, *Emotion expression and support*). For this reason, he considered his son's involvement with music had changed their lives for the better. It had reintroduced to them a sense of purpose and meaning and had shown them life was worth living again. This was achieved as a result of a commitment to music-making by P3, and consequently P3's father was able to commit time to supporting MMP and finding meaning through a new found interest (see Photographs 91 and 92).

Photograph 91: P3's father standing (on left) by the minibus he is responsible for. P2 is getting off the bus and P1's father on the right.

Photograph 92: P3's father driving the minibus, David Stanley on right and tutor Jenny Hitchcock on left

MMP provided P4's sister and her two brothers with an important route of communication which she found to be very helpful. She often found the carers involved with supporting P4

were not always efficient at communication with the family. Due to the large number of carers and often high staff turnover rates, communication was often erratic and confused. P4's sister felt that MMP provided a reliable method of communicating issues concerning the WB of P4 and his brother. She found the staff at MMP to be concerned for P4 and thus MMP was important in managing the care of her brother. If this wasn't the case, this would have been the responsibility of P4's sister, and with her brothers living in separate locations this would have been logistically difficult to organise. P4's sister mentioned her fond memories of the recording session for the 'Music is Magic' album CD, where she had sung one of the choruses. This was a completely new experience for her and she said it made her feel like a 'real popstar'. Her brothers thought this highly amusing (see Photograph 93).

Photograph 93: P4's sister being a 'real popstar' for the day with Shabby Road Studios

An exciting addition to the 'Music is Magic' show was the successful Guinness World Record attempt for the largest ever triangle ensemble. David Stanley composed a 'Triangle

Concerto' specifically for the event, which involved audience participation alongside the 200 MMP performers. Fifty auditors had the challenging task of overseeing the attempt and counting the number of triangle players. The record breaking total of 1521 triangle players exceeded the previous world record of 876 (see Photographs 94, 95 and 96). David Stanley commented: 'They are all world record holders! It was such a thrilling night at the Palladium and to break the world record was a fantastic achievement' (Stanley, 2017).

Photograph 94: The researcher (far right) and co-tutor Jenny Hitchcock conducting the Guinness World Record attempt at the London Palladium 2017 (Photograph courtesy of Paul Carpenter Films)

Photograph 95: Aerial shot of audience participating in Guinness World Record attempt at the London

Palladium 2017 (Photograph courtesy of Paul Carpenter Films)

Photograph 96: The official certificate recording the MMP Guinness World Record

Indeed, this MMP event could be described as a 'life changing experience' for the London Palladium theatre, as never before in its long standing performance history had there been a show performed solely by people with LDs.

Summary: Positive impact on family

The *positive impact* on these four families was easy to identify. They all recorded their differing perspectives on how their family member's musical involvement had added to their life outcomes. These varied in accordance with the needs of the family, for example, for P2's mother it prevented isolation, and for P3's father it had provided a worthwhile activity during challenging times. For these families MMP had proved to be flexible and had adapted to theirs' and their children's needs. Music had been at the centre of this process and this demonstrated the wide variety of family support mechanisms which can be achieved through this pursuit.

Negative impact on family

Negative impact on family was concerned about any potential disadvantages for the family that may have been the result of either music participation, or through the involvement with MMP in the wider sense. This may include factors not directly related to music but were the indirect result of music participation, for example, time commitment required. The families of P2 and P3 reported that there was no negative impacts of MMP at all that they could identify. Neither of these families could pinpoint any disadvantages associated with music participation or anything related to MMP.

The only slightly negative impacts reported by the families of P1 and P4 were the issues of tiredness and lack of time. For the family of P1 this was largely the result of ongoing health problems for P1's father. Mobility was a significant issue for him, so concerts in London or MMP tours created logistical problems for him in this regard. Although he did comment that with the addition of the minibus this problem had been greatly reduced (see Photograph 91).

For P4's family, the problem was more work related for P4's sister and her husband. They felt frustrated at times that they were not more available during the week and this restricted the amount of activities P4 could participate in. Also, because P4 lived semi-independently, this often created logistical problems with regard to his transport to and from events. However, both families felt that these were very minor concerns compared to the wide range of benefits that they received from their involvement with music at MMP. They acknowledged these factors were more of a reflection of their individual circumstances than anything related to either MMP or music.

Summary: Negative impact on family

Two of the four families (P2 and P3) involved in this study reported no *negative impact* at all from their involvement with MMP. Concerns raised by the other two families (P1 and P4) were minor and directly linked to their individual life situations. They felt these issues were insignificant in comparison to the positive impact they received.

<u>5.7.3.3. Meaning conclusion</u>

The two sub-themes which formed the overarching theme of Meaning are summarised in

Table 5.6 below.

Table 5.6: Summarised sub-themes for the overarching theme of Meaning

Sub-theme	Summary
Significant to life	
	Two sub-sub themes formed the sub-theme of 'significant to life' (*importance of MMP* and *life changing experiences and opportunities*). From these findings it would appear that all four participants found their involvement with MMP and music as 'significant to life'. This was achieved through a combination of both similar and different experiences for each individual. For example, all four reported MMP to be their 'favourite activity', and family reports confirmed this. Their perceived outcomes of this were all unique to them and their individual preferences and abilities. Their music-making had created many significant life opportunities that had the potential to make a lasting positive impact on their lives. Arguably the most significant of these was the 2017 London Palladium show 'Music is Magic'. All the participants found this event to be a major positive addition to their lives.
Significant to family	
	Two sub-sub themes combined to form the 'significant to life of family' sub-theme (*positive impact on family* and *negative impact on family*). MMP involvement provided an overall positive impact to the lives of the families of the participants. Advantages were unique to the varied circumstances of the families and were thus able to support their varied needs and adapted to their life situations. For example, P1's family enjoyed the opportunity to travel with MMP; P2's mother found it provided her with many social opportunities; P3's family had felt supported in their time of grief; and P4's sister felt it helped to keep their family bonded together. Any negative impact, such as lack of time, were far outweighed by the positive aspects.

In conclusion, a sense of Meaning was apparent in all four participants, and this extended out into their families. MMP was a key activity in the participants' lives and provided a wide range of life changing opportunities such as West End performances; travel; meeting celebrities; and, participation in a successful Guinness World Record attempt. The impact on the families was highly positive and had the potential to enhance their WB as a result. Very little negative impact was reported, and only in relation to specific life circumstances.

5.7.4

Overarching theme 4: Accomplishment

The overarching theme of Accomplishment was present for all four participants, across three categories of data collection (participant interview, family interview and journal of field notes). Three related sub-themes combined to generate the overarching accomplishment theme, including: (1) sense of achievement, (2) sense of self confidence, and (3) practical support.

5.7.4.1 Sense of achievement

The sense of achievement sub-theme involved any experiences of having done something worthwhile and difficult, as perceived by the participant and/or their family, which resulted in feelings of *satisfaction and/or pride*. Consideration had to be given to the fact that for people with LDs, relatively small achievements can often demand a huge amount of perseverance and determination for success to be perceived. This could be a feeling experienced directly by the participant, or by their family, for example, satisfaction through a specific musical achievement, or parental pride through a public performance.

Satisfaction and pride

Satisfaction and pride referred to any occasion where the participant demonstrated a combined feeling of contentment and pleasure relating to something they had achieved either musically, or directly as a result of their music participation. This could include the fulfilment of expectations and needs specific to that individual. For P1, performance was key to him feeling a sense of satisfaction and experiencing contentment. He talked in detail about the Christmas concerts that had just taken place the previous two evenings and how he felt this was an 'outstanding' evening for him, with lots of people coming to watch. P1 also talked enthusiastically about concerts that were coming up and how he wanted people to

come and watch him perform. An enthusiastic and appreciative audience would appear to be important in helping to create a feeling of satisfaction for P1. This seemed to provide him with a sense of achievement and pride – maybe this created a certain degree of affirmation of his value as a performer and musician. This external validation seemed to support his individual need for a sense of value and self-worth. In addition, P1 discussed how he felt it was important for all the parents and families to come along and watch their (adult) children perform, as this supports them too. This was an interesting perspective, demonstrating how P1 not only expressed the benefits to his own satisfaction and achievements, but he was also considerate regarding the feelings of his peers.

P1 expressed with much exuberance how proud he was to be a student ambassador for MMP (see Section 5.7.3.1, *Importance of MMP*). This gave him a huge sense of pride and a role he worked hard to fulfil. This was evident on many occasions, for example, in his commitment to handing out information about MMP events to the general public. He even kept a notebook full of 'important MMP information' (see Photograph 97) which he brought with him each week:

> Talking to them, what I have been doing. I give all the leaflets out to the people, what shows coming up, like the London Palladium. Yes I do, yes, and Christmas concerts, and anything, everywhere, yes. Sometimes I get photocopies. Different areas I get photocopies, and then they give me a whole lot, now that's why I give people more leaflets. And that's what help, that's what student ambassadors are there for. (P1, interview)

P1 appeared proud to talk to people about his involvement with MMP. He appeared to gain much satisfaction from his musical identity.

Photograph 97: P1 (with fellow student ambassador) and his MMP notebook

Field notes reported P1 to be a very proud student ambassador who was keen to demonstrate this, for example, through his regular interactions with the public, or on occasion with the press for interviews regarding his MMP involvement and performances (see Photograph 98). He would always start these conversations off by explaining how he was a student ambassador for MMP.

Photograph 98: An immensely proud P1 (with fellow student ambassador) being interviewed prior to the London Pallidum concert (Photograph courtesy of Paul Carpenter Films)

As seen in the previous three overarching themes for P1, the conducting opportunities gave him a true sense of identity and importance. When he was holding his conducting baton he seemed to step into a different persona and this new found identity was something he was immensely proud of (see Photograph 99).

Photograph 99: P1 wielding his conducting baton during a professional photoshoot for MMP (Photograph courtesy of Paul Carpenter Films)

P2 also mentioned how she felt proud when she was performing. Interestingly, like P1, she mentioned the impact of the audience and how this made her feel: 'It makes the audience proud, oh yeah! (Laughing) Happy, it's smiling, oh people happy (double thumbs up)…I got standing up, the audience' (P2, interview). Again, similar to P1, this recognition as a musician appeared to reaffirm P2's sense of self-worth and identity. She was a young lady

who was rightly proud of her musical accomplishments. P2 further commented on how she liked to rehearse for the shows: 'We do practise for Christmas concerts. I like practising a lot, and practices for the London Palladium' (P2, interview). This desire to improve through rehearsing indicated a pride in P2's attitude to her music-making. She wanted to be sure she was ready for each performance and was overtly proud of this fact (see Photograph 100). P2's mother further made the point regarding how her daughter really thrived on having people come and watch her perform:

She goes 'where will you be sitting, where will you lot be?' And I have to name everyone who is coming to see her. She has got her fan club, it's all part of her and what makes her tick. (P2's mother, interview)

Photograph 100: P2 proudly modelling the galactic space bibs in preparation for the Royal Albert Hall show in April 2019

Field notes described P2 as a confident young lady who had become an accomplished performer. The following extract describes a part of P2's day at the London Palladium concert:

> The day has finally arrived, the day everyone has been building up to – the day of the 'Music is Magic' concert at the London Palladium. The students have arrived and all four case study participants are now here at the London Palladium theatre. I have just spent some time talking to P2. She is so excited she can hardly speak. She is fully aware of the enormity of the occasion. She knows exactly who has come to watch her and where they will be sitting. It is hard to imagine anybody being more excited about anything than P2 is at the moment. P2's mother said her daughter was up 'at the crack of dawn, dressed showered and ready to go all before 6am!' At the time I spoke to them it was still four hours till curtain up, so it could be a long wait! This was a very proud day for P2 and her family. (Fieldnotes, 15th October, 2017)

P3 described how he felt about his achievements on a day to day level, for example when he had been working hard to master some new lyrics, or a new glockenspiel part. He recalled how he had to concentrate hard and keep on trying even when he felt cross and frustrated at his lack of progress. P3 then said he felt 'so happy inside' when he could finally do what he had been struggling to achieve – a real sense of pride was clear through his body language. He stood up and did a fist pump, with a huge smile on his face. He even demonstrated what we had been discussing to emphasise his point. Although P3 described his feelings as 'happy', I felt they were actually much more than this. He appeared proud of his accomplishments and a sense of satisfaction was evident, although possibly P3 lacked the expressive language skills to accurately describe these emotions.

P3's father felt one of the main reasons his son achieved so much satisfaction from his music-making was the fact that he really understood what he had to do. Whereas at other activities he had attended in the past, for example football training, he was often confused and unsure of what was going on, but at MMP he knew exactly what was required of him at all times. This reduced his frustration and anxiety levels and gave him the necessary space to be a successful participator.

When speaking about his son, P3's father mentioned how 'he loves it when people applaud'. This was a shared experience with P1 and P2. Again this appreciation for the audience seemed to be a significant feature for this participant – in fact arguably the case for any serious performer. This could signify an understanding of the importance of pleasing others during performing and not merely participating for their own benefit. Their performance was something to be shared and not simply for their own pleasure. This would then facilitate the resulting sense of satisfaction these individuals experienced. Another similarity shared with P1 was the immense pride P3 attributed to being a MMP student ambassador.

Field notes provided further support for the sense of satisfaction P3 received from his musical accomplishments (see Photograph 101), as shown in the following journal extract regarding one of the regular weekly sessions:

> P3 was very keen for me to watch him during his music class and to know whether I thought he was 'good'. I told him I thought he was 'fantastic' and he said he was going to tell all his friends about that. It was very important for P3 to feel that he was being recognised for his musical skills and he would seem to feel a huge amount of reward and accomplishment from doing so. (Field notes, 14th March, 2017)

Photograph 101: P3 leading the charge during rehearsal

This journal extract further exemplifies the pride experienced by P3 and his father during a weekend workshop tour:

> The opportunity for these students to go and teach others is so empowering. They are the experienced performers delivering a performance-based workshop to a new group just starting out. P3 is right at the centre of this looking proud and confident with what he is doing (his dad is looking on with pride written all across his face)…another positive benefit of music participation – the chance to spend a weekend away with like-minded friends spreading the joy of music even further. (Field notes, 3rd February, 2017)

These journal entries demonstrated how satisfaction was felt within both the regular weekly session and when away performing with the group, for example at conferences. Regular music participation was creating a similar experience of satisfaction to that felt when away

performing, thus highlighting the importance of both aspects of musical involvement (see Photograph 102).

Photograph 102: P3 (to the right of David Stanley, P1 to the right of P3 in second row) ready to perform at the opening of the annual Royal College of Psychiatrists conference

P4 displayed a quiet air of contentment about life and he seemed to 'come alive' when he was talking about MMP. He liked to tell his support worker how he had got on when he attended his music lesson and it was encouraging to hear that they showed an interest in his achievements: 'I will tell, I get home, I will tell the staff. Right, erm, and how you got on. Right, and erm, I said 'alright'. Erm, I kept thinking, right, I done really well' (P4, interview). P4 provided a good indication that he gained satisfaction and a feeling of achievement from his time spent at MMP. He was delighted when he was presented with an achievement award at the Mencap annual presentation evening:

> Last time I went to the Plaza, right, and last time I got award. And erm he said, David was
>
> reading it, right, and I practise at home my music. I practise at Music Man and I got
>
> award of it. (P4, interview)

This recognition of P4's achievements gave him a public acknowledgement of his work, of which he was duly proud. He was also very proud of his involvement with the London Palladium show. P4's sister thought these performances were a major source of satisfaction for her brother. She felt he experienced a huge boost to his sense of self-worth through these opportunities, which resulted in them all experiencing vicariously a sense of accomplishment on P4's behalf. The benefits were shared throughout the family and she felt they lasted for a considerable amount of time after the event.

Summary: Satisfaction and pride

It was easy to observe a high level of *satisfaction and pride* within the four participants. For P1, P2 and P3 performance was central to this, whereas P4 seemed to gain satisfaction from a more personal perspective, such as his Mencap achievement award. These feelings of satisfaction extended into providing a deep sense of accomplishment which provided a benefit to the participant and their wider family network. The differing nature of how this was achieved was a reflection of their unique personalities, and how they each perceived and understood their own values and expectations.

Parental and family pride

The majority of parents want to be proud of their children and the majority of children want to make their parents proud (Pickhardt, 2014). For people with LDs this can be more complex and require additional consideration. Achievements often require a great deal of determination and learning time frames are frequently much longer. For these reasons, parental pride towards children (including adult offspring) with LDs is particularly powerful.

P1 liked to surprise his parents at his performances – he tried hard (although often unsuccessfully) to keep what he would be doing a secret:

> He didn't want us to know, he doesn't want us…he's always got something to surprise us with. Yeah, like when he walked on the stage at the London Palladium the first time and we didn't know he was gonna do it. I knew something was up because the previous number he disappeared from the stage. He had to go and get his coat on. So I knew something was gonna happen but I didn't know what till he walked on to do the conducting. What a lovely surprise that was! (P1's father, interview)

Parental pride was clear to see in P1's father – in fact he became emotional just remembering the day and it was apparent this was a proud moment that the family would recall with many happy memories for years to come.

Not surprisingly, P2's mother was extremely proud of everything her daughter had achieved through her involvement at MMP:

> I think Music Man makes her feel valued. 'Cos she participates, she's at the London Palladium for goodness sake! Who would have ever thought, people sometimes say 'oh I'm going to the Palladium'. I say no not going, they are on stage. They are performing. (P2's mother, interview)

Remembering back to the tremendous battles for the right medical support for P2, P2's mother was very aware of the wonderful achievements that had taken place throughout her daughter's life. When P2 was a small child, P2's mother had dared not to think about what the future might hold and now she was healthy and experiencing a positive life fulfilled

through music. Pride was easily detectable when talking to P2's mother and she was keen to share this with others. She also described how these achievements provided both her and her daughter with much satisfaction and through this they felt privileged to be a part of MMP: 'I'm so proud. Yeah, I'm really proud! Proud and grateful that she has the opportunities' (P2's mother, interview). P2's mother felt immensely grateful that groups such as MMP gave her daughter the right kind of support to allow her to flourish and develop into the young adult that she had become. She felt a combination of pride and relief at how things had turned out for them as a family.

P3's father felt his son's appointment as a student ambassador was a significant turning point for his son and he too felt proud of his son's progress within the group, following the challenging times they had recently endured. P3's father spoke of his pride not just for his son but for all the students: 'So proud, so proud. I'm proud of all of them, I am so proud of them all' (P3's father, interview, see Photographs 103 and 104).

Photographs 103 and 104: The standing ovation received after the London Palladium show 2017

(Photographs courtesy of Paul Carpenter Films)

P4's sister also mentioned how the whole family felt proud to see P4 so happy and thriving in his musical community:

We love seeing him up there on the stage. He's doing something we can't do isn't he? I love it – he's my little brother and I'm so proud of him and all he has achieved. Without the music he would never have had all these experiences, doing something he enjoys so much. He wouldn't have been anywhere near as active. He would probably just be sitting in his flat, the music has made such an impact on his life and our lives too. (P4's sister, interview, see Photograph 105)

Photograph 105: P4 (centre right) making his family proud, on stage at the London Palladium (Photograph courtesy of Paul Carpenter Films)

Summary: Parental and family pride

The level of *parental pride* felt by these families was extensive and resulted in a sense of achievement experienced vicariously through the achievements of the participants. All four families expressed gratitude for the opportunities that music-making had created and through this the lives of the participants had become worthwhile and valued. Despite some historical negativity experienced by some of the families, for example P2 and her difficult access to the correct medical care, fulfilling lives with much satisfaction and pride had become the shared experience through participation in music.

5.7.4.2 Sense of self-confidence

For the purposes of this study, self-confidence referred to the trust the participants demonstrated in their own ability and judgement within the realm of music, and where this had extended further, in relation to music participation. P1 repeatedly spoke voluntarily of how confident he felt with regards to him being the MMP assistant conductor. When asked how he felt when he was conducting he replied: 'Confident, very strong with confidence.' (P1, interview). Not only did P1 use the word 'confident' voluntarily, he also linked this with feelings of strength. From this it would seem that music participation was providing a true sense of empowerment for P1. He also described how pleased he was with himself when he had mastered a new skill and how that too provided him with a sense of confidence. When asked if he felt any different to before he started coming to MMP, he thought the main difference was him now being 'very independent'. This independence could be viewed as an extension of the confidence that had developed through P1's musical achievements. He now felt more confident about life in general and was a more capable young man, who was prepared to tackle the challenges that he was presented with on a day to day basis.

P1's father felt that the confidence his son experienced at MMP was one of the main motivating factors that committed him to attending. He described how this confidence had changed since his son started music sessions, and had subsequently extended into other areas of P1's life, particularly in social situations:

I think it's given him an awful lot of confidence. Erm, in the early days with P1, if you were going somewhere, you literally had to get there very early. 'Cos if the room was full of people, it was hard work getting him in. He didn't want to go in. If the room was empty he would go in and he'd be alright with other people joining him, but he didn't want to enter a room full of people. Yeah erm, now he's just not bothered. You know, his self-confidence has built up tremendously since he has been doing the music. (P1's father, interview)

P1's father thought that the big shows such as the London Palladium were a good example of how his son's confidence was now so strong:

Well I, I'm amazed how he can get up there and do that as if nobody is watching him…yeah I mean, the confidence thing, the best example I can think of that is when he walked across the stage at the Palladium, to do the conducting. And I've got a photograph on the side here that was one of Paul Fox's and you look at him and you'd think he'd been doing it for years. The absolute confidence there. (P1's father, interview)

P1's stepmother also added that this improvement in confidence was already taking place even before he started the conducting, the music participation in general was encouraging this social confidence to develop.

When P1's father was asked why he felt this change had taken place, he thought the encouraging nature of MMP and the staff was primarily responsible:

> Well I think David, David's always encouraging. Not just to P1, to everyone. He treats them like adults. The idea of the way he runs things is that - come on you have a go at this, you have a go at that. And that gives the youngsters confidence because if you say to somebody have a go at doing this, well he must think I can do it. So that's confidence building and from that confidence, the skill comes. Yeah there's nothing like thinking I can do this! You know, erm, I think he's just got the right technique. (P1's father, interview)

This would suggest that an upward spiral of learning and self-confidence was present, through the skill of dedicated and experienced staff. It seemed that P1 (and the other students) were being given the right support to encourage learning, and this successful learning then resulted in a high level of self-confidence in the ability to achieve. Moreover, evidence from field notes described P1 as demonstrating self-confidence and self-esteem on a regular basis as indicated by the following extracts:

> Self-confidence and esteem evident…confident behaviour with lots of smiling…great levels of confidence shown…it is amazing to watch how P1's confidence and musicality has developed during the period of study…equal amounts of confidence and style shown. (Field notes, 7th July 2017)

P2 detailed how she thought that since she had joined MMP, she had found that she now felt more confident around people in general. She said she now really 'enjoyed being with people'. This social confidence appeared to be creating a significant positive impact on the life of this participant. This ability to get along with others meant that P2 now experienced a

much fuller and more active lifestyle. P2's mother described how she had seen her daughter's confidence develop and change for the better over the last couple of years, since joining MMP. When questioned about how it had changed for her daughter, she commented:

> Now it's loads, just loads! Because she has met a whole new group of people that she considers friends/family – the Music Man, the Music Man family…and that in turn makes her feel better about herself 'cos she's got people who care, she feels it so there you go. (P2's mother, interview)

In a similar way to P1's father, she also highlighted the way David Stanley interacted with the students and how this led to the students' belief in their own abilities:

> He leads, she's got confidence in him so therefore she's got confidence – I can do this! Yeah it's boosting, it's all about the confidence…and feeling good. You know, imagine every day you feel good? Doing something that you love. How nice is that? (P2's mother, interview)

It would seem that David Stanley and the staff were creating a sense of confidence within these musicians, through their high expectations and trusting belief in what could be achieved. This could only be reached through the expertise of the tutors and their unique knowledge of their student's individual strengths and challenges. P2's mother went on to describe how her daughter felt valued at MMP and she thought this was central to her increased level of self-confidence:

> They make her feel so valued, so that's a huge thing isn't it? P2's never quiet in the corner, she's always out there taking part with everyone…but she is also, I think she feels she's got everyone behind her. (P2's mother, interview)

A sense of feeling valued was contributing to P2's ability to value herself and had allowed her to develop her self-confidence as a member of MMP. This self-belief could then potentially transfer into other areas of life, which indeed P2's mother reported was happening, particularly within social situations.

Field notes reported P2 to be a highly valued member of MMP. Not only was she a confident and competent performer, but more importantly her positive and happy nature was a real asset to the group as a whole. Her mother reported that this had not always been the case and she had seen a change since P2 started regularly attending music sessions. It would appear the music was at least in part responsible for these positive changes that were taking place. For P2, learning to value herself was central to her being able to mature into the confident young lady she now was.

P3 revealed how he believed that his self-confidence had improved considerably, particularly when around people, since being a part of MMP. He thought this was because he 'loved it so much'. For P3 this expression of his enjoyment of participating in music went hand in hand with his escalating level of confidence. The opportunity to take part in something that P3 felt was pleasurable had the additional benefit of allowing him to find his trust in his own abilities and to be proud of his achievements. P3's father had witnessed a considerable improvement in his son's self-confidence: 'He's suddenly gone from being shy to wanting to be centre stage' (P3's father, interview). This dramatic change was a source of relief for P3's father, who believed that his son was now finally getting back to being his 'old self' since the loss of his mother:

Definitely, it's definitely improved. Erm, 'cos it took a bit of a hit obviously when his mum passed away. He's always been a fairly confident boy. I mean he would always be – we go somewhere new and he'd be the one up the stairs first. But he went through a little bit of 'no you go first dad'. Whereas now, he's getting it back. His mojo is coming back…yes its creeping back. Whether it would have come back anyway I don't know but I'm sure Music Man has helped, definitely helped. (P3's father, interview)

Participating in music had potentially expedited the return of P3's previous self-confident nature and made this difficult time more tolerable for him and therefore his father too.

 P4 was keen to show off his musical accomplishments to others. This extended beyond the performances at MMP and into other areas of his life. For example, when on holiday at Butlins, he performed one of his MMP songs to the audience on his ukulele. This suggested that P4 was confident in his ability to perform – arguably the result of having a reliable degree of self-confidence. This was further exemplified while P4 visited 'The Hub'. This was a day centre for people with LDs. He told me they had an African drum there and he gave the other attendees a demonstration of various songs that he knew, again from the MMP repertoire:

I said about a drum, right, and erm I played, I played the drum of 'Sizanani'. Yeah I know why right, you said about African drum. Right, we got African drum in erm, 'The Hub'. Yeah, yeah, I done 'Sizanani. (P4, interview)

African drumming was notably an area that P4 was particularly confident with – it was his responsibility at MMP to start the crotchet pulse for each African drumming session that took place. On the odd occasion when the teacher forgot this, P4 was quick to remind them of

their mistake. This demonstrated confident behaviour within the group setting – feeling able to speak out and be heard.

According to P4's sister, he had always been quite a confident person. However, she felt that being part of MMP and the related musical activities helped P4 to maintain this level of confidence as he matured into older age. The attitude of the staff had supported P4 in this way: 'Yes, yeah, definitely. P4 will, P4 will feed off of people with their confidence and he will, he will grin like a Cheshire cat' (P4's sister, interview). This highlighted the importance of the attitude of the tutors – their feelings and expectations directly influenced the students' expectations of themselves.

P4's sister spoke of how being active at MMP was helping her brother to maintain his independence. Through his large circle of friends he was encouraged to participate in social opportunities:

> There is such a big friendship circle there, and erm, that helps keeping his independence really. You know if he hadn't got that, 'cos a lot of Down's syndrome people, they sort of gradually go back. They need that all the time. (P4's sister, interview)

She felt that through her brother keeping involved, this supported him in maintaining his self-confidence. This helped him to recognise that he could successfully achieve when he tried, and this led to him feeling confident about himself as a member of the MMP community.

Summary: Sense of self-confidence

For all four participants there was an evident improvement to and/or support of their level of self-confidence. For P1, P2 and P3 there was a marked improvement seen in their confidence, since the onset of their participation in music. All three families mentioned how the confidence that the staff had in the students resulted in the students having a sense of belief in themselves and their own abilities. P4's family felt that through the opportunities created at MMP, P4 was able to remain more independent and maintain his existing high level of confidence. It would appear that the differing backgrounds of the participants all benefitted from the opportunity to take part in musical activities and this created a unique way for these individuals to become more confident adults.

5.7.4.3 Practical support

There were two separate but related aspects of *practical support*: *practical support given to MMP students by the participants*; and *practical support given to MMP staff and helpers by the participants.* Both of these resulted in the participant feeling a sense of accomplishment from their efforts. For example, this could be a participant helping a less able student on a task, or helping to set up before or after the daily session.

Support given to MMP students by participants

P1 presented as a particularly helpful young man for whom nothing was too much trouble. He felt his role as a student ambassador placed him in a position of care and duty to the other students: 'Student ambassadors do help to learning disabilities, erm, what skills that they need to learn. And that's what I help, that's what student ambassadors are for' (P1, interview). The way in which P1 supported other students was a real asset to the class. He was extremely patient and took pleasure in being able to help others. A further example of practical support by P1 emerged when discussing the winter nights: 'Yes I support, yes. Erm,

if it's dark, for example, if it's really dark I need to come in and help. When it's dark I mean, I will help you' (P1, interview). P1 was often spotted outside helping students to and from their cars during the dark nights. Many of the students do not like the dark and P1 was sensitive to this and helped where he could to alleviate their fears. His sense of accomplishment was evident through his willingness to undertake these additional roles on a regular basis. P1's existing high levels of satisfaction, pride and confidence would have placed him in a good position for being able to support other students in this way.

In addition to being a valuable source of help to the other students at MMP, P1 was also particularly supportive to new groups when he visited these. He would often be seen showing the students how to play the instruments or helping them up and down from their seats. Being able to help others appeared to provide P1 with a feeling of value. His being placed in a position of empowerment within the MMP environment created a significant sense of accomplishment for P1.

Field notes reported P2 offering help to other MMP students on numerous occasions. For example, she was often seen to be encouraging other quieter individuals to get up and join in. She would help them up and show them the actions or dance routine. She would often lead the group with her dancing and took time to support the less physically able students (see Photograph 106).

Photograph 106: P2 leading the other students (including P1 on left and P3 on right)

When another MMP group visited for a rehearsal, she was most welcoming to the visitors, offering help and friendly guidance. At one of the MMP fundraising concerts, P2 helped to lead the audience in a rehearsal for the forthcoming Guinness World Record attempt, which took place at the London Palladium 2017 show. She was highly organised in both handing out and then collecting in the triangles, along with helping to keep the audience in time with their playing.

P4 had a particularly strong friendship with one of the other students. They often sat together during the session (see Photograph 107) or ate lunch together (see Photograph 73). This student had complex physical needs and was often in pain, and P4 always tried to help her feel more comfortable. For example, he would organise a hot water bottle or bring her a warm drink. The support shown was empathetic and provided without prompting. P4's sister

also noted how the students all helped one another, and how it appeared to be something that just happened at MMP, without having to be requested.

Photograph 107: P4 and his friend with her hot water bottle

Summary: Support given to MMP students by participants

Although all four participants supported other students in their own way and in varied situations, P1 and P4 were particularly sensitive to the needs of others. They demonstrated a high degree of empathy and responded appropriately in the *practical support* they offered. For example, P1 was readily available for whatever was required, and regarded this as part of his student ambassador duties. The sensitivity of P4 to the physical limitations of others was commendable. The willingness to support others demonstrated selflessness and resulted in the participants experiencing a sense of accomplishment for their efforts.

P1 was also one of the regular helpers for setting up and tidying away the equipment at each session. He did not have to be reminded of this, he just quietly got on with the job (see Photograph 108).

Photograph 108: P1 tidying away at the end of the day

This mature behaviour helped to ensure the group ran efficiently, particularly when the instruments needed moving during class time. This ensured the tutors were free to continue the lesson without any unnecessary disruption to teaching. For example, if the vocal microphone needed moving between performers. P1's father confirmed his son's enthusiasm to help others and how the students were all extremely supportive of each other: 'They all support each other, yeah, and I mean he's willing to muck in and you know help people' (P1's father, interview).

P1's father also remembered how when the students went away for a concert, everybody helped in getting the instruments inside and ready for the performance:

> The logistics can be quite hard can't they? Everybody joined in…I mean when we went to the, was it the Salvation Army one? You know, we pulled up at the back or something, to unload. But we had to pull up at the side road and everything had to be carried right the way round…to get all those instruments round they all joined in and carried something…I don't think any of them would think about getting off the bus and not helping. Even if they only carry a drum. Or a box with the triangles in, or something like that. Everybody does something. (P1's father, interview)

Being able to support others provided P1 with feelings of reward and accomplishment. P1's father was asked to summarise the benefits of MMP for his son and this was his response: 'I would say that, it's difficult to sum up something like that. It's so rewarding in so many different ways. I can't think of anything else, I can't think of a better way to spend time' (P1's father, interview). This would suggest that both P1 and his father experienced a sense of achievement in many different ways associated with music and MMP. Their musical involvement created a sense of achievement that they both seemed to value and they appreciated the benefits this was providing to them on an ongoing basis.

P3's father explained how the small jobs that the ambassadors undertook provided them with a massive sense of accomplishment. For example, P3 liked to arrive early before the session started and help the staff to prepare the drinks for break time. He would pour the juice and place the biscuits on a plate, so everything was ready on the tray for the students' break.

Field notes also found P3 to be a keen volunteer to help when needed. P3 was particularly

keen to help David Stanley, being a favourite member of staff for him (see Photograph 109).

Photograph 109: P3 helping David Stanley pack away

Summary: Support given to MMP staff by participants

P1 and P3 were particularly keen to offer 'practical support' to the staff and this was encouraged and viewed as an asset to the group. These two participants were student ambassadors for MMP and this position of responsibility helped them to achieve a sense of value in their work. Their families felt this created a sense of achievement within the individuals, which was an aspect of MMP of which they were appreciative. This allowed them the freedom to support the running of the group in whichever way suited them, whether that be in setting out the instruments or serving drinks at break time.

<u>5.7.4.4 Accomplishment conclusion</u>

The three sub-themes which formed the overarching theme of Accomplishment are

summarised in Table 5.7 below.

Table 5.7: Summarised sub-themes for the overarching theme of Accomplishment

Sub-theme	Summary
Sense of achievement	Two sub-sub themes were combined for the sub-theme of 'sense of achievement' (*satisfaction and pride* and *parental and family pride).* A high level of satisfaction and pride was observable in all the participants, particularly with regard to the varied MMP shows put on throughout the year. All four families reported feeling a huge sense of pride relating to the achievements of their family members. MMP and music-making had created a wealth of opportunities for these individuals which resulted in this sense of achievement. Each participant had the chance to achieve in whichever way suited their unique strengths, and this created confident musicians who lived their musical life at its full potential.
Sense of self-confidence	All participants displayed good levels of self-confidence and trust in their own abilities to achieve a task. This was further confirmed through parental reports of improved confidence since participating in music. There were varied opportunities to develop self-confidence, such as social activities and performance events. The participants each experienced a unique sense of value through these and confidence levels increased accordingly. This self-confidence also spread beyond the realm of music-making into other areas of life. This created more confident adults who were able to function more effectively within their community.
Practical support	Two sub-sub themes were merged in the sub-theme of 'practical support' (*support given to MMP students* and *support given to MMP staff).* Practical support offered to either other students or members of staff was

an effective means for the participants to create feelings of accomplishment. They were able to develop their own identities within the group and they each experienced different ways in which to achieve these roles. Being able to help others was rewarding and empowering and these individuals took every advantage of these opportunities wherever possible. Their differing strengths and characters resulted in varied ways of supporting others but all achieved a sense of accomplishment through their selfless efforts.

A sense of Accomplishment was evident in each of the participants. This was observed within the realm of music-making and further afield in their everyday lives. Satisfaction and pride was experienced on a regular basis, and parental and family pride was palpable. Confidence levels were maintained and improved upon, creating individuals who were capable of functioning effectively within their communities. The opportunity to be able to support other students, and in particular the staff, provided an opening in which life skills could be developed and a sense of accomplishment achieved. These results indicated that music participation at MMP had the potential to enhance this area of WB.

5.8 CONCLUDING DISCUSSION

The following section takes each of the components of the PERMA model and discusses how these relate to the findings of Study 1.

5.8.1 Positive Emotions (P)

Positive emotions are linked to something that makes us feel good; activities that we enjoy and look forward to (Seligman, 2011). With regard to the themes identified in Study 1,

positive emotions emerged as an overarching theme for all four participants. Three sub-themes combined to form this overarching theme (pleasure providing, sense of anticipation and emotion management and support), and six sub-sub-themes combined to produce the three sub-themes (enjoyment, positive experience, looking forward/forward planning, anticipating performances and concerts, emotional expression and support and, positive attitude of staff; see Chapter 5, Table 5.3). All four participants expressed positive emotions in a variety of different ways and situations. For example P1 and his love of conducting and performing, and for P3 the pleasure gained from becoming a part of the MMP community of musicians. Their families also described the varied ways in which music participation had added positive emotions to their WB. For example, P2's mother explained how her daughter's musical involvement had added considerably to her own positive emotions through social opportunities, and how for P3's father the opportunity to be alongside his son through his musical journey had created a highly positive environment following the passing of his wife due to cancer. Positive emotions were clearly evident for the participants and therefore demonstrated that this component of the PERMA model can be supported through music-making for people with DS. In line with existing research in the field of positive psychology and positive emotions, these findings support other studies in the field. For example, Lyubomirsky and Sin (2009) found that the use of positive interventions can enhance feelings of WB. These interventions can be highly diverse and result in creating a feeling of positive emotions. Bolier *et al.* (2013) carried out a meta-analysis of the effectiveness of positive intervention strategies and their results showed that these could enhance subjective and psychological WB. The experience of positive emotions can be effective in managing and reinforcing levels of WB.

5.8.2 Engagement (E)

Engagement is concerned with finding 'flow' in our life, or experiencing a feeling of being fully immersed and involved with an activity (Seligman, 2011). Engagement did not emerge as a specific overarching theme in Study 1. However, engagement can arguably be found in all four of the overarching themes from Study 1, within varied and context-specific experiences. For example, the sub-sub-themes of looking forward/forward planning, anticipating performances and emotional expression (positive emotions); the sub-sub-themes of musical education and additional learning opportunities (educational development); the sub-sub-themes of life changing experiences and opportunities (meaning); and, the sub-sub-theme of self-confidence (accomplishment) all demonstrated elements of engagement from the unique experiences of the participants (see Chapter 5, Table 5.3). For these participants, engagement can be viewed as a unique combination of individually-specific aspects of the four overarching themes. For example, P2 could frequently be seen totally immersed in performance, whether that was at the London Palladium or during her regular weekly music session at MMP. P3's father described how his son could often be seen completely focussed and engaged with his musical endeavours and how this skill was extending out into other areas of his life, such as now being able to follow a sequence of instructions. Engagement was dependent on specific situations and circumstances for each participant. This was unique to each individual and formed an essential contribution to their WB, as identified by the components of the PERMA model. Indeed, the ability to engage through music participation has been found to be advantageous for WB in several target populations including older people (Creech *et al,* 2013; Perkins and Williamon, 2014) and mental health service users (Fancourt *et al.,* 2016). The review reported in Chapter 3 (see Section 3.5) identified only 12 studies directly relating to WB, music and LDs and with only one exception, these all reported positive findings through engagement with the arts (primarily music). The findings

of Study 1 further support the notion that engaging in music-based activities can provide benefits to WB for people with DS.

5.8.3 Relationships (R)

This aspect of WB is linked with experiencing lasting authentic connections with others, or participating in meaningful and positive relationships (Seligman, 2011). This was seen particularly in two of the four overarching themes: positive emotions and educational development. In positive emotions this was identified in the sub-sub-themes of emotional expression and support and positive attitude of staff. In educational development this was seen in the sub-sub-themes of role modelling, friendships, relationships with staff and social activities (see Chapter 5, Table 5.3). For example, P3 referred to David Stanley as being 'like a brother', and P2's mother talked of her daughter's complete trust in him. Meaningful relationships made through music participation at MMP were apparent in all of the participants and these created a positive impact in their lives. The resulting benefits contributed to their overall sense of WB. According to the PERMA model, the ability to develop and maintain positive relationships with others is crucial for maintaining successful levels of WB. Other WB studies have similarly reported on the significant social benefits of music participation (Arts, Health and Wellbeing, 2009; Creech *et al.,* 2013; Kreutz, 2014; Stewart and Lonsdale, 2016).

5.8.4 Meaning (M)

Meaning is concerned with leading a purposeful life; experiencing a meaningful existence. This involves identifying our values and what is important to us as individuals, and provides the necessary motivation and determination required to succeed. Meaning was identified as

one of the four overarching themes. Two sub-themes combined to create this overarching

theme (significant to life and significant to family), and four sub-sub-themes combined to

create the two sub-themes (importance of MMP, life changing experiences and opportunities,

positive impact on family and, negative impact on family; see Chapter 5, Table 5.3). All

participants found that participating in music added meaning to their lives. For example, P4

and his family found that through music they were able to share a common joy which served

to bring them together on a regular basis. The opportunities offered to these musicians

through their musical endeavours clearly made a significant lasting impact within the

families. Their music participation resulted in unique experiences for each of them and

provided their lives with a positive sense of meaning in a wide variety of scenarios. In line

with the recommendations of the PERMA model, a meaningful life is central to experiencing

a satisfactory level of WB. There was plentiful evidence that this was the case for these

participants. In line with other WB studies, a sense of meaning was enhanced through music

participation (Arts, Health and Wellbeing, 2009; Creech *et al.,* 2013; Perkins and Williamon,

2014).

5.8.5 Accomplishment (A)

Accomplishment is feeling a sense of achievement in one's life; a feeling of satisfaction and

doing things well. This involves the development of positive ways to achieve individual

goals. Accomplishment emerged as one of the four overarching themes. Three sub-themes

merged together to form this overarching theme (sense of achievement, sense of self-

confidence and practical support), and five sub-sub-themes created the three sub-themes

(satisfaction and pride, parental and family pride, self-confidence, support given to MMP

students and, support give to MMP staff). The participants and their families expressed how

MMP had provided the opportunity to feel a sense of accomplishment – something that was arguably otherwise difficult to find for some of these students. Whether progress was made during class time on a set task, or a solo performed on stage at a major concert, all achievements were celebrated and enthusiastically received by everyone. Confidence levels were high and both participant and family pride were in abundance. All participants expressed their satisfaction and sense of achievement in their music participation and appeared to have discovered a way to feel valued through their many accomplishments. For the participants, the opportunity to perform and succeed improved their self-image and confidence, and created a strong sense of pride. Again, the PERMA model cites accomplishment and achievement as crucial for a sense of WB to be maintained. A sense of accomplishment is also recognised within other WB studies as being a contributing factor (Laukka, 2007; Creech *et al.*, 2013) (see Chapter 8, Section 8.3, Study 1, for further discussion).

5.8.6 Reliability and trustworthiness of data collection and analysis (Study 1)

As discussed in Chapter 4 (see Section 4.2.2), the professional position of the researcher and any potential bias concerns were made clear and transparency was maintained throughout Study 1. Bearing these points in mind, the researcher felt the data collected was an accurate representation of the participants and their musical activities and thus provided a reliable source of data for subsequent analysis. Participants responded with honest and thoughtful details of their experiences, which was further supported and verified by reports made in the journal of field notes and via photographic evidence. IPA data analysis was undertaken following seven detailed steps (see Section 5.6), with regular validation being sought from

supervisors at each stage of analysis. Chapter 8 (see Section 8.6) provides further discussion on limitations).

In conclusion, through IPA of the data obtained in Study 1, four overarching themes were identified: Positive Emotions; Educational Development; Meaning; and Accomplishment (see Table 5.3). These themes can be directly linked to WB and indeed provide evidence that MMP supports all five elements of the PERMA model of WB.

CHAPTER 6: STUDY 2

6.1 INTRODUCTION

Study 2 comprised a specifically designed online survey, distributed to all the UK Mencap partner groups (approximately 400) which had either a web site; a publically available email address; or a social media account (see Appendix 6). Mencap is the UK's leading charity supporting people with LDs and their families. The survey aimed to investigate the prevalence of music participation as an activity within these Mencap groups, aiming to help establish the view of this leading national organisation on the benefit of music on WB among their adult members. The study ran from June – December 2017. This chapter provides a brief background to the history of Mencap, details on the specifically designed online survey, data collection and analysis methods, participants, and research findings.

6.2 BACKGROUND TO MENCAP

The Royal Mencap Society is the UK's leading LD charity. Mencap has campaigned tirelessly for equal opportunities for people with LDs since the 1940s. Mencap state their primary vision as: 'a world where people with a learning disability are valued equally, listened to and included. Our challenge, alongside people with a learning disability and their families, is to make this world a reality' (Mencap, 2015). Their mission is to: 'transform society's attitudes to learning disability and improve the quality of life of people with a learning disability and their families' (Mencap, 2015).

A brief chronological timeline highlights the main achievements of Mencap to date:

- 1945 – Judy Fryd, a mother of a child with LDs, formed 'The National Association of Parents of Backward Children'. She wrote to Nursery World magazine after her daughter was turned away from a mainstream school. Hundreds of parents followed her example and expressed their anger and frustrations at the lack of services available for their children.

- 1955 – The association changed its name to The National Society for Mentally Handicapped Children (subsequently abbreviated to Mencap) and opened its first major project, the Orchard Dene short stay residential home.

- 1958 – The National Society launched the Brooklands Experiment, which compared the social, emotional and verbal progress of children living in hospital settings to those within family environments. The children in the home environments showed marked improvements in their development and the results were published around the world.

- 1963 – First training centre established for adults with LDs.

- 1966 – Gateway Clubs introduced, offering sport and leisure opportunities for people with LDs.

- 1975 – The Pathway Employment Service commenced, offering suitable employment opportunities for people with LDs.

- 1976 – Mencap Trust Company was formed, as a discretionary support service to families including a person with a LD.

- Early 1980s – People with a LD were now included in the Further and Higher Education Act, through various campaigns. First community-based accommodation was set up for people with a LD.

- 1985 – Mencap's service for people with profound and multiple LDs was established.

- 1995 – The Disability Discrimination Act passed through government.

- 2001 – Valuing People white paper published by the government.

- 2004 – Mencap launched Equal Chances, a five year corporate strategy which centred on providing equal opportunities for all people with a LD.

- 2005 – Government published the Improving the Life Chances of Disabled People report, which set out plans to improve the quality of life for people with a disability by 2025.

- 2009 – Department of Health published Valuing People Now, a three year plan for the improvement of LD service provision in England. The UK finally sanctioned the United Nations Convention on the Rights of Persons with Disabilities. This confirmed that people with disabilities have the same rights as non-disabled people. The International Paralympic Committee voted to re-admit athletes with a LD into the Paralympic Games.

- 2016 – Mencap's 70th anniversary, celebrated at the London Palladium with a sell-out performance by MMP UK with their original 'Music is Magic' show.

Through many services, projects and campaigns, Mencap works to improve the lives of people with a LD. For example through direct care and support, activities, education and advice. Their latest major campaign, entitled 'Treat me well' is a three year project (launched February 2018) with a focus on improving health care in hospitals for people with a LD.

With Mencap being the UK's leading charity for supporting people with LDs, their use of music and their attitudes towards it are important. Given that music has been found to be

beneficial in supporting WB for other target groups, the views of this national charity regarding music provision can provide useful information regarding their experiences on any potential WB effects. In order to achieve this a specifically designed online survey was distributed to all the UK Mencap groups. The main aims of this study were to identify: (i) whether music participation (in comparison to other activities) is used as an activity for adults, and if so, (ii) why it is used, (iii) in what capacity it is used, (iv) how it is funded, (v) and why it is not used more (if appropriate). This information could then serve to facilitate support, where sought, for music provision in the future within the Mencap organisation.

6.3 METHODS

6.3.1 Online survey

A specifically designed online survey was created using SurveyMonkey (2017) as a platform, as this provided an easily accessible means to electronically deliver this to a large number of recipients. The survey consisted of 12 focussed questions which took on average 6 – 7 minutes to complete (see Appendix 7). Ethical approval was granted by the CUK REC (June, 2016) and consent was obtained online at the start of the survey.

Question 1 consisted of a two-part compulsory question: (i) providing confirmation that the background information on the research project had been read; and, (ii) providing consent to taking part in the project. Both parts required completion before the remaining questions could be accessed, thus all respondents completed this initial question. Questions 2-5 requested basic background information relating to each respondent's Mencap group.

Question 2 identified which particular Mencap groups contacted had completed the survey. The purpose of this was to be able to identify which groups had already taken part, and thus be able to identify those that had not yet responded for the purpose of sending reminder emails. These details were not linked to the responses in any way.

Question 3 requested the job description of the individual completing the survey, so as to understand their role and whether or not they were in a position of authority.

Question 4 concerned the geographical location of the Mencap groups. This question identified the different UK regions of these groups, and thus allowed for comparisons between these regions.

Question 5 requested information about the number of adult service users each Mencap group supported.

Question 6 concerned the different activities that each Mencap group provided for their adult members. This question provided an insight into the type of activities each group valued, not involving any primary musical involvement.

From Question 7 onwards the question content concerned detailed musical information from each of the respondents, and their relevant views regarding its importance as an activity. Question 7 ascertained whether or not the groups offered music-based activities of some kind. Participants who reported that they did not provide any sort of music activities were directed straight to the final question.

Question 8 requested information about the different kinds of musical activities provided, and how frequently these activities took place.

Question 9 asked the participants to rate their reasons for providing music from most important (1), to least important (4), on a Likert scale of 1 to 4, according to four predetermined categories:

a) To help people develop skills and self-esteem.

b) To support well-being and emotion regulation.

c) To help people develop socially and connect with people.

d) To support or provide a physical activity.

These categories were selected bearing in mind the components of WB, including the PERMA model of Seligman (2011; see Chapter 2, Section 2.1.2).

Question 10 concerned the annual budget allocated by each group for their music provision.

Question 11 requested information about the source of funds allocated to music provision within the Mencap groups. This question allowed for more than one response.

Question 12 asked the participants to rate their reasons for not providing more music activities, from most important (1), to least important (6), on a Likert scale of 1 to 6, according to the following six predetermined categories:

a) Lack of available funds

b) Not enough staff

c) Not enough experience amongst available staff in music teaching

d) There is already felt to be enough music

e) Lack of interest from service users

f) Lack of evidence to support the benefits for people with learning disabilities

6.3.2 Respondents

The respondents (participants) were individuals involved with UK-based Mencap groups. Their role/position within the organisation was recorded (Question 3) for information purposes. These many different partner groups all have a shared history and values but they operate as separate charities and organisations in their own right. These diverse groups range from very large scale service providers, through to much smaller parent led groups who maybe only meet once a week for a social gathering. Although approximately 400 groups were initially contacted, it was likely that a percentage of these were not suitable for questioning on account of their particular focus; it was not always possible to know the particular interest of each individual Mencap group through the title of their organisation. For example, some may have been completely sports focussed, although this was not apparent from their club name.

6.3.3 Procedure

The survey was emailed to each Mencap group on up to three separate occasions:

1) June 2017: First emailing of survey to individual Mencap groups.

2) October 2017: First chaser emailed to those groups not already responded.

3) November 2017: Second/final chaser emailed to those groups still not responded.

Data were collected electronically via the SurveyMonkey platform (2017) and each Mencap group were only eligible to respond once.

6.3.4 Analysis

201 groups (50.25% response rate) responded and completed at least part of the survey, with the majority of responders completing all the questions. Table 6.1 shows the response rate for each of the 12 questions. Questions 8-11 have slightly lower response rates as these were only relevant for the responders who provided music-based activities.

Table 6.1: Table to show response rate of questionnaire delivered to Mencap groups

Question number	Number of responders (n = 201)	Response rate (%)
1	201	100
2	177	88.06
3	177	88.06
4	176	87.56
5	172	85.57
6	151	75.12
7	151	75.12
8	109	54.23
9	109	54.23
10	109	54.23
11	109	54.23
12	138	68.66

Analysis was both descriptive and inferential. Descriptive statistics included, for example: percentage analysis of geographical spread of groups; detailed musical information, such as frequency of barriers to music provision; and, group size. Analysis was carried out using IBM SPSS Statistics (Version 25.0).

A binomial logistic regression analysis was applied in order to predict the likelihood of certain factors influencing whether a group might or might not provide music for their attendees. A 3-step model was used to identify any associations between the following predictors (Questions 5, 6 and 12, independent variables), and to ascertain what increased the odds of a participating Mencap group offering music or not as an activity (Question 7, dependent variable):

i) Group size by number of adult members

ii) Provision of other non-music activities

iii) The following six barriers to music provision, scored on a Likert scale of 1 – 6 (most to least important):

- Lack of available funds

- Not enough staff

- Not enough experience amongst staff in music teaching

- Already felt to be enough music

- Lack of interest from service users

- Lack of evidence to support the benefits for people with LDs

6.4 RESULTS

6.4.1 Descriptive results

Geographical location

As can be seen from Figure 6.1, the South East (25.58%) and South West (22.09%) regions combined accounted for almost half (47.67%) of the total responses received for this question. Figure 6.2 highlights the number of Mencap partner groups contacted, compared to the number who responded, by region.

Figure 6.1: Chart to show regional spread of responses received

Figure 6.2: Map showing number of Mencap groups contacted by region, with number in brackets indicating the number of responses received

Total number of Mencap groups contacted via email for survey completion = 400

Total number of survey responses received = 201

Scotland 1 (0)

24 (5) Northern Ireland

North East 12 (5)

Yorkshire & the Humber 25 (7)

38 (16) North West

East Midlands 30 (8)

35 (16) West Midlands

East of England 50 (15)

29 (8) Wales

London 42 (13)

44 (38) South West

South East 66 (45)

Note: 4 Mencap groups did not identify as one of these regions

25 responders failed to answer this question

Group size

As can be seen from Figure 6.3, there was a large variation in the number of adult users regularly attending each group, ranging from 0 to 200+.

Figure 6.3: Chart to show size of Mencap groups, categorised by number of adult service users attending

The most frequently occurring Mencap group size (29.07% of responses) were those which served between 51-100 adults. The least frequently occurring Mencap group size (12.79% of responses) were those which served between 101-200 adults.

Non-music activities provided

Figure 6.4 illustrates the varied (non-music) activities provided by the Mencap groups. In addition, 75 groups (37.31%) also reported that they carried out a range of other activities not listed including: self-advocacy, retail skills, bowls, bingo, board games, educational programmes and many more.

Figure 6.4: Chart to show variety and regularity of (non-music) activities provided by the Mencap groups for their adult service users

As can be seen from Figure 6.4, according to the five categories of activity availability, the following activities were the most frequently provided (or not):

(i) Daily: Life skills (19.21%), cookery (15.23%), and arts/crafts (15.23%)

(ii) Weekly: Friendship/social club (59.60%), arts/crafts (40.40%), and exercise/sport (40.40%)

(iii) Monthly: Disco (37.75%), trips/outings (23.18%), and friendship/social club (12.58%)

(iv) One-off: Trips/outings (43.05%), keeping safe classes (34.44%), and disco (25.83%)

(v) Never: Dating evening (90.73%), DIY skills (74.17%), and photography/film making (62.91%)

Music activities provided

This question ascertained whether or not the group provided any type of musical participation. 117 groups (77.48%) responded that they did provide some kind of music-based activity, while 34 groups (22.52%) did not provide any musical activities whatsoever to their group members (Figure 6.5).

Figure 6.5: Pie chart to show number of Mencap groups who provide musical activities

Percentage of Mencap partner groups who offer music as an activity to their adult service users

No 23%

Yes 77%

■ Yes ■ No

Types of music activities

Figure 6.6: Chart to show variety and regularity of musical activities provided by the Mencap groups for their adult service users

From the musical categories listed, the following results were found:

1. Group music listening was the most frequently seen activity for both the daily and weekly categories (9 and 30 groups respectively).

2. Karaoke singing was the most frequently seen activity for the monthly category (26 groups).

3. Performing to others was the most frequently seen one-off activity (52 groups).

44 groups responded with a response of other. This category included activities such as: pop fit, informal dancing, rapping, music quizzes and watching musicals.

Reasons for music provision

The following chart shows the response scores received regarding reasons for music provision. The responses were provided on a Likert scale of 1 – 4 (from most to least important).

Figure 6.7: Chart to show Mencap group responses (1 – 4 on Likert scale) to reasons for music provision

Overall, the most important reason reported for providing musical activities from the listed categories was to help people develop socially and connect with people (35.78% of

responses). The least important reason reported was to support or provide a physical activity (66.97% of responses).

Figure 6.8 below shows the spread of budget allocation for music provision.

Figure 6.8: Chart to show spread of responses according to annual budget allocation for music provision

Spread of responses according to annual budget allocation for music provision

As can be seen from these results, just over half (53.21%) of the responses received did not have a specified budget for music provision. Just 22.93% of responders allocated in excess of £500 per annum for their music-based activities. Funds are sourced for music provision in a number of ways (see Figure 6.9).

Figure 6.9: Chart to show the varied sources of funding for music provision within the

Mencap groups

Sources of funding for music provision within the Mencap groups

Fundraising and self-funding were the two most frequently reported sources of funding for

music provision. Sources of 'other' funding included local authority fees.

Barriers to music provision

The detailed responses to why more music was not being provided are shown below in

Figures 6.10. The answers were recorded on a Likert scale of 1 – 6 (from most to least

important).

Figure 6.10: Chart to show responses to barriers to music provision (1 – 6 on Likert scale)

As can be observed from these results, a lack of available funds was the most frequently reported 'most important' reason (43.55% of responses) for not providing more music, and a lack of evidence to support the benefits for people with LDs was cited as the 'least important' reason (47.66% of responses).

6.4.2 Predicting musical activities

To further explore the associations between the descriptive variables, a binomial logistic regression analysis was carried out as detailed in Section 6.3.4 above.

The 3-step model was found to be statistically significant (Chi-square = 17.97, df = 7, p = .012), when the Omnibus Tests of Model Coefficients was applied. This test assesses how well the model predicts categories compared to no independent variables. Likewise, the Hosmer and Lemeshow Goodness of Fit Test indicated that the model was not a poor fit (Chi-square = 5.15, df = 8, p = .741). This result should not be statistically significant, otherwise this would suggest a poor fitting model. Variation in the dependent variable for the 3- step model varied from 16.5% (Cox and Snell R Square) to 34.4% (Nagelkerke R Square). This is an indication of how much variance in the dependent variable (whether or not music was provided) can be explained by this model. Nagelkerke R Square is a modification of Cox and Snell R Square, thus it is preferable to report the Nagelkerke R Square value. Generally speaking, the higher the value the better the model fit is considered to be. Compared to Block 1 (8.7%) and Block 2 (13.4%), this figure (34.4%) was an improvement which suggests the final model was the best in predicting the variance in the dependent variable (whether or not music was provided).

Table 6.2 highlights the main findings of this analysis. The results provided an insight into possible associations between these variables and whether or not a group might provide music (see Appendix 8). The results of the logistic regression analysis showed that the only significant variable was the *not enough experience among staff* barrier to music provision (p = .046; 95% CI [1.023, 16.582]; OR = 4.118), i.e. the variable *not enough experience among staff* was the only significant variable in predicting whether or not music (dependent variable) was provided by a Mencap group.

Table 6.2: The 3-step logistic regression model showing the prediction of the likelihood of the presence of music, based on group size, other activities and barriers to music

Step	Var.	*B*	SE	Wald	df	Sig.	Exp(B)	CI 95% Lower	CI 95% Upper
0	Music or not	1.288	.200	41.599	1	.000	3.625		
1	Group size	.006	.003	3.625	1	.057	1.006	1.000	1.011
2	Other activities	.371	.546	.460	1	.497	1.449	.497	4.227
3	Barrier (funds)	.561	.585	.922	1	.337	1.753	.557	5.513
	Barrier (Staff)	.503	.570	.778	1	.378	1.653	.541	5.055
	Barrier (experience)	**1.415**	**.711**	**3.965**	**1**	**.046**	**4.118**	**1.023**	**16.582**
	Barrier (enough)	-.081	.470	.030	1	.864	.922	.367	2.316
	Barrier (interest)	.370	.554	.445	1	.505	1.447	.488	4.289
	Barrier (evidence)*	-	-	-	-	-	-	-	-

* = Barrier (evidence) automatically excluded from analysis due to this cell having too few cases

6.5 CONCLUDING DISCUSSION

This study provides an insight into the use of music as an activity for adult members of Mencap groups, and what variables might be associated with this. In terms of geographical location, the two most southern regions had the most number of Mencap groups present. These areas also provided the highest overall response rate to the survey. In line with recent research on the north/south divide, evidence suggests this is still as prominent as ever: the southern regions are continuing to experience cultural, economic and social benefits over their northern counterparts (Gardiner, 2018). Despite this higher prevalence of groups and responses from the southern areas of the country, there was not found to be a significant

result for music provision within these regions, i.e. there was not a significantly higher incidence of music provision in the southern counties, in comparison to the northern counties. Thus the north/south divide phenomenon may not explain the lack of music provision within these groups, therefore other factors may be responsible. Further work in this area would be beneficial in order to understand why these groups were not providing more music as an activity.

A stepwise logistic regression analysis explored three additional potential variables with regards to predicting the likelihood of music being offered as an activity. Firstly, *size of the Mencap group* was not found to be a significant factor. It is worth noting that a couple of the larger groups based in London did not provide music and this possibly affected the analysis accordingly. Following further investigation, it emerged that music was being provided through various other means in these London areas, so potentially there was considered to be sufficient music provision already in place. Secondly, whether *other activities* were provided (on a weekly basis) was added for consideration into the model. This was an insignificant variable, suggesting the provision of other activities had no association with whether or not music was available. This might suggest that any activities provided by the groups was dependent on a wide variety of factors, for example, whether staff were available, or sufficient interest from members. Finally, when looking at the *barriers to music provision,* only one of the six listed was found to be significant. This was the *not enough experience among staff* barrier. Interestingly, this barrier has the potential to be addressed through training and development of staff in music teaching, whereas the majority of the other barriers would be more problematic to tackle (for example, lack of funds). With this in mind, the researcher suggests a more thorough investigation to address this issue of inexperienced leaders feeling ill-equipped to deliver music sessions. For example, organisations such as

MMP UK offer training and ongoing mentoring to interested parties, which could help to reduce this barrier in the future. A detailed exploration of this possibility could help to create experienced musically-trained staff within the Mencap organisation.

6.5.1 Reliability and trustworthiness of data collection and analysis (Study 2)

The design of the survey, e.g. question wording and question order, was carefully planned in order to gain reliable results from the participants. Question design was simple and easy to complete, and encouraged honest and reliable responses. There is always a risk of either misinterpretation or dishonest responses, which needs to be kept in mind when interpreting findings. A response rate of just over half of the groups contacted could also be a source of bias. Data analysis was statistical and this provided a more objective interpretation of the findings, upon which to base the conclusions. Chapter 8 (see Section 8.7) provides further discussion on limitations.

To conclude, Study 2 aimed to investigate the prevalence of music participation as an activity within the UK Mencap organisation. This was executed through a specifically designed online survey emailed to all UK Mencap groups. Data analysis using descriptive and inferential statistics has provided findings that have contributed to an understanding into the use of music by this leading charity supporting people with LDs (see Chapter 8, Section 8.4 Study 2 for further discussion).

CHAPTER 7: STUDY 3

7.1 INTRODUCTION

Study 3 is a within-subjects intervention study that aimed to investigate the impact of a 10 week programme of music-making on the WB of adults with DS. The study ran from April - December 2018. Ethical approval was received through CUK REC (February, 2018) and each participant provided informed consent at the start of the intervention.

7.2 METHODS

7.2.1 Participants

The participants were recruited through local day care and activity centres for people with LDs, along with advertisements displayed on appropriate social media pages. The majority of participants were invited personally, facilitated through support staff at LD centres, while some responded to the advertisements on social media pages seen by family or friends. A total of 30 adults were invited to participate in a free weekly two hour (10am – 12pm) music session over a period of 10 weeks, of whom 26 signed up and consented to take part (see Section 4.5.4, Study 3*).* Inclusion criteria included >18 years of age, a formal diagnosis of DS, and no previous regular exposure to music lessons. The majority of these participants were relatively high functioning. Most were able to write their own names and addresses, could read their adapted consent forms and demonstrated good language skills. Some had attended main stream school (with support) and were living semi-independently.

Participants were assigned to one of two groups (Group 1 and Group 2). Two groups were offered for two main reasons: (1) by offering alternative dates participants were afforded more flexibility, therefore increasing the chance of a larger sample, and (2) if all participants attended together, this would make the group large for teaching purposes which would compromise the participants' musical experience. Participants were assigned to groups depending on the dates they selected for attendance. The time of day of the session, venue, teaching staff and other regularly attending students were consistent throughout both groups. The two groups ran in consecutive academic terms in order to align with the ongoing regular MMP teaching sessions that the participants were joining. Each group was allocated a similar numbers of participants (Group 1 = 13 participants; Group 2 = 11 participants).

Two participants attended only the initial session (-10 week baseline assessment) so these were removed from the final data set. Attendance at a minimum number of three music sessions was required for inclusion in the final analysis and a total of 24 participants provided data. These participants were aged between 22 – 64 years (Group 1 mean age = 47.31 years, SD = 9.72; Group 2 mean age = 41.27 years, SD = 11.15; combined mean age = 44.54 years; SD = 10.83; 12 females and 12 males).

7.2.2 Procedure

Group 1 participants attended between April - July 2018, and Group 2 between September - December 2018. The participants joined an ongoing established music group which was run by MMP (see Chapter 5, Section 5.2). The music sessions were led by a highly experienced teacher in the field of LDs (David Stanley, founder and director of MMP), with equally experienced teaching and support staff. Data were collected by the researcher at four time

points throughout the intervention period, along with a non-music control session. Each participant was assigned an identification number to ensure anonymity.

Study 3a focused on the *longitudinal* effects of the programme on WB. Data were collected at -10 weeks (baseline measure), week 1, week 6 and week 10. Study 3b focused on the effects of *individual sessions* on WB. Data were collected before and immediately after week 1, week 6 and week 10, as well as before and immediately after a single non-music comparison session. The non-music session was completed six weeks after the intervention period, to provide a means of comparison and control.

7.2.3 Data collection

Levels of WB were monitored at multiple time points during the intervention period, using two WB measures (see Chapter 4, Section 4.5.4). The first scale was the Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS). With minimal adaptation by including a pictorial (as well as a written description) response option, this was suitable for people with LDs, for example, non-verbal participants. This measure was used in Study 3a. Secondly, the UCL Museum Wellbeing Measures Toolkit was applied. This scale is freely available online and is particularly suitable for pre-test/post-test comparisons. Again, with minimal adaptation by means of including a pictorial response option, this was suitable for use with people with LDs. This measure was used for both Studies 3a and 3b. As discussed following the Pilot study, a quiet room was arranged to facilitate the completing of the WB measures. Also, where needed, participants were supported by the researcher in completion of the forms, e.g. reading of the questions, or helping with definitions of words (such as 'optimistic' in SWEMWBS). Table 7.1 highlights the data collection points.

Table 7.1: Time points and measures used for data collection in Study 3

WB MEASURE	Designated use	Wk -10	Wk 1 (B)*	Wk 1 (A)*	Wk 6 (B)	Wk 6 (A)	Wk 10 (B)	Wk 10 (A)	Wk non-music (B)	Wk non-music (A)
SWEMWBS	Measures impact of a project on WB; overall measure of WB	✓	✓			✓		✓		
UCL Generic Questionnaire	Measures WB <u>after</u> an activity			✓		✓		✓		✓
UCL Generic Positive Umbrella	Measures pre/post-test comparisons of WB; overall measure of WB	✓	✓	✓	✓	✓	✓	✓	✓	✓
UCL Generic Negative Umbrella	Measures pre/post-test comparisons of WB; overall measure of WB	✓	✓	✓	✓	✓	✓	✓	✓	✓

*(B) = Before;

*(A) = After

Data collected at <u>-10 weeks</u> provided a means of identifying a baseline measure of WB for each participant. It also demonstrated whether or not WB was stable throughout the ten weeks leading up to the intervention period (i.e. from week -10 to week 1). A single measure (as no intervention took place at -10 weeks) was taken using SWEMWBS and UCL Generic Positive and Negative Wellbeing Umbrellas. SWEMWBS was suitable for this initial assessment because it provides an overall WB score at a single point in time. Likewise, both the UCL Generic Positive and Negative Wellbeing Umbrellas are suitable as one-off measures of WB. The UCL Generic Wellbeing Questionnaire was not used at this initial assessment stage, as this is primarily designed to measure the impact of an intervention activity that has taken place.

<u>Week 1</u> was the first session of the music intervention. Pre-session, three measures were taken: SWEMWBS; UCL Generic Positive Wellbeing Umbrella; and, UCL Generic Negative Wellbeing Umbrella. SWEMWBS was used at this point as a means of reference to the baseline data collected at -10 weeks, along with providing a data set for the start of the intervention (Study 3a). The two UCL Generic Positive and Negative Wellbeing Umbrellas served as both the initial time point regarding the longitudinal data collection (Study 3a) and provided a pre-intervention score for the before/after comparison (Study 3b). Post session, both UCL Generic Wellbeing Umbrellas were used again to complete the before/after session comparison (Study 3b). In addition, the UCL Generic Questionnaire was taken, to provide an additional measure of WB post session (Study 3b).

<u>Week 6</u> data collection pre-session included both UCL Generic Positive and Negative Wellbeing Umbrellas. These provided data for the longitudinal study (Study 3a), and were then repeated post-session to allow for pre/post-test session comparisons (Study 3b). SWEMWBS was also recorded post-intervention for an ongoing overall measure of WB, which then could be compared to both the -10 week baseline score and Week 1 (Study 3a). In addition, the UCL Generic Wellbeing Questionnaire was used to provide a post-session comparison with data taken after Week 1 (Study 3b).

<u>Week 10</u> data collection was a repeat of Week 6 and thus provided an additional set of scores and marked the end of the intervention period.

<u>Non-music week</u> data collection took place six weeks after the intervention period had finished. The intention was to provide a session that did not include any music participation,

for means of comparison and control with the music sessions. Both UCL Generic Positive

and Negative Wellbeing Umbrellas were scored pre and post-test for the non-music session

(Study 3b), along with the UCL Generic Questionnaire post session only (Study 3b).

7.2.4 Analysis

Attendance was recorded throughout the intervention period (mean number of sessions

attended = 9.46; median = 8.5; SD = 2.78) with six participants attending every session. 24

participants (92.31% attendance rate) took part in the intervention programme (see Appendix

9). The main reasons for absence from sessions were either illness of the participant, or a

lack of availability of support staff. For analysis the two groups were combined, with no

significant difference seen between the two sets of baseline scores obtained from

SWEMWBS or the UCL Generic Positive and Negative Wellbeing Umbrellas, as tested using

Wilcoxon signed ranks test.

Analysis of both Study 3a and 3b included descriptive statistics (for example, mean score and

standard deviation) and inferential statistics (for example, Friedman test and Wilcoxon signed

ranks test). Analysis was carried out using IBM SPSS Statistics (Version 25.0). The majority of

data (9 out of 16 measures) were not normally distributed and this was taken into account

when selecting appropriate statistical tests. For Study 3a, a Friedman test was used in order

to compare means across repeated measures. This test is particularly suitable where there are

more than two time points (i.e. week -10, week 1, week 6, week 10 and non-music week) and

for non-normal data distribution. Post hoc analysis was carried out using a Wilcoxon signed

ranks test, in order to compare two means and identify the differences between the relevant

weeks; Bonferroni corrections were applied as appropriate.   A Wilcoxon signed ranks test

was also used for analysis of Study 3b data, as this set of scores provided two sets of means for comparison (pre and post-test), again with non-normal data distribution.

7.3 RESULTS (STUDY 3a)

Study 3a was concerned with the *longitudinal effect* of music participation on WB, over the 10 week intervention period. This explored the long term effect of music participation on WB at the three time points of data collection i.e. week 1 (before intervention), week 6 (post intervention) and week 10 (post intervention), compared with the previous 10 week control period (i.e. week -10 to week 1).

7.3.1 SWEMWBS

Data were collected through SWEMWBS at weeks -10, 1, 6 and 10. Table 7.2 shows the mean and standard deviation scores for each week, out of a minimum score of 7 and a maximum score of 35 (raw scores from SWEMWBS were transformed into metric scores using the SWEMWBS conversion table, as required prior to analysis).

Table 7.2: Mean SWEMWBS scores per week (Study 3a)

	Wk -10	**Wk 1 (B)**	**Wk 6 (A)**	**Wk 10 (A)**
N	24	24	20	21
Mean	21.91	21.09	29.34	31.26
Std. deviation	3.57	3.86	4.44	3.46
Minimum	14.08	9.51	21.54	23.21
Maximum	29.31	28.13	35.00	35.00

(B) = Before intervention;

(A) = After intervention

As can be seen in Table 7.2, the mean scores for week -10 and week 1 were similar. The mean scores then increased over both week 6 and week 10, with the biggest increase occurring between week 1 and week 6. Figure 7.1 highlights how the scores changed throughout the intervention period (with standard error bars).

Figure 7.1: Line graph to show changing mean scores for SWEMWBS data (Study 3a)

Line graph to show changing mean scores for SWEMWBS data over time

A Friedman test was run to determine if there were significant differences in WB scores over the different time periods. WB scores were found to be overall significantly different at the different time points during the intervention period, $x^2(2) = 36.324$, $p < .001$. A large effect size of .908 was calculated using Kendal's W (Coefficient of concordance). Using Cohen's interpretation of scores, $\geq .5$ represents a large effect size, indicating strong agreement between the participants (Cohen, 1992). In order to identify where the differences actually occurred, a Wilcoxon signed ranks test was applied to the relevant pairs of data (week -10 vs. week 1, week 1 vs. week 6, week 1 vs. week 10). This post-hoc analysis with Wilcoxon signed ranks test was conducted with a Bonferroni correction applied, resulting in a significance level set at $p < .0167$ ($p = .05/3$). Median WB scores were as follows, week -10, 22.35 (19.43 to 24.80), week 1, 20.73 (19.25 to 22.35), week 6, 30.70 (24.34 to 32.55), week 10, 32.55 (30.01 to 33.78). There was no significant difference between week -10 and week 1 ($Z = -1.065$, $p = .287$). However, there were statistically significant differences between

weeks 1 and 6 (Z = -3.920, p < .001), and weeks 1 and 10 (Z = -4.015, p < .001), with

significantly higher WB scores seen at weeks 6 and 10, compared with week 1.

7.3.2 UCL Generic Positive Wellbeing Umbrella

Data were collected through the UCL Generic Positive Wellbeing Umbrella at weeks -10, 1,

6 and 10. Table 7.3 shows the mean and standard deviation scores for each week, out of a

minimum score of 6 and a maximum score of 30.

Table 7.3: Mean UCL Generic Positive Wellbeing Umbrella scores per week (Study 3a)

	WK -10	**Wk 1 (B)**	**Wk 6 (A)**	**Wk 10 (A)**
N	24	24	20	21
Mean	22.33	20.79	27.80	27.10
Std. deviation	5.223	4.978	2.726	3.687
Minimum	12	9	20	19
Maximum	30	30	30	30

(B) = Before intervention;

(A) = After intervention

As can be seen in Table 7.3, the mean scores dropped between week -10 and week 1. Again

the largest increase in mean scores was seen between week 1 and week 6. Figure 7.2 shows

the mean WB scores collected throughout the intervention period (with standard error bars).

Figure 7.2: Line graph to show changing mean scores for UCL Generic Positive Wellbeing Umbrella data (Study 3a)

Following Friedman analysis, WB scores for this measure were found to be statistically significant at the different time points during the intervention period, $x^2(2) = 23.194$, $p <$ .001. A large effect size of .580 was calculated using Kendal's W (Coefficient of concordance). In order to identify where the differences actually occurred, a Wilcoxon signed ranks test was then applied to the relevant pairs of data (week -10 vs. week 1, week 1 vs. week 6, week 1 vs. week 10). Due to the Bonferroni correction, the significance level was again set at $p < .0167$. Median WB scores were as follows, week -10, 23.50 (18.00 to 26.50), week 1, 21.00 (17.25 to 23.00), week 6, 28.00 (28.00 to 29.75), week 10, 29.00 (24.00 to 30.00). There was no significant difference between week -10 and week 1 ($Z = -1.687$, $p = $ .092). However, there were statistically significant differences between weeks 1 and 6 ($Z = -3.643$, $p < .001$), and weeks 1 and 10 ($Z = -3.786$, $p < .001$), again with significantly higher WB scores seen at weeks 6 and 10, compared to week 1.

7.3.3 UCL Generic Negative Wellbeing Umbrella

Data were collected through the UCL Generic Negative Wellbeing Umbrella at weeks -10, 1, 6 and 10. This measure records negative WB, so a high score indicates high negative aspects of WB, e.g. feeling irritable, and a low score indicates low levels of negative WB. Table 7.4 shows the mean and standard deviation scores for each week, out of a minimum score of 6 and a maximum score of 30.

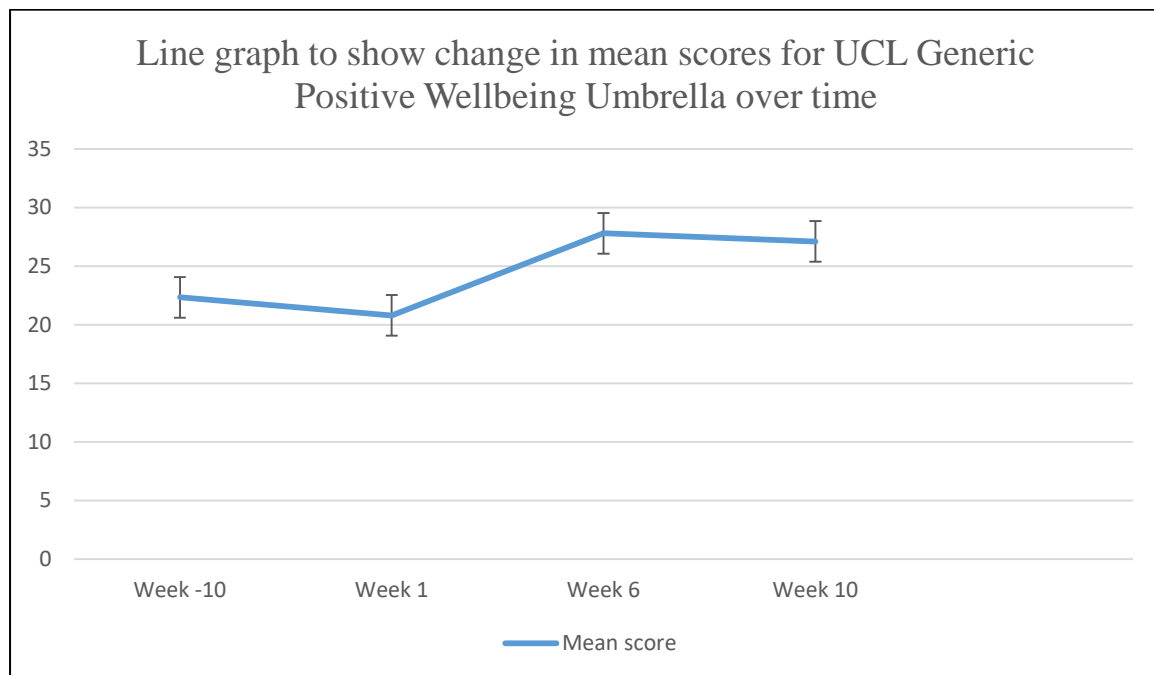Table 7.4: Mean UCL Generic Negative Wellbeing Umbrella scores per week (Study 3a)

	WK -10	**Wk 1 (B)**	**Wk 6 (A)**	**Wk 10 (A)**
N	24	24	20	21
Mean	17.33	17.21	6.50	7.29
Std. deviation	6.302	6.941	.761	2.125
Minimum	6	6	6	6
Maximum	27	28	8	13

(B) = Before intervention;

(A) = After intervention

As can be seen in Table 7.4, the mean scores for weeks -10 and 1 were almost identical. The largest drop in mean scores was seen between weeks 1 and 6. Figure 7.3 shows the mean negative WB scores collected throughout the intervention period (with standard error bars).

Figure 7.3: Line graph to show changing mean scores for UCL Generic Negative Wellbeing Umbrella data (Study 3a)

WB scores for this measure were found to be statistically significant at the different time points during the intervention period, $x^2 (2) = 33.556$, $p < .001$. A large effect size was calculated as .839. In order to identify where the differences actually occurred, a Wilcoxon signed ranks test was then applied to the relevant pairs of data (week -10 vs. week 1, week 1 vs. week 6, week 1 vs. week 10). Post-hoc analysis with Wilcoxon signed ranks test was again conducted with a Bonferroni correction applied, resulting in a significance level set at $p < .0167$. Median WB scores were as follows, week -10, 18.50 (13.00 to 22.75), week 1, 17.00 (13.00 to 22.75), week 6, 6.00 (6.00 to 7.00), week 10, 6.00 (6.00 to 7.50). There was no significant difference between week -10 and week 1 ($Z = -.243$, $p = .808$). However, there were statistically significant differences between weeks 1 and 6 ($Z = -3.826$, $p < .001$), and weeks 1 and 10 ($Z = -3.826$, $p < .001$), with improved negative WB seen in weeks 6 and 10, compared to week 1.

7.3.4 Overall summary of results (Study 3a)

Table 7.5 provides an overall summary of Study 3a results from all three WB data sets.

Table 7.5: Summary of Wilcoxon signed ranks test results for Study 3a

Measure	Wk -10 vs. Wk 1	Wk 1 vs. Wk 6	Wk 1 vs. Wk 10
	Sig. (+/-%)	Sig. (+/- %)	Sig. (+/- %)
SWEMWBS	.287 (-3.74%)	**.001 (+39.12%)**	**.001 (+48.22%)**
UCL Generic Positive Wellbeing Umbrella	.092 (-6.90%)	**.001 (+33.72%)**	**.001 (+30.35%)**
UCL Generic Negative Wellbeing Umbrella	.808 (-0.69%)	**.001 (-62.23%)**	**.001 (-57.64%)**

SWEMWBS showed a significant result for improved WB reported between weeks 1 and 6 (+39.12%) and weeks 1and 10 (+48.22%). The UCL Generic Positive Wellbeing Umbrella showed a significant result for improved WB reported between weeks 1 and 6 (+33.72%) and weeks 1 and 10 (+30.35%), while the UCL Generic Negative Wellbeing Umbrella showed a significant result for reduced negative WB reported between weeks 1 and 6 (-62.23%) and weeks 1 and 10 (-57.64%).

7.4 DISCUSSION (STUDY 3a)

The results from SWEMWBS suggest that active music participation can lead to significant increases in the self-reported WB of the participants. The absence of a significant change in scores from week -10 to week 1 indicates that WB remained stable for these participants throughout a 10 week period where no intervention was taking place. On comparing week 1 scores with week 6, this was the time when the largest increase in WB scores was observed, with a significant increase also seen between week 1 and week 10.

To put this into perspective, a 39 % increase in mean SWEMWBS scores was seen between weeks 1 and 6, and a 48% increase in mean scores between weeks 1 and 10. The New Economics Foundation (2014) suggests five levels of wellbeing according to SWEMWBS scores, based on a quintile analysis of data collected in the UK Understanding Society Survey (2009): poor (up to 22), below average (22-24), average (25-26), good (27-28) and excellent (above 28) (NEF, 2014). According to these categories, the SWEMWBS mean scores progressed from 'poor' to 'excellent' throughout the intervention period.

Results from the UCL Generic Positive and Negative Wellbeing Umbrellas demonstrate how the WB scores changed throughout the period of intervention, in a similar way to the SWEMWBS results. These results also suggest that active music participation can lead to significant increases in the self-reported WB of the participants. As with SWEMWBS, when comparing the baseline scores taken -10 weeks prior to the intervention period with the scores collected at week 1 before the music session had taken place, there was no significant difference found between these two sets of data. This again demonstrated how WB remained stable for these participants throughout a 10 week period where no intervention was taking

place. On comparing week 1 scores with week 6, this was the time when the largest increase in positive WB, and decrease in negative WB, was observed. Further, a significant improvement was also found between week 1 and week 10. Both SWEMWBS and UCL Generic Positive and Negative Wellbeing Umbrellas were recorded at exactly the same time points, i.e. week -10 (baseline), week 1 (before), week 6 (after) and week 10 (after). The similar results are encouraging, adding strength to the findings. Interestingly, both measures found the largest increase in WB scores between weeks 1 and 6, indicating that most impact was experienced during the first six weeks of the programme.

7.5 RESULTS (STUDY 3b)

Study 3b was concerned with exploring the effect of music participation within the *individual weekly music sessions* (data collected pre/post intervention session at week 1, week 6, week 10 and non-music week) and the effect of a music session versus a non-music session (data collected post intervention only at week 1, week 6, week 10 and non-music week). This explored the short term effect of music participation on WB at the three time points of data collection during the intervention period and the non-music control session. The measures used were both the UCL Generic Positive and Negative Wellbeing Umbrellas and the UCL Generic Wellbeing Questionnaire. For the UCL Generic Positive and Negative Wellbeing Umbrellas, scores were taken before and after each session to provide a pre/post-test comparison. Scores were recorded post-session only for the UCL Generic Wellbeing Questionnaire, to measure the impact of the individual session (music or non-music). A Wilcoxon signed ranks test was used to analyse the WB scores for each week of data collection.

7.5.1. UCL Generic Positive Wellbeing Umbrella

Data were collected (pre- and post-test) through UCL Generic Positive Wellbeing Umbrella at weeks 1, 6, 10 and non-music. Table 7.6 shows the mean and standard deviation scores for each week (pre and post-test), out of a minimum score of 6 and a maximum score of 30.

Table 7.6: Mean pre/post-test scores for UCL Generic Positive Wellbeing Umbrella (Study 3b)

	Wk 1		Wk 6		Wk 10		Wk non-Music	
	B	A	B	A	B	A	B	A
N	24	24	20	20	21	21	22	22
Mean	20.79	26.58	23.10	27.80	22.10	27.10	24.95	23.27
Std. deviation	4.978	3.309	5.946	2.726	5.744	3.687	2.497	4.516
Minimum	9	20	11	20	9	19	20	16
Maximum	30	30	30	30	30	30	28	30

B = Before intervention (pre-test);

A = After intervention (post-test)

As can be seen in Table 7.6, there was an increase seen in post-test mean positive WB scores for weeks 1, 6 and 10, and a decrease for the non-music week. The largest pre/post-test mean score difference was seen in week 1. Figure 7.4 shows the pre/post-test comparisons for each week (with standard error bars).

Figure 7.4: Chart to show pre/post-test mean scores for UCL Generic Positive Wellbeing
Umbrella data (Study 3b)

Due to the non-normal distribution of data, a Wilcoxon signed ranks test was applied to
compare the paired pre/post-test mean scores for each time point and the non-music control
session. Median WB scores were, week 1 (pre) 21.00 (17.25 to 23.00), week 1 (post) 28.00
(24.00 to 30.00), week 6 (pre) 25.00 (20.25 to 28.00), week 6 (post) 28.00 (28.00 to 29.75),
week 10 (pre) 24.00 (17.50 to 26.00), week 10 (post) 29.00 (24.00 to 30.00), non-music (pre)
25.00 (23.00 to 28.00), non-music (post) 24.50 (19.50 to 27.00). Analysis with Wilcoxon
signed ranks test was conducted with a Bonferroni correction applied, resulting in a
significance level set at $p < .0167$. Significant results were found for week 1 ($Z = -3.737$, $p < .001$), week 6 ($Z = -3.516$, $p < .001$), and week 10 ($Z = -3.743$, $p < .001$). A non-significant
result was obtained for the non-music control session ($Z = -1.577$, $p = .115$).

7.5.2. UCL Generic Negative Wellbeing Umbrella

Data were collected (pre- and post-test) through UCL Generic Negative Wellbeing Umbrella at weeks 1, 6, 10 and non-music. Table 7.7 shows the mean and standard deviation scores for each week (pre and post-test), out of a minimum score of 6 and a maximum score of 30.

Table 7.7: Mean pre/post-test scores for UCL Generic Negative Wellbeing Umbrella (Study 3b)
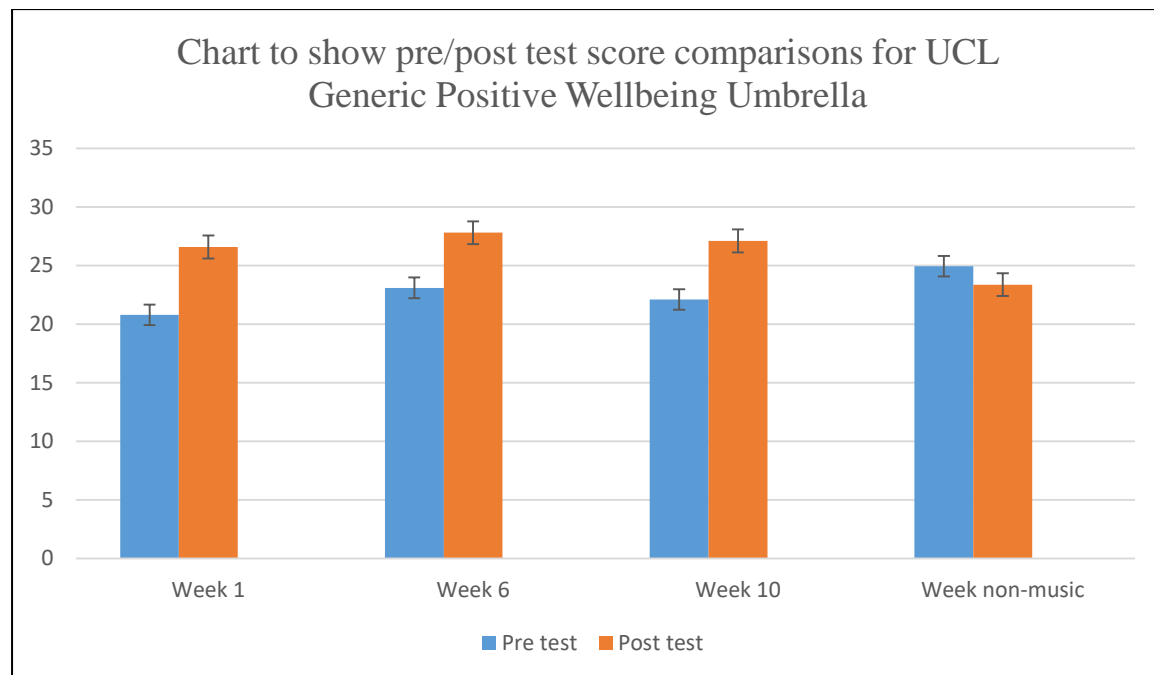
	Wk 1		Wk 6		Wk 10		Wk non-Music	
	B	**A**	**B**	**A**	**B**	**A**	**B**	**A**
N	24	24	20	20	21	21	22	22
Mean	17.21	9.33	11.00	6.50	11.48	7.29	12.18	11.77
Std. deviation	6.941	4.125	5.341	.761	5.259	2.125	5.820	5.789
Minimum	6	6	6	6	6	6	6	6
Maximum	28	20	23	8	23	13	22	23

B = Before intervention;

A = After intervention

As can be seen in Table 7.7, there was a decrease seen in post-test mean negative WB scores for weeks 1, 6 and 10, and for the non-music week the scores remained very similar. The largest pre/post-test mean score difference was again seen in week 1. Figure 7.5 shows the pre/post-test comparisons for each week (with standard error bars).

Figure 7.5: Chart to show pre/post-test mean scores for UCL Generic Negative Wellbeing

Umbrella data (Study 3b)

A Wilcoxon signed ranks test was applied to the data. The median scores were as follows,

week 1 (pre) 17.00 (13.00 to 22.75), week 1 (post) 8.50 (6.00 to 11.50), week 6 (pre) 9.50

(6.25 to 13.75), week 6 (post) 6.00 (6.00 to 7.00), week 10 (pre) 10.00 (7.50 to 14.00), week

10 (post) 6.00 (6.00 to 7.50), non-music week (pre) 10.50 (7.00 to 18.00), non-music (post)

9.50 (6.75 to 18.00). Analysis with Wilcoxon signed ranks test was again conducted with the

Bonferroni correction applied, resulting in a significance level set at $p < .0167$. Similar to the

UCL Generic Positive Wellbeing Umbrella, significant results were found for week 1 ($Z = $ -

3.833, $p < .001$), week 6 ($Z = -3.298$, $p = .001$), and week 10 ($Z = -3.534$, $p < .001$). A non-

significant result was obtained for the non-music control session ($Z = -1.259$, $p = .208$).

7.5.3 UCL Generic Wellbeing Questionnaire

Data were collected through UCL Generic Wellbeing Questionnaire at weeks 1, 6, 10 and non-music week (post intervention only). Table 7.8 shows the mean and standard deviation scores for each week, out of a minimum score of 6 and a maximum score of 30.

Table 7.8: Mean scores for UCL Generic Questionnaire per week (Study 3b)

	Wk 1 (A)	Wk 6 (A)	Wk 10 (A)	Week non-music (A)
N	24	20	21	22
Mean	26.67	28.00	28.81	23.91
Std. deviation	2.899	2.772	2.015	4.286
Minimum	21	20	22	14
Maximum	30	30	30	30

(A) = After intervention

As can be seen in Table 7.8, mean scores for each music intervention week (week 1, week 6 and week 10) were higher than the non-music week. The mean score for the non-music week showed a lower WB score in comparison to the mean WB scores where music participation took place. Figure 7.6 highlights the music week/non-music week comparisons (with standard error bars).

Figure 7.6: Chart to show post-test mean scores for UCL Generic Questionnaire data, compared to non-music week (Study 3b)

A Wilcoxon signed ranks test was carried out on the relevant pairs of data i.e. week 1 vs. non-music week, week 6 vs. non-music week and week 10 vs. non-music week. This would compare the WB scores after each individual music session with the non-music week, and identify any perceived changes. The median scores were as follows, non-music week 25.00 (22.00 to 28.00), week 1 27.50 (24.25 to 29.00), week 6 29.00 (27.25 to 30) and week 10 30.00 (28.50 to 30.00). Analysis with Wilcoxon signed ranks test was conducted with a Bonferroni correction applied, resulting in a significance level set at $p < .0167$. There were significant differences found for each of these comparisons, week 1 and non-music week ($Z = -2.648$, $p = .008$), week 6 and non-music week ($Z = -3.087$, $p = .002$), and week 10 and non-music week ($Z = -3.814$, $p < .001$). These results showed a significant decline in WB scores after the non-music week, compared to WB scores after each of the music sessions. Higher

WB scores were recorded post music intervention, in comparison to the non-music
(socialising) session.

7.5.4 Overall summary of results (Study 3b)

Table 7.9 provides a summary of Study 3b results from both the UCL Generic Positive and
Negative Wellbeing Umbrellas (pre and post-test).

Table 7.9: Summary of Wilcoxon signed ranks test results for Study 3b (UCL Generic
Positive and Negative Wellbeing Umbrellas)

Measure	Wk 1 Pre/post-test	Wk 6 Pre/post-test	Wk 10 Pre/post-test	Wk non-music Pre/post-test
	Sig. (+/- %)	Sig. (+/- %)	Sig. (+/- %)	Sig. (+/- %)
UCL Generic Positive Wellbeing Umbrella	.001 (+27.85%)	.001 (+20.35%)	.001 (+22.62%)	.115 (-6.73%)
UCL Generic Negative Wellbeing Umbrella	.001 (-45.79%)	.001 (-40.91%)	.001 (-36.50%)	.208 (-3.37%)

The UCL Generic Positive Wellbeing Umbrella showed a significant result for improved WB
reported before and after the music session for week 1 (+27.85%), week 6 (+20.35%) and
week 10 (+22.62%). The UCL Generic Negative Wellbeing Umbrella showed a significant
result for reduced negative WB reported before and after the music session for week 1 (-
45.79%), week 6 (-40.91%) and week 10 (-36.50%). There was no significant difference

found between pre/post-test scores for either of the measures for the non-music week. Table 7.10 provides a summary of Study 3b results from the UCL Generic Wellbeing Questionnaire (post-test).

Table 7.10: Summary of Wilcoxon signed ranks test for Study 3b (UCL Generic Wellbeing Questionnaire)

Measure	Wk 1 vs. Wk non-music	Wk 6 vs. Wk non-music	Wk 10 vs. Wk non-music
	Sig. (+/- %)	Sig. (+/- %)	Sig. (+/- %)
UCL Generic Wellbeing Questionnaire	.008 (-10.35%)	.002 (-14.61%)	.001 (-17.01%)

In terms of comparing the long term effects with the short term effects, the longer term scores reported across the 10 week intervention period (Study 3a) revealed a higher percentage change in perceived WB compared to the short term pre and post-test scores reported within the individual sessions (study 3b), using the UCL Generic Positive and Negative Wellbeing data (see Table 7.11).

Table 7.11: Comparison of short term and long term wellbeing scores using UCL Positive and Negative Generic Wellbeing Umbrellas (percentage changes)

Measure	Wk 1 vs. Wk 6	Wk 1 vs. Wk 10	Wk 1 pre/post test	Wk 6 pre/post test	Wk 10 pre/post test
UCL Generic Positive Wellbeing Umbrella	+33.72%	+30.35%	+27.85%	+20.35%	+22.62%
UCL Generic Negative Wellbeing Umbrella	-62.23%	-57.64%	-45.79%	-40.91%	-36.50%

As can be seen here, the benefits of the longer term intervention are higher in percentage terms than the short term benefits reported within the individual sessions. Week 1 to week 6 (Study 3a) produced the highest perceived improvement to WB, along with the largest perceived decrease in negative WB. However, all comparisons provided statistically significant improved positive WB scores and statistically significant decreased negative WB scores, with these two measures.

7.6 DISCUSSION (STUDY 3b)

The analysis of the data collected pre and post-test using the UCL Generic Positive Wellbeing Umbrella showed how the WB scores increased during each of the three sessions included in Study 3b, i.e. week 1, week 6 and week 10. These results suggest that music participation can lead to significant increases in short term WB scores. During the first week of intervention, a significant improvement was reported indicating that a single music session can lead to an improvement in perceived WB. This is in line with other music intervention

studies, for example with mothers and infants (Fancourt and Perkins, 2018a) and using group drumming with age and gender-matched participants (Bittman *et al.,* 2001). In comparison, the non-music week (socialising with a hot drink) saw a slight decline in WB scores. These results suggest that music participation can lead to significantly enhanced levels of WB, which was not seen in the non-music control session.

The same pattern is seen using the data collected with the UCL Generic Negative Wellbeing Umbrella. Negative WB scores decreased during every music session i.e. week 1, week 6 and week 10. These findings correspond with the findings of the UCL Generic Positive Wellbeing Umbrella and suggest that music participation can lead to significant decreases in negative WB scores. In comparison, the non-music week scores were very similar without any significant change noted. These results suggest that music participation can lead to significantly reduced levels of negative WB, which was not seen in the non-music session scores.

The UCL Generic Wellbeing Questionnaire provides a WB score in relation to a specific event, i.e. music session or non-music session. Data analysis indicated that each of the music sessions provided a higher WB score in comparison to the non-music session. These results suggest that a single music session can lead to significant increases in short term WB scores, which was not seen in the non-music comparison session. The results support the findings of the pre and post-test data collected from the UCL Generic Positive and Negative Wellbeing Umbrellas, which also found lower WB scores for the non-music session.

7.7 CONCLUDING DISCUSSION (STUDY 3)

Study 3 set out to explore the potential benefits that participating in music can provide for adults with DS in terms of their WB. The study is original in terms of both methodology and methods used, as there were no validated WB measures suitable for adults with LDs available at the time of study. A within-subjects design was used to measure the impact of two hour participatory music sessions, for a period of 10 weeks. A non-music control session (socialising with a drink) was undertaken following the intervention period, for control and comparison purposes.

The pragmatic approach of using two different WB measures (providing four separate data sets) produced an in-depth understanding of how music participation benefits people with DS, and has thus provided a significant contribution to knowledge in this under-researched field of study. The results showed that both longitudinal (Study 3a) and immediate (Study 3b) benefits to WB were experienced by the participants. There were significant improvements to positive WB and significant reductions in negative WB. The largest improvements in WB were seen after week 6 of the intervention period, in line with other music intervention studies, for example, the use of music participation to alleviate symptoms of post-natal depression in new mothers (Fancourt and Perkins, 2018b).

These findings support research using music interventions to support other target groups, including older people (Creech *et al*., 2013; Perkins and Williamon, 2014); 'at risk' young people (Faulkner *et al*., 2012); psychiatric hospital patients (Tague, 2012); social workers (Maschi, MacMillan and Viola, 2013); and, university students (Mungas and Silverman, 2014). Given the specific behavioural and cognitive profile associated with DS (Buckley *et*

al., 2002; Fidler *et al*., 2008), music-making is not surprisingly a useful intervention strategy for this target group. Bearing in mind the lack of research focussing on WB and LDs, this is an encouraging outcome and had laid the foundation for future research in the field of DS and music-making (see Chapter 8, Section 8.8).

7.7.1 Reliability and trustworthiness of data collection and analysis (Study 3)

The participants in Study 3 were cooperative and engaged with the project. The researcher felt that the data was reliable and statistical analysis produced a large effect size for each data set. Care was taken not to influence responses and encouragement and support were provided during data collection as needed. For these reasons, the researcher felt that the data provided was a reliable and trustworthy representation of the participants' experiences. Data analysis was statistical and much time was taken in selecting appropriate statistical tests for the non-normal distribution of data scores, and guidance was taken from supervisors to this effect. Chapter 8 (see Section 8.7) provides further discussion on limitations.

Chapter 8 will now address all three studies of the thesis, discussing each in terms of the original research question and aims, with reference to the PERMA model of WB (Seligman, 2011). Limitations of the studies and further research suggestions are also proposed.

CHAPTER 8: DISCUSSION AND CONCLUSIONS

8.1 INTRODUCTION

This chapter draws together the findings from each of the three main studies. Each study is discussed in terms of the overarching research question: 'What is the effect of active music participation on well-being among adults with Down's syndrome?' To recap, four research questions (including the overarching one above) and six research aims were presented (see Chapter 4, Section 4.5) as follows:

The overarching research question was further sub-divided into the following individual questions:

2) What is the most appropriate method for assessing well-being among adults with Down's syndrome? (See research aim (i))

3) What counts as effective active music participation for adults with Down's syndrome? (See research aims (ii), (iv) (v) and (vi))

4) To what extent does the PERMA model fit the emerging data from the participants? (See research aim (iii))

The individual research questions were explored through the following specific research aims, linked to individual studies (Pilot, Study 1, Study 2 and Study 3):

(i) To scrutinise potential tools to measure WB among adults with LDs, recognising a lack of validated measures for this target group (see Chapter 4, Section 4.5.1, Pilot study).

(ii) To obtain an in-depth understanding of what taking part in regular active music sessions means for four adults with DS, and their families (see Chapter 4, Section 4.5.2, Study 1; Chapter 5).

(iii) To explore how well the PERMA model fits the data from the participants (see Chapter 4, Section 4.5.2, Study 1; Chapter 5).

(iv) To investigate the prevalence of music participation as an activity within the Mencap organisation and to provide an insight into their view of music-making on WB for their adult members (see Chapter 4, Section 4.5.3, Study 2; Chapter 6).

(v) To investigate the impact of a one-off music intervention on WB among adults with DS (see Chapter 4, Section 4.5.4, Study 3; Chapter 7).

(vi) To investigate the impact of a 10 week programme of music-making on the WB of adults with DS (see Chapter 4, Section 4.5.4, Study 3; Chapter 7).

Bearing these in mind and with reference to the PERMA model of WB (Positive emotions, Engagement, Relationships, Meaning and Accomplishment, Seligman, 2011), this chapter discusses how each study addressed its corresponding aim, relating findings to key literature in WB and LDs as appropriate. The chapter then moves to consider the practical implications of the research and limitations of the thesis, before concluding with suggestions for future work, as well as the contribution to knowledge.

8.2 PILOT STUDY: THE EXPLORATION OF POTENTIAL TOOLS (Research questions 1 and 2)

The findings of the pilot study helped to identify some of the specific challenges that needed consideration when working with this population. Bearing in mind the difficulties experienced, for example, the faces and figures used in the Wong-Baker scale and Self-assessment Manikin scale, it was decided that these were not suitable for use. Therefore, alternative measures were sought for the remaining studies below, as these were not deemed appropriate for this population. Data analysis was not carried out due to the problems highlighted (see Chapter 4, section 4.5.1).

8.3 STUDY 1: THE MEANING OF TAKING PART IN REGULAR ACTIVE MUSIC SESSIONS (Research questions 1, 3 and 4)

Research questions 3 and 4 were answered through an ethnographic case study of MMP UK (see Chapter 5, Study 1), following four adults with DS for a period of 12 months. Each participant provided rich and detailed accounts of what participating in music meant to them and how it supported their WB, as well as the WB of their immediate family members. Four overarching themes were identified (Positive Emotions, Educational Development, Meaning, and Accomplishment) and can be linked to the PERMA model of WB (Seligman, 2011).

Referring to the themes identified in Study 1, *Positive Emotions* emerged as an overarching theme for all participants. This included music as: pleasure providing, providing a sense of anticipation and giving emotion management and support. Additionally, at the level of sub-sub-themes, music was linked to: provide enjoyment, a positive experience, looking forward/forward planning, anticipating performances and concerts, emotion expression and

support and positive attitude of staff (see Chapter 5, Table 5.3). Positive emotions were expressed according to the different experiences of the four participants, showing that the links between music and WB are very idiosyncratic (Perkins *et al.*, 2020). Positive emotions were indeed present for these participants and therefore demonstrated that this component of the PERMA model can be supported through music-making for people with DS. As discussed in Chapter 2 (see Section 2.1.2), these findings are in line with existing research in the field of positive psychology and positive emotions, for example Ascenso *et al.,* (2018) working with mental health service users. According to the PERMA model (Seligman, 2011), positive emotions are an important aspect of WB and serve to enhance the WB of the individual. The experience of positive emotions, facilitated through music, can be effective in managing and reinforcing levels of WB for this target group.

Engagement did not emerge as a specific overarching theme in Study 1, however, it can arguably be found in all four of the overarching themes identified, within individual and context-specific circumstances. For example, the sub-sub themes of musical education and additional learning opportunities were observed in the overarching theme of educational development. For these participants, engagement was a unique combination of individually-specific components of the four overarching themes. Again, this was dependent on the specific situation for each participant. How this contributed to and formed an essential integral part of WB was highly individualistic. These findings are in line with other studies linking music and engagement, such as Dingle *et al.* (2012) working with disadvantaged adults including LDs.

The effect of *relationships* was seen particularly in two of the four overarching themes: positive emotions and educational development. For example, in positive emotions this was identified in the sub-sub-themes of the positive attitude of staff, and in educational development this was seen in the sub-sub-themes of role modelling, friendships and relationships with staff (see Chapter 5, Table 5.3). Meaningful and authentic relationships made through music participation at MMP were evident in all participants and these created a positive impact in their lives and on subsequent WB. Social bonding was strengthened through the activity of music, which served to enhance WB through the interaction of the participants within the group. This supports other findings in the field of social bonding and the benefits of participating in music, for example the work of Pearce *et al.* (2016). The researchers suggested group singing could serve to enhance social bonding between less familiar individuals in a cooperative situation, whereas competitive singing could reduce closeness within a tight knit group.

Meaning was identified as one of the four overarching themes in Study 1. Two sub-themes combined to create this overarching theme (significant to life and significant to family), and four sub-sub-themes combined to create the two sub-themes (importance of MMP, life changing experiences and opportunities, positive impact on family and, negative impact on family; see Chapter 5, Table 5.3). All participants found that music participation had the ability to add meaning to their lives. Music-related opportunities offered to these musicians clearly had a significant lasting effect on them and their families. This created a positive sense of meaning in a broad range of scenarios. In line with the recommendations of the PERMA model, a meaningful life is central to experiencing a satisfactory level of WB. Evidence to demonstrate that this was the case for these participants was abundant. In support of other WB studies, a sense of meaning was enhanced through music participation

for this target group (Arts, Health and Wellbeing, 2009; Creech *et al.,* 2013; Perkins and

Williamon, 2014; Ascenso *et al.,* 2018).

Finally, *Accomplishment* also emerged as one of the four overarching themes. Three sub-

themes merged together to form this overarching theme (sense of achievement, sense of self-

confidence and practical support), and five sub-sub-themes created the three sub-themes

(satisfaction and pride, parental and family pride, self-confidence, support given to MMP

students and, support give to MMP staff). Families and the participants described in detail

how MMP had provided the opportunity to feel a sense of accomplishment, which was hard

to identify in other areas of their lives. All progress was celebrated enthusiastically and

confidence levels were high. These participants had found a way to feel valued through their

many musical accomplishments. Performances improved their self-image and created a

strong sense of pride. According to the PERMA model (Seligman, 20011), accomplishment

and achievement are crucial for a sense of WB to be maintained. A sense of accomplishment

is also recognised within other WB studies as being a contributing factor (Laukka, 2007;

Creech *et al.*, 2013; Perkins and Williamon, 2014).

The findings of Study 1 support the idea that participating in music can support all

components of the PERMA model for people with DS. The mechanisms through how this

was achieved were unique for each individual and context-specific, however the overall

benefit to WB was significant for all participants and their families.

8.3.1 PERMA and learning disabilities: a critical evaluation (Research questions 1 and 4)

A study of this nature will always involve a high degree of subjective interpretation, and the world perspective of the researcher is impossible to remove. This was acknowledged and discussed with regard to transparency being maintained. A strength of the PERMA model (Seligman, 2011) is the broad nature of the five categories that contribute to WB. The model adopts a holistic approach which highlighted the similarities and differences between the participants in terms of their WB in relation to music-making. For these four adults with DS, there appeared to be very little that did not fit into one or other of these categories. The flexibility of the model is a strength which allowed the overarching themes of the case studies to be related to and discussed with reference to one or more of the PERMA categories. To counter this view, however, one could also argue that this flexibility is a weakness of the model. Study 1 in particular has provided an opportunity for evaluation of the PERMA model in relation to the data obtained. Most findings can be related to one of the categories and therefore more specific details could be omitted. For example, the sub-theme of practical support was related to the overarching theme of Accomplishment. However, it could be argued that certain aspects of practical support (other than the sense of accomplishment felt through supporting others) did not exactly fit this theme and was therefore potentially overlooked to a certain degree. The design of the PERMA model potentially omitted participant specific nuances on occasion.

A frequent criticism of the PERMA model is the failure to directly address physical health as a contributing factor (Friedman and Robbins, 2012). However, none of the participants specifically mentioned how music participation affected their physical health. Seligman

argued that physical health was addressed through one or more of the other five components and it is possible that this was indeed the situation here. Another often debated omission of the PERMA model is the failure to mention having control over one's own life (Friedman and Robbins, 2012). People with LDs do not typically have total control over their own lives. Some degree of support is frequently necessary in all areas of their lives and complete independence and autonomy is unlikely to be either practical or in the best interests of the individual. This appeared to be a factor that was successfully managed within each individual family, according to the specific needs of the participant. Through music-making, a degree of control over the participants' lives was seen, for example, deciding whether to perform a solo or not, or through providing ideas for song lyrics and melodies. This was observed in both Study 1 and Study 3 with the participants exhibiting a sense of agency, which was evident through their individual contributions to the sessions and through being a part of the wider music-making community. The participants themselves also chose whether to attend MMP, thus providing another source of independence through decision making.

While the PERMA model provides a useful umbrella for WB, the impact for these individuals was very occasionally more detailed than this allowed for. There is the possibility that some behaviours were overseen through the wide nature of the categories. PERMA is intentionally simplistic and easy to apply, and this could also be regarded as a weakness. Although it can be argued that other models of WB are more scientific in terms of empirical support (for example, Westerhof and Keyes - The Two Continua Model Across the Lifespan), this model removes the need for complex theories and people find it easy to relate to. However, when using any type of WB model to understand human experiences, there will always be a degree of difficulty and this should be acknowledged. A theoretical approach to interpreting complex human behaviour is always likely to involve a degree of compromise.

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In conclusion, the PERMA model provided a solid foundation for assessing WB for this LD target group and no significant concerns with its use emerged throughout either data collection or subsequent analysis. The broad and flexible nature of the model meant that the varied needs of the participants could be highlighted, while also organised and made sense of through the five suggested categories of WB.

With reference to the original overarching research question, there was a large qualitative effect of active music participation on the WB of the four case study participants. They described life changing opportunities for themselves and their families and they discussed experiences that both directly and indirectly supported their WB. Music appeared to add a dimension to their lives which had not been achieved elsewhere, and for this reason music participation could be regarded as central to their individual positive life outcomes and facilitated the achievement of a strong sense of WB.

8.4 STUDY 2: THE PREVALENCE OF MUSIC PARTICIPATION IN MENCAP ORGANISATIONS (Research questions 1 and 3)

This study was an exploration of the use of music within the Mencap organisation, which is the UK's largest charity supporting people with a LD. The view and understanding of this organisation is significant in understanding their experiences with music participation and the potential WB benefits. Although music was available in 78% of the participating Mencap groups, this was typically seen in the form of passively listening to music rather than actively participating in music-making. Other than singing (for example, karaoke and performing songs), there was little reference to having the opportunity to make music using instruments, and on a regular ongoing basis. From these results, it would appear that Mencap was not

currently offering active music participation on a regular basis and where it was present this tended to be for a one-off special event. As seen in the discussion of the case studies above (and also in the results of Chapter 7, Study 3, Sections 7.4 and 7.6), there are considerable WB benefits seen in individuals who have music participation as a key feature in their lives (Daykin *et al.,* 2017; Warren *et al*., 2019; Perkins *et al.,* 2020). This is potentially an area that Mencap is not fully taking advantage of, in their provision of WB support for their adult members.

The results of the binomial logistic regression (see Chapter 6, Section 6.4.2) indicated that the only significant variable was one of the barriers to music: *not enough experience among staff.* This significant barrier to music provides an interesting discussion point and is potentially able to be addressed through training and mentoring of Mencap staff.   This barrier could also be influencing the fact that the majority of music being provided was passive in nature and thus did not require staff to be experienced in delivering music sessions. A similar concern is often cited by teachers within the primary school sector, who are required to provide a general music education without the requisite skill set to do so capably and confidently (Paul Hamlyn Foundation, 2020).   Adequate training of staff and volunteers could serve to increase the provision of active music-making within the Mencap organisation, which in turn would provide an easily accessible means of supporting WB on a regular basis. Alongside MMP providing training workshops and mentoring in person, in light of the current Covid 19 pandemic, training could be provided online, for example via Zoom meetings and online workshops.

Referring back to the original research question, it would appear that the Mencap groups did make use of music to a certain extent to support the WB of their members. However, improved use of music as a participatory activity could be advantageous, in order to further support the WB of their members. Although music is a frequently seen activity within the Mencap groups, there is the potential for a more structured approach through the support and training of staff and volunteers to equip them with the necessary skills and confidence to deliver successful music sessions.

8.5 STUDY 3: THE IMPACT OF INDIVIDUAL SESSIONS OF MUSIC-MAKING AND A 10 WEEK PROGRAMME OF MUSIC-MAKING ON THE WELL-BEING OF ADULTS WITH DOWN'S SYNDROME (Research questions 1 and 3)

Study 3a focused on the *longitudinal* effects of a 10 week music programme on WB while Study 3b focused on the effects of *individual sessions*. Moving first to consider the measurement tools used, the UCL Positive and Negative Umbrellas along with the UCL Generic Wellbeing Questionnaire (see Chapter 4, Section 4.5.4, Study 3) appeared to work particularly well with the participants, who quickly understood how to respond either verbally or visually. In addition, the short and concise wording of SWEMWBS also caused minimal problems, and the participants responded readily to the questions.

Table 7.5 (see Chapter 7, Section 7.3.4) provides an overall summary of the results for Study 3a, demonstrating that participants' WB scores improved significantly more over the 10 week music intervention period than in the previous (no music intervention) 10 weeks. As can be seen in Table 7.5, positive WB increased and negative WB decreased. In terms of the length of intervention, the highest WB score changes were seen after week 6 and not week 10. In

fact both of the UCL umbrellas showed a small decrease in WB scores between weeks 6 and 10. This is an interesting finding as it would not be unreasonable to expect 10 music sessions to produce higher scores than 6 music sessions. There could be a variety of explanations for this and further research would help to deepen the understanding of the most effective length of intervention period. One suggestion could be that by week 6 the majority of participants had reached their maximum WB level and then began to settle into a new level of WB. Potentially the initial 'excitement' at attending the sessions had begun to dissipate after week 6 and the week 10 scores were actually more realistic levels of WB. The results from Study 3a are very encouraging and highlight the potential WB benefits that can be achieved through having access to regular active music sessions.

Table 7.9 (see Chapter 7, Section 7.5.4) provides an overall summary of the results for Study 3b (pre and post-test). Both the UCL Generic Positive and Negative Wellbeing Umbrellas showed significant results within the individual sessions. Positive WB scores were found to increase and negative scores decreased. The largest impact (for improved positive WB and decreased negative WB) was reported during week 1. Again, this could have been due to the novelty of attending something new and in subsequent weeks the scores settled to a more realistic but still significant level. In contrast, the non-music session provided a non-significant result for both UCL positive and negative WB scores. With regard to the UCL Generic Wellbeing Questionnaire, this showed significantly higher WB scores (post-test) compared to the non-music session for each week (week 1, week 6 and week 10). As in Study 3a, these results are very encouraging with regards to the benefits of music participation for people with DS. Short term benefits to perceived WB were reported, alongside long term benefits, throughout the 10 week intervention period. In terms of comparing the short term effects with the long term effects, the longer term scores revealed a

higher percentage change in perceived WB, although all produced significant improved WB scores.

With regards to the main research question, for these participants the 10 week programme of music-making had a significant positive impact on their WB, both over the full 10 weeks and within individual sessions. These participants experienced improved WB through music-making and this should be given due consideration for the development of future programmes of support. Based on these findings, music can be viewed as a valuable tool for supporting WB for adults with DS and thus this approach could be utilised more readily within the LD community.

In order to draw together the main findings, the following points should be borne in mind. Study 3 highlighted significant quantitative differences in WB scores following a 10 week programme of music-making. Study 1 demonstrated *why* these differences in scores might have been achieved following regular music participation, through detailed qualitative data analysis. Given these findings from Studies 1 and 3, Study 2 explored how a main LD support charity viewed and used music as an activity, and indeed suggested how this could be enhanced in future WB management initiatives.

8.6 PRACTICAL IMPLICATIONS

There are multiple implications that arise from the findings of this research. Given that both Studies 1 and 3 demonstrate that music-making provides a valuable means of supporting and enhancing WB, music participation for people with LDs should be given serious

consideration and become more readily available as a means of WB support. Group music sessions are both economically viable and easily accessible, providing a cost effective alternative to other available activities such as 1:1 music therapy or any other type of 1:1 support. The style of teaching provided at MMP is a model that could be replicated through the provision of training for teachers in the LD sector and also for those who work alongside adults with LDs. For care homes and day care centres, music provision could be a highly advantageous use of time and funds for the people who use these services. The group aspect of MMP is also a valuable social asset for people who are frequently isolated through their LD. As seen in the four case study participants in Study 1, the opportunity to come together with others and share an enjoyable time of music-making is a very worthwhile use of resources.

In line with research in other target groups, such as the elderly (Laukka, 2007; Perkins and Williamon, 2014), among cancer patients (Fancourt, Williamon *et al.,* 2016), and mental health service users (Fancourt, Perkins *et al.,* 2016), these results support the findings within these groups and add further to understanding the benefits of music specifically for people with DS. It would be prudent for the National Health Service to be advised on these matters, in particular LD nurses, various therapists and health and social care workers. Further, seeking publication in peer-reviewed journals is an effective means of dissemination of research findings, alongside informing other interested parties and communities within the field of LDs. Clinical Commissioning Groups, which are clinically-led bodies responsible for planning health and care services, should be approached.

The Economic and Social Research Council (ESRC) brings together the UK's seven research councils, in order to create the best environment for research and innovation to flourish. Through partnerships and public engagements, ESRC aims to raise public awareness of research that will translate into benefits for society and individuals (ESRC, 2020), and could thus be approached to promote these findings to the relevant bodies. Government initiatives providing music as an option for people with LDs could potentially reduce spending in other areas, such as the mental health care costs of hospitalisation, therapy and/or medication. For example, Creative Health: The Arts for Health and Wellbeing Report (Culture, Health and Wellbeing, 2017) suggested significant financial savings can be made through use of the arts. An Arts on Prescription project reduced GP visits by 37% and hospital admissions by 27%, creating a net saving of £216 per patient for the NHS. An increased availability of music participation for people with LDs could provide a viable support mechanism for their WB, not forgetting the enjoyment experienced by all those taking part. This could also provide another valuable source of income for musicians who could train to work in this field, in an ever declining pool of professional performance opportunities and shrinking music teaching posts available within schools and the community. In addition, research has shown that involvement in community type music teaching programmes can serve to enhance the WB of the music facilitator, as well as that of the participator (Forbes and Bartlett, 2020).

Finally, organisations such as MMP could work to develop a nationwide programme of music training and education which could support Mencap UK in providing regular music sessions. Support and mentoring could be offered to all Mencap groups wishing to improve their music provision through the acquisition of the relevant skills to facilitate this. This could therefore serve to support and enhance the WB of their members through this new provision. Thus

there would appear to be the potential to develop such a music programme for these main reasons:

i) Music sessions are economically accessible and cost effective (Stanley, 2015; Culture, Health and Wellbeing, 2017).

ii) Study 1 demonstrated the WB benefits to those who regularly participated in MMP music sessions.

iii) Study 2 highlighted how Mencap currently use music and the existing barriers they encounter.

iv) Study 3 demonstrated the WB benefits of a 10 week programme of music-making for adults with DS.

v) The success of the MMP model, as demonstrated in this research, has the potential to be replicated even further.

The existing MMP model of music provision is already being replicated within the UK and overseas. However, as seen in the Mencap survey, there is still room for further expansion. Also, there are other organisations who support people with LDs that could also benefit from the same musical opportunities, for example, smaller independent LD charities, day care centres and residential facilities. Music teachers could be equipped to include students with additional needs and health and education policies could reflect a change in emphasis to further use music in special schools and within the wider LD community.

The MMP model is a viable means to achieve such a programme of music-making through the following actions:

i) Identification of charities/care homes and people responsible for adults with LDs.

ii) Invitation to participate in MMP model with training and support provided.

iii) Day workshops provided to introduce staff and students to MMP teaching methods.

iv) Intellectual property available for use (for example sheet music, song book, training CD and DVD).

v) Ongoing contact with support and mentoring available as required.

vi) Fundraising opportunities and ideas suggested and supported.

vii) Contract/agreement provided to ensure guidelines are adhered to and the quality of teaching provided meets the required standard as set by MMP.

With regard to the multiple practical implications that have been identified, the use of music-making as a tool to support WB opens the door to a variety of possible applications to suit the specific needs of the individual.

8.7 LIMITATIONS

LD research is an area that many researchers have tended to avoid in the past. It is a complex topic that requires specialist understanding of LDs and also experience working within this community. Nevertheless it is a community equally deserving of research and thus every effort should be taken to further understanding and knowledge in the field. The hugely varied spectrum of LDs needs to be managed as far as is possible, and for that reason this project focussed on a specific LD, i.e. DS, in order to avoid further complications resulting from the LD itself. Nevertheless, there are several limitations that should be acknowledged.

8.7.1 Study 1

The small number of participants (n = 4) included in the study requires acknowledgment. Although time restraints and practicalities would make the inclusion of larger numbers problematic, the decision to focus on four participants and their families was made to enable a depth of data and the possibility of recording in detail the individual participant's experiences. Indeed, such an approach is common within qualitative approaches (Hooper and Lindsay, 1992; Nelson and Hourigan, 2016; Perkins, Yorke and Fancourt, 2018).

Researcher bias is another potential complication of the case study method. This was acknowledged by the researcher and was carefully monitored throughout the period of study. For example, the researcher was mindful during interviews not to probe for specific responses from the interviewees. Relationships with participants can lead to misinterpretations or even subjective rather than objective judgements. However, bearing this in mind, the researcher felt that the relationships with the participants significantly helped the collection of 'real life' data. There was no apparent issue with either lack of trust or shyness with the participants. Every effort was taken to maintain accurate and impartial field notes, while being conscious of these possible pitfalls (see Chapter 4, Section 4.2.2).

The longitudinal aspect and the vast amount of data collected can lead to problems if not adequately managed. For example, errors of interpretation can easily happen if data is not organised efficiently at the outset. Data was carefully organised from the start with detailed note taking and observations regularly documented, for example, through photographic supporting evidence.

8.7.2 Study 2

Surveys can be problematic with regard to honesty and integrity of responses (Smith, 2008).
This should be kept in mind, along with inaccuracy of reading and understanding the
questions. Although most responses to the questions were complete, a small number had
only completed the question in part and this could have been due to misunderstanding the
instructions provided.

Furthermore, the response rate (50.25%) provides just half of the view of this target
population. If anything, the findings were likely to reflect a bias of organisations that do
engage with music-making, so it may be that the levels of music engagement reported are
over inflated. Overall though, this study provides an appreciation of the nationwide view of
Mencap on the use of music participation and as such highlights the areas which could be
addressed in future studies, whilst accepting the recruitment challenges inherent with a study
of this nature.

8.7.3 Study 3

Recruitment of participants for Study 3 was challenging on occasions. Frequently attitudes
towards music for people with LDs still appear to be lacking in any true understanding of the
potential underlying benefits. For example, a local charity supporting adults with LDs was
invited to consider participation in the study. The Managing Director of the charity replied
how he thought the project 'sounds good but we don't have anybody that would benefit'.
This type of response was not unusual and leads on to the question of whether the person
with DS had actually been asked whether they would like to take part in the project, or
whether a decision had been made on their behalf. In addition, this target group is dependent

on others for support, for example, transport arrangements. Practical restrictions were an issue for some who may have wanted to attend but did not have the opportunity to do so.

There is always the risk that participants will drop out of the study. In this case two of the original participants who signed up failed to attend after the initial session. This represents a very low drop-out rate. A within-subjects design is difficult to control, with the carryover effect possibly influencing the results of the non-music session. Time and practical restrictions would not allow for extended control sessions in this instance, although this could be an area for further exploration in the future. Finally, the 10 weeks (control period) prior to the 10 weeks intervention (experimental period) is difficult to control and could therefore impact WB. For example, weather conditions could have been better during the experimental period (or vice versa), thus promoting better WB through natural seasonal changes. While acknowledging all the challenges and limitations, this research is still the first to explore the impact of active music participation on the WB of adults with DS.

8.8 FUTURE WORK

There are many avenues for future research in this area. Qualitative case study approaches could be extended to focus on other types of LDs, for example, people with Williams syndrome, who often exhibit strong musical abilities, or autism type disorders, where communication can be a particular difficultly. Intervention studies could seek to recruit more participants in order to have a larger sample. One option would be to visit day centres and run the intervention programme 'in house'. This would remove the issue with provision of transport and the support staff required to travel, potentially allowing more people to make their own decision about participation. Future intervention studies could be extended further

by comparing varying levels of cognitive impairment, for example differences seen between mild, moderate, severe, profound or complex needs.

It would also be useful to understand more about the lasting benefits of intervention programmes. Very little is currently understood about the lasting effects of music intervention programmes on WB, for example, how long any benefits remain after the intervention period has ended. This would provide knowledge that would support the development of future intervention programmes.

Studies could also use a randomised controlled trials (RCTs) design to attempt to further isolate the impact of music over and above other social activities. Quantitative outcome measures could be taken with qualitative designs (for example, interviews) running alongside, to gain insight from the participants' perspective about what they are actually experiencing at that moment in time.

Finally, research could investigate in more detail how significant barriers to music could be addressed. This could include a survey to ascertain how Mencap groups could be supported through this process, with plans developed for future music programmes to be provided and evaluated. Research with practitioners leading music sessions for people with LDs would also support the development of the resources and skill sets required to scale up such work.

8.9 CONTRIBUTION TO KNOWLEDGE

The contribution to knowledge of this research is primarily twofold. In the first instance, there is the contribution to the understanding of the methods and tools used for this target group. In Study 1, the interview sessions worked well with this cohort. However, it is worth noting that the researcher was already well known to the participants. This doubtless removed any initial anxiety caused at the outset by having to develop a relationship with the participants and gain their trust. This could have been a cause for concern if the researcher had been previously unknown to the participants, or alternatively inexperienced in the field of LDs.

In Study 3, the use of UCL Museums Wellbeing Measures Toolkit was exploratory for this group of people. The UCL Positive and Negative Wellbeing Umbrellas were easily understood by the participants and they quickly grasped the idea of how to respond. They enjoyed the bright colours and found them fun to complete. The short and simple design of UCL Generic Wellbeing Questionnaire was also successful for this target group. Again, the exploratory use of SWEMWBS was well received. This was easily understood by the participants. With the short sentence structure and simple usage of language, this measure appeared not to cause the participants any issues of responding accurately. However, this may have not been the case with a target population with more severe LDs.

Secondly, there is the contribution of the findings to the newly emerging LD and WB research pool. As far as the researcher is aware, this is the first study of this nature to demonstrate that active music participation can support the WB of adults with DS. The findings are therefore important in terms of setting a precedent to other researchers, and also

in terms of furthering the understanding of the use of music to support WB. This should have a far reaching impact and will be of interest to those who work or live alongside people with DS including parents, teachers, educators, academics, support staff, LD charities and organisations, day care centres, residential care homes, health care workers, social workers, occupational therapists, GPs, policy makers and local and national government. As can be seen from this extensive list, the impact of this research has the potential to reach many different sectors and therefore influence future opportunities for improved WB support for people within the LD population.

The overarching research question 'What is the effect of active music participation on well-being among adults with Down's syndrome?' has been answered through three studies and each has provided a new perspective through their different research aims:

1) Study 1 (Research questions 1, 3 and 4)

Aims: (ii) To obtain an in-depth understanding of what taking part in regular active music sessions means for four adults with DS and their families.

(iii) To explore how well the PERMA model fits the data from the participants.

Finding: Regular music participation through MMP had a considerable impact on the WB of these participants, as described by themselves and their families. On occasion, this was described as providing positive life changing outcomes for the individuals concerned.

2) Study 2 (Research questions 1 and 3)

Aim: (iv) To investigate the prevalence of music participation as an activity within the Mencap organisation and to provide an insight into their view of music-making on WB for their adult members.

Finding: Approximately ¾ of Mencap organisations use music in some form, typically passively listening to music rather than actively participating. The largest barrier to NOT providing more active music participation was a lack of confidence of staff to deliver the sessions.

3) Study 3 (Research questions 1 and 3)

Aims: (v) To investigate the impact of a one-off music intervention on WB among adults with DS.

(vi) To investigate the impact of a 10 week programme of music-making on the WB of adults with DS.

Finding: The impact on these adults was significant, both in terms of improving positive WB and reducing negative aspects of WB.

In conclusion, the use of active music participation as a support to WB for adults with DS is highly beneficial for both those who have been participating regularly for some time, and also for those who are new to music participation as an activity. This research makes an original

contribution to knowledge and has provided qualitative and quantitative evidence to support this claim.

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LIST OF APPENDICES

UCL Museum Wellbeing Measures Toolkit
Generic Wellbeing Questionnaire Short 6-item version

Please circle a number for each statement to indicate how much you agree with it.

1) I felt happy

None of the time 1	Not very often 2	Some of the time 3	Very often 4	All of the time 5

2) I felt engaged

None of the time 1	Not very often 2	Some of the time 3	Very often 4	All of the time 5

3) I felt comfortable

None of the time 1	Not very often 2	Some of the time 3	Very often 4	All of the time 5

4) I felt safe and secure

None of the time 1	Not very often 2	Some of the time 3	Very often 4	All of the time 5

5) I enjoyed the company of other people

None of the time 1	Not very often 2	Some of the time 3	Very often 4	All of the time 5

6) I talked to other people

None of the time 1	Not very often 2	Some of the time 3	Very often 4	All of the time 5

The Short Warwick-Edinburgh Mental Well-being Scale

(SWEMWBS)

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5

Positive Wellbeing Umbrella
Generic

© UCL Museums & Public Engagement 2013

Six words are printed around the edge of this umbrella. Please score how much you feel each word by circling a number from 1 to 5, e.g. 'Alert', if you feel *fairly* alert, then you should circle 3.

- I feel extremely
- I feel quite a bit
- I feel fairly
- I feel a little bit
- I don't feel

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Negative Wellbeing Umbrella
Generic

Six words are printed around the edge of this umbrella. Please score how much you feel each word by circling a number from 1 to 5, e.g. 'Upset', if you feel *fairly* upset, then you should circle 3.

- I feel extremely
- I feel quite a bit
- I feel fairly
- I feel a little bit
- I don't feel

Pictorial response option

ROYAL COLLEGE OF MUSIC

STUDENT QUESTIONNAIRE 1

Before we start it would be useful to know a little bit about you.

When were you born?   ……/……/……..   Male/female

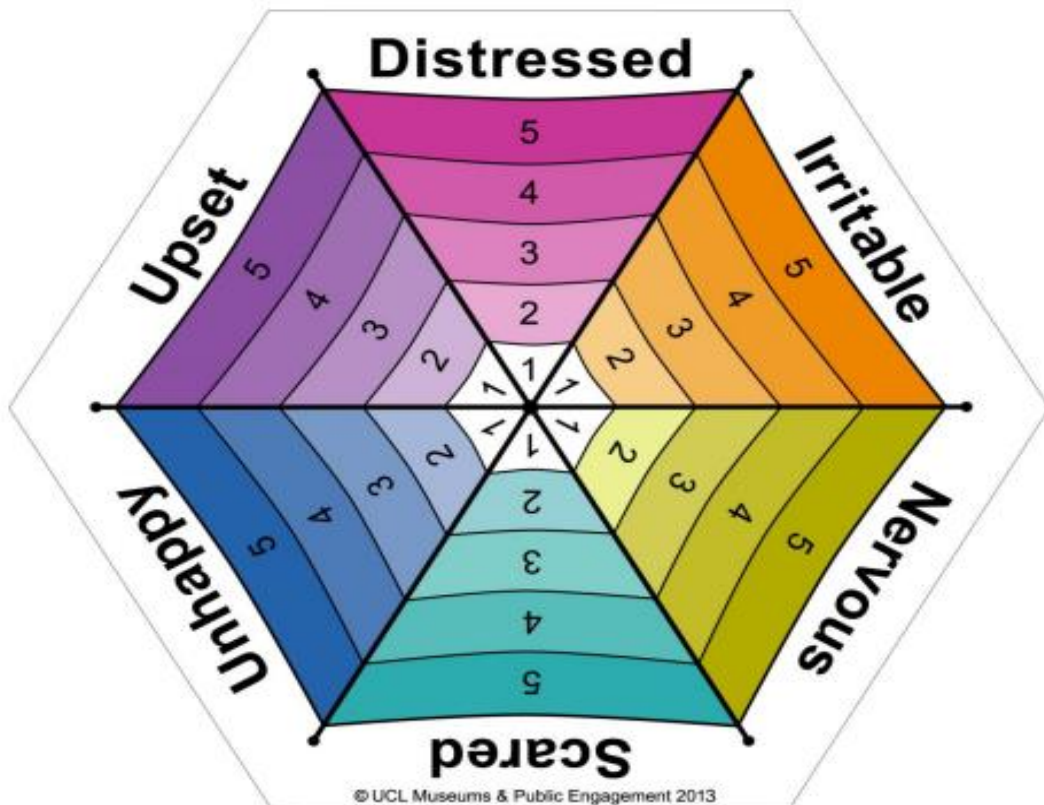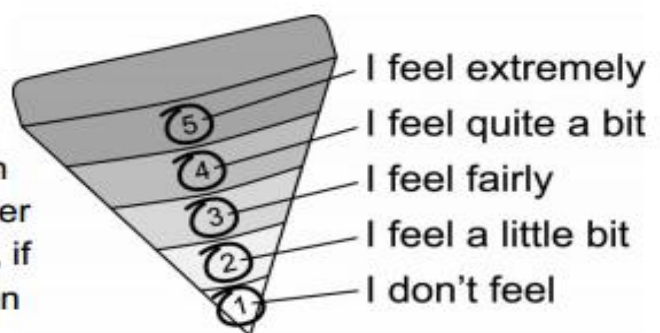Who do you live with?   ………………………………….

1. Are you looking forward to the music group? (5 point faces scale)

2. Have you done any music classes before?   YES/NO

3. Do you think you will meet new friends today? (5 point faces scale)

4. How are you feeling today? (Manikin valence scale)

5. How are you feeling inside your body today? (Manikin arousal scale)

6. Which one of these pictures is most like you? (Manikin dominance scale)

7. How is your health today? (5 point faces scale)

8. Are you in any pain today? (Wong-Baker faces scale)

ROYAL COLLEGE OF MUSIC
STUDENT QUESTIONNAIRE 2

Now you have finished, I would like to ask you some more questions.

1. Did you enjoy your music group today? (5 point faces scale)

2. Would you like to do some more music in the future? (5 point faces scale)

3. Did you meet new friends today? (5 point faces scale)

4. How are you feeling now? (Manikin valence scale)

5. How are you feeling inside your body? (Manikin arousal scale)

6. Which one of these pictures is most like you? (Manikin dominance scale)

7. How is your health now? (5 point faces scale)

8. Are you in any pain now? (Wong-Baker faces scale)

9. Did you learn some new things today? (5 point faces scale)

10. What was your favourite thing about the music session today? …………

…………………………………………………………………………..

Manikin valence scale

Manikin dominance scale

Manikin arousal scale

5 point faces scale

Wong-Baker scale

0	1	2	3	4	5
NO HURT	HURTS LITTLE BIT	HURTS LITTLE MORE	HURTS EVEN MORE	HURTS WHOLE LOT	HURTS WORST

PARTICIPANT INTERVIEW SCHEDULE 1

Topic: Background and motivation

Date: 10/11/17

Ensure participant provides consent for recording   yes/no

1. Background information

a) How often do you come to Music Man?

b) Which days do you come on? Is that all day or just the morning/afternoon?

c) How long have you been coming for? (…a long time/number of years etc?)

d) Do you go to Saturday Music School as well? (If so, how long for).

2. Motivation for attending Music Man Project

a) Can you tell me why you come to Music Man?

- What is the main reason that you come along each week?

b) Why did you start coming to Music Man in the first place?

c) And what is it that makes you want to keep coming?

- How much do you want to keep coming?

d) How important is Music Man to you…and compared to the other activities that you do?

e) Do you look forward to coming?

- Why is that…can you tell me a bit more about that please?

f) What are the best activities that you do at Music Man?

- What is your most favourite thing?

- Why do you like it so much?

- How does that make you feel…what are some of the feelings you get?

g) What are your least favourite things about coming to Music Man?

- And the very worst?

- What do you not like about it?

- And how does that make you feel?

Thanks for your time, can we chat a bit more next week?

Topic: Emotions, engagement and relationships.

Date: 24/11/17

Ensure participant provides consent for recording   yes/no

3. Emotions/feelings about attending Music Man

a) How do you feel about coming to Music Man?

- Can you describe to me what that feels like? Are they good or bad feelings?

b) How do you feel in the morning before you come to Music Man…while you are getting ready?

- Can you tell me a bit more about your feelings before you come each week?

c) How would you feel if you couldn't come for a week…if you were ill, or had to go somewhere else?

d) How do you feel while you are actually here taking part?

- Can we talk about that a bit more?

e) Do you think that it affects your mood?

- In what way, better, worse or the same?

f) How do you feel after your Music Man session?

- What are some of the things that you feel afterwards?

- Do you feel worse, the same or better?

g) Do you think that music helps you to show how you are feeling?

- To be able to express your emotions while you are here?

- How do you do that?

- And how does that make you feel?

4. Engagement at Music Man.

a) What does it feel like to be part of the Music Man Project?

- Can you describe that to me?

b) Do you like to do things as part of the group, or do you prefer doing activities on your own?

c) Do you like being part of activities where you are concentrating hard to learn things…such as rehearsing for a show? Or do you not enjoy that maybe?

- How does it feel when you are working on something and concentrating hard?

d) Do you think being at Music Man has helped you to learn to concentrate more or not?

- Why do you think that?

5. Relationships at Music Man

Can we talk a bit about how you get on with the other people here at Music Man?

a) How would you describe David – Teacher, friend or something else?

b) How important is David to you?

c) How would you describe Jenny? – Teacher, friend or something else?

d) How important is Jenny to you?

e) How do you get along with the other students at Music Man?

- Would you say they are your friends or not?

f) Do you like being with people here at Music Man?

g) Do you feel that you all support each other when you are doing things – like performances?

- Do you feel relaxed or worried when with them?

h) Do you think that you have made more friends by coming here?

i) Are there any other people here that you like spending time with?

- Or anyone that upsets you?

j) Do you think that Music Man has helped you to get along with people better or not?

- Maybe in the way that you talk with the others?

- Do you feel more confident around people compared to before you started coming?

Is there anything else you would like to tell me today about Music Man?

Thanks for your time and I look forward to chatting again next time.

INTERVIEW SCHEDULE 3

Topic: Meaning, accomplishment and performance

Date: 8/12/17

Ensure participant provides consent for recording   yes/no

6. Meaning provided by attending Music Man Project.

a) What does being part of Music Man Project actually mean for you? Can we talk about that in a bit more detail?

b) What do you think that the main thing the Music Man adds to your life?

c) What does that mean to you?

d) How does that make you feel?

e) Can you describe that to me?

7. Accomplishment provided by attending Music Man Project

a) How do you feel after you have learnt something new at Music Man, such as a new instrument or song?

b) Is that a good feeling or a bad feeling, or neither?

c) Why is that?

d) Can you describe that to me?

e) What are some of the other feelings you get from learning new skills here at Music Man?

f) What does that mean to you?

g) How does it feel to have things like concerts to look forward to?

h) Do you think that is important to you, or not?

8. Performance

a) What are your thoughts about doing Music Man shows - like our recent 'Music is Magic' concert at the London Palladium?

b) How do you think that performing helps you?

c) How does performing up on the big stage make you feel?

d) Is that a good thing or a bad thing?

e) Can you describe how that feels?

If you had to describe Music Man in a couple of words, how would you describe it?

Is there anything else you would like to tell me today about Music Man?

Thank you very much for talking with me today.

FAMILY/FRIENDS INTERVIEW SCHEDULE

Topic: All

Date: December 2017

Ensure participant provides consent for recording: yes/no

Date of birth?

Living arrangements?

Any major health issues?

1. Background information

a) How often does x come to Music Man?

b) Which days?

c) Does x attend Saturday Music School as well?

d) How long has x been coming?

e) How did you originally become involved with Music Man?

2. Motivation for attending Music Man

a) Why did x start coming to Music Man in the first place?

b) What do you think are the main reasons for x attending?

c) What do you think makes x want to keep coming back each week?

d) Do you think that x looks forward to coming each week?

e) How important do you think Music Man is to x?

f) How important is Music Man to you and your family?

3. Emotions/feelings about attending Music Man

a) How do you think x feels about being part of the Music Man community?

b) What do you feel about x being part of Music Man?

c) Do you view Music Man as a family involvement or just something for x?

d) Do you think it helps to support x's emotions in any way, whether positive or negative?

e) Do you think it provides support for either you or your family's emotions in any way?

f) Does it bother x if he/she has to miss a week for any reason…how does it affect him/her?

g) Does attending the sessions seem to affect his/her mood in any way, either positively or negatively?

h) Would you say Music Man is more of a positive or negative support of emotions for x?

i) And what about for you and the family too?

4. Engagement at Music Man.

a) What does it feel like to be part of the Music Man community?

b) What do you think that means to x too?

c) Do you think that being engaged within Music Man helps support x in any way?

d) Do you think that being engaged in activities at Music Man has helped x to concentrate and focus more?

e) Do you feel being engaged at Music Man has supported x's self-confidence?

f) And his/her social skills?

g) Do you think being engaged with Music Man has helped either x or you and your family in any other ways?

5. Relationships at Music Man

a) How would you describe x's relationship with David?

b) What are the positive and negative aspects?

c) Would you think this is a generally overall positive or negative experience?

d) How would you describe x's relationship with Jenny?

e) What are the positive and negative aspects?

f) Again, would you say this is a generally overall positive or negative experience?

g) Do you feel the relationships with the other students help support x in any way?

h) How do you think these relationships have affected x's self-confidence?

i) And what about his/her social skills?

6. Meaning provided by attending Music Man?

a) Do you feel that being part of Music Man adds meaning to x's life?

b) How does it do that for him/her?

c) What do you think are the main things that being part of Music Man adds to x's life?

d) Do you think that music provides meaning for x in a way that other activities can't?

e) Does it provide any meaning for either you or the family in any way?

7. Accomplishment provided by attending Music Man Project.

a) Do you think that Music Man provides x with an opportunity to feel a sense of accomplishment?

b) What are the main ways that this happens?

c) How do you recognise that in him/her?

d) How do you feel when you see this happening?

8. Performance

a) What are your thoughts about the Music Man shows – like the London Palladium, for example?

b) What are some of the benefits that you feel these events provide to x?

c) And any negative factors?

d) Or for you and the family…either positive or negative?

If you had to describe Music Man Project to someone regarding the benefits it provides, in just one sentence – what would you say?

If you had to identify any negative aspects, again in one sentence – what would you say?

SUPPORT STAFF INTERVIEW SCHEDULE

Topic: All

Date: January 2018

Ensure participant provides consent for recording: Yes/No

1. Background information

a) What is your relationship to X?

b) How long have you known X?

c) Can you give me a brief summary of X's background? (Family/education/living)

d) Does X have any major health concerns?

e) Date of birth?

2. Motivation for attending Music Man

a) What do you think motivated X to attend Music Man in the first place?

b) And to keep on returning back each week?

3. Emotions/feelings about attending Music Man

a) Do you think Music Man provides emotional support for X?

b) If so, how does it do that? (Examples)

4. Engagement at Music Man

a) Do you feel Music Man provides an opportunity for X to feel engaged in something?

b) If so, how does it do that? (Examples)

5. Relationships at Music Man

a) How would you describe X's relationship with David Stanley – positive/negative aspects?

b) How would you describe X's relationship with Jenny – positive/negative aspects?

c) How about her relationships with the other staff – positive/negative aspects?

d) And students – positive/negative aspects?

6. Meaning provided by attending Music Man

a) Do you think Music Man adds meaning to X's life?

b) If so, how does it do that? (Examples)

7. Accomplishment provided by attending Music Man

a) Do you think attending Music Man provides X with a sense of accomplishment?

b) If so, how does it do that? (Examples)

8. Performance

a) Do you think performing at the shows supports X's well-being in any way?

b) If so, how does it do that? (Examples)

c) Any negative aspects of performing? (Examples)

If you had to describe how MMP supports X's well-being in just a few words, what would you say? Are there any negative aspects at all?

ADAPTED PARTICIPANT INFORMATION SHEET

Project
How does having fun with music making help people?
You are being asked to take part in an exciting project taking place at the Royal College of Music in London. I am going to tell you what this is about so you can choose if you want to take part. Thank you for listening.

Why is this happening?
Some people think that taking part in music can help people in all sorts of ways. I feel it is important to find out more about this idea. This information could then be used in the future to help people to learn all sorts of different things through music and how this makes them feel.

Why me?
You have been asked as you come along to music classes with Music Man Project (or other music group), or have volunteered to come along.

Do I have to do it?
No, it is only if you want to, and you can stop at any time too.

What do I have to do?
Nothing that is scary or too hard. There will just be a few questions to answer before and after your class.

Is there anything bad about taking part?
No, it will only take a few minutes to answer the questions.

How might this help people?
This could help by showing how music might help other people in the future.

Will you tell anybody what I say?
No, everything will be private between us and it will not have your name on it.

What happens afterwards?
You will be told some more about the project and all the results will be kept private.

Is the project safe?
Yes it is, other important people have also said that it is safe too.

Thank you very much and have fun with your music!
February 2018

Title of Project: What is the effect of active music participation on well-being among adults with Down's syndrome?

Name of Researcher: Natalie Bradford

Participant Identification Number for this project: Unknown at this stage

Please initial box

1. I confirm that I have read and understand the information sheet/letter
   dated February 2018 for the project in which I have been asked to take part and have had the
   opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time
   without giving any reason.

3. I understand that my responses will be anonymised before analysis. I give permission for
   members of the research team to have access to my anonymised responses. I understand
   that all personal data about me will be kept confidential.

4. I understand that the researcher must adhere to the BPS Code of Human Research
   Ethics.

5. I agree to take part in the above research project.

_____   _____   _____
Name of participant   **Date**   **Signature**

_____   _____   _____
Researcher   **Date**   **Signature**

Copies
One copy for the participant, and one copy for the researcher.

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Adapted consent form for participants with learning disabilities

Title of Project: How does having fun with music making help people?

Name of Researcher: Natalie Bradford

Participant Identification Number for this project: Unknown at this stage   Please initial box

1. I have read and been told about this project which is starting in February 2018
    and I know I can ask any questions if I want to.

2. I know that I only have to take part if I want to and I can stop at any time.

3. I know that anything I say will be private between me and the person talking to me and they
    will not tell anybody else, except for the people that are working with them.

4. I know that the person working with me must not do anything to upset or hurt me.

5. I would like to be part of this project.

_____   _____   _____

Name of participant   **Date**   **Signature**

_____   _____   _____

Researcher   **Date**   **Signature**

Copies
One copy for the participant, and one copy for the researcher.

Example of recording consent form:

<div align="center">INTERVIEW 3 (CONSENT)</div>

I agree to my interview with Natalie Bradford being recorded and to be used for her research on music and well-being.

DATE:

NAME (PARTICIPANT):

SIGNED (PARTICIPANT):

NAME (RESEARCHER):

SIGNED (RESEARCHER):

Examples of interview transcription:

PARTICIPANT 1

R: And how do you feel, sort of in the morning before you are coming when you are looking forward to it, how does that make you feel?

I: Erm…happy.

R: Does it?

I: Exciting.

R: Good.

I: See my friends. See David as well.

R: Yep. Fantastic, and what would you say are the best activities that you do here at Music Man?

I: Erm.

R: What do you like doing the most?

I: Conducting.

R: Yeah I thought you might say that.

I: Yes, because going back in 'Music is Magic' at the Cliffs Pavilion.

R: Yes.

I: I watched Jenny Hitchcock, she was the first conductor.

R: Ah right so you watched her conducting?

I: I keep an eye all the time, then I want to become a conductor.

R: And you have become a conductor, haven't you?

I: Yes I have yes.

R: And how does that make you feel?

I: Confident, very strong, with confidence.

R: Wow that's amazing, isn't it?

R: And what would you say are some of your least favourite things about coming to Music Man…is there anything you don't like about it?

I: I just love music.

R: You just love music, ok.

R: So there is nothing that you don't like about it at all?

I: Not really no, I love music because my step-mum Barbara, she wanted me to mix with my friends.

R: Yep.

PARTICIPANT 2

R: So would you say that they are all about the same, or Music Man is better or worse, or the same? How would you say… all your activities?

I: I would say it's the best.

R: You would say it was your best activity would you?

I: Yeah.

R: Your favourite one.

I: Yeah.

R: So do you look forward to coming then?

I: (Nods).

R: And how do you feel in the morning before you are coming then?

I: I feel, get up, get ready, go Music Man!

R: And how does that make you feel?

I: Happy.

R: Happy, good.

R: And what is the best activity that you do when you are here…what is your favourite thing?

I: My favourite thing?

R: About Music Man, what do you like doing best?

I: Practices for concerts.

R: Practices for concerts, yep.

I: Err.

R: So you like the concerts do you? You like doing the rehearsals for those.

R: And what other favourite things do you like doing here… do you like the singing, or the instruments?

I: I like the instruments and singing.

R: You like both of those, ok.

I: Yeah.

R: And when you are doing your singing and playing instruments, doing things at Music Man, how does that make you feel?

I: Happy.

PARTICIPANT 3

I: Yeah.

R: And how does it feel to have the concerts to look forward to – do you think about them beforehand?

I: Yeah.

R: And do you look forward to the concerts?

I: Yes.

R: So how does that make you feel?

I: Happy.

R: Happy. And what are your thoughts about doing our Music Man shows, like our recent one at the London Palladium? What did you think about doing that?

I: Nervous.

R: You were nervous, 'cos it was such a big place wasn't it?

I: My, my first show.

R: Your first show was it, wow? So your first big show? So you were a bit nervous, but then how did you feel afterwards?

I: Happy.

R: Happy, yeah. So how does, if you were standing up on that big stage at the London Palladium, how did that make you feel?

I: Happy.

R: So would you say that performing is a good thing or a bad thing?

I: Good.

R: Good. So if you had to describe Music Man in just a couple of words, if a friend was asking you 'what is Music Man about then', how would you describe it?

I: Good.

R: Good.

I: And nice.

R: Brilliant. So is there anything else you would like to tell me about Music Man while we are having our chat today? (Pauses) Any other thoughts or feelings you have got about how it supports you or helps you, or…

I: When I sing I think of Mum.

R: It makes you think of Mum does it? Did your Mum like music then?

I: Mum loved, Mum loved music.

PARTICIPANT 4

R: And do you think that being here at Music Man, does that effect your mood, how you are feeling? Does it make you feel happier or sad, or…

I: I happy coming to Music Man.

R: Happy?

I: Yeah.

R: And when you get home after you have been to Music Man, when you get home tonight and you think about what you have been doing today…

I: Yeah.

R: How do you think about that?

I: I will tell, I get home, I will tell the staff.

R: Yeah.

I: Right, and erm, how you got on.

R: Yeah.

I: Right, and erm, and I said 'alright'.

R: So you talk about it once you get home?

I: Yeah.

R: And do you think that music helps you to show how you are feeling?

I: Music is fine, right. The songs I know, right, and erm I learned it, I learned it at home.

R: Yep so you have remembered it.

I: Yeah.

R: And what do, how would you describe it as being part of the Music Man Project, the whole big thing, how or what does it feel like to be a part of that?

I: Erm, I kept thinking, right, I done really well.

R: You have, really well, yeah you have.

I: Yeah.

R: And do you like doing things as part of the group, or on your own, or both?

I: On me own, right, it's that, well I know, right, its erm, 'Bring him home', right, by erm Alfie Boe.

R: Yep from Les Mis?

I: Yeah, yeah.

Examples of field notes extracts:

PARTICIPANT 1

Hello song   3rd March 2017 (pm)
- David walks to front during hello song and takes mic + does an extra solo.
- Remains attentive throughout hello song.
- Making plans and talking about Palladium show - fully attentive and enjoying the planning of the show.
- Rehearsing for show - full of emotion in appropriate sections (musical).
- Supportive of other students - taking turns at solos etc.
- lots of dancing + singing (Note by Note) — clearly having great fun and enjoying the physical participation with the songs.
- excellent at identifying songs when only played first couple of notes
- (Hey There) - Singing throughout, starting to look tired → towards end of day, but still joining in, communicating with person sitting next to him (Peter).
- helping Peter get ready to leave.
- back to singing next song.

21/4/17
- rehearsing for Palladium - marches - conducting (see photos).
- Very proud to be conductor, wearing bow tie and tail coat! Very attentive.
- Takes his conducting role very seriously and gives him a real sense of importance → self confidence & esteem evident.
- very musically aware and has really risen to the occasion of being conductor. → high expectation resulted in high achievement.
- Peace + hope - knows which bell he needs (green) without being reminded.
- Aware where he needs to play even when bell before missed out. Adds to confidence following conducting previously.
- Aware of others around and when might need help.

Sense of achievement.

PARTICIPANT 2

Performed with empathy and understanding of other performers & looking at them to ensure musical security of the piece. communication skills
- looking at others when starting and stopping, lots of smiling and looking as though having a wonderful evening (see pics).
2) Note by Note - S. mum's favourite! This has a dance section in the middle which S. loved as she is a keen dancer (see pics).
S. loves to twirl around when she is dancing with her hands up in the air - she never seems to get dizzy.
3) Triangle concerto - this was a warm up for the world record attempt which is going to happen at the Palladium show. S helped to [Support to audience] show everybody (audience participation) what to do and also helped to hand out and collect up all the triangles. This piece was a great success and helpful bodes well for the Guiness World Record attempt later in the year.
- S spent the best of the evening participating in [enjoys performing and.] all the dancing + fun activities that took place and her confidence in this musical celebration was apparent throughout the evening and it was such a pleasure to see. conf. in new surroundings

26.5.17

- Today S. is wearing Sunglasses. Its very hot + she was putting sun cream on her face. She accidently rubbed it into her eye which is now very red and sore. The Sunglasses are helping to protect her eye.
- Lovely singing throughout Music is magic still enh.

PARTICIPANT 3

+ musical ed.
skill enh.
role model of tutors
relationships with staff

Concert at Nazareth House on 14/3/17
- First trip out in Ludwig minibus
- Sat on front seat next to G for journey,
- G. very excited about concert and new minibus. *look forwards to shows*
  - G. kept singing 'We wish you a Merry Christmas'. - When asked
why he replied that: 'I am so happy it feels like — *happiness* Christmas today!'
The driver asked G. to be quiet after a while as the
singing was affecting his concentration. *social skill dev.*
  G. obliged but then instead started chatting non-stop
about anything that came into his head. eg. Lets go to the
pub, I would like a beer!'. *role of ambassador imp.*
At the concert G. was very helpful in setting out the instruments
ready for the performance. eg. putting out beaters for glocks etc.
  - G. performed enthusiastically while remembering how to *enthusiasm* behave while on stage as a performer — *creates sensible attitude.* *enjoys perf.*
He readily accepted the offer of singing a solo and did so
with sensitivity. *support to others.* *happy to achieve / succeed.*
  G. helped pack away the instruments back into the mini-bus.
  For the return journey G + I sat together on the
front seat again.
  - It wasn't long before 'We wish you a Merry Christmas'
started up again!
  - He was reminded about not distracting the driver so
  G. stopped singing and apologised. — *empathy / understanding*
  - We then chatted about his solo performance — he was very
keen to know if I had seen him perform and whether I
thought he was good. — *pleased with achievements*
I told him he had performed brilliantly and he said
good and that he was going to tell all his friends
about it. *evident pride.*
  - A funeral car pulled up alongside the mini bus —

empathy / understanding (left margin, vertical)

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PARTICIPANT 4

26/5/17

- P. has missed a couple of sessions due to ill health.

- Arrived today and had lunch with students. The weather is very hot + sunny. P. is wearing shorts + T. Shirt + is enjoying the warm weather.

- This is the last day before half term.

- At the end of lunch P. helps Abbey back to her emp. Seat — very kind and thoughtful, always a understanding gentleman. Sits next to Abbey for the afternoon.
  Support to others
  Empathy / understanding

- He notices his drum is missing and asks about it before the start of the afternoon session. — good observation and planning ahead. — forward planning
  encourages concentration *Encour. conc.*

- 'Here we are' — good singing and signing throughout.
  skill enhancement

- 'Hello Song' — loud + rhythmic singing. Tapping on leg in time and Smiling. Rubbing hands together. Tapping on shoulder again in time — clearly enjoying participating when others are singing too.
  enjoyment *role modelling of tutors* *group activities*

- Arms folded and watching David to follow what is happening — rubbing hand on chair and looking thoughtful and expectant.

- Looking around and smiling.
  happiness *forward planning*

- Singing happy birthday with others to Michelle.

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Example of creative writing (P4)

6

There is David walking to Park and
saw Sam marsh, Sam, H, Daniel Cum
they said to him what are you going?

I am going to the Park having pickin

It is lovely Sun day it was fab pick in
David. We are perforce in O2 music
is magic at O2 after meal out in
Southend restaurant Called Chinese
when they went to Cinema to watch
Frinding Noem—SP

Daniel J Cato

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Summary table for Participant 1

OVERARCHING THEMES	RESEARCHER INTERVIEW WITH P1	RESERCHER INTERVIEW WITH FATHER OF P1	RESEARCHER FIELD NOTES FOR P1
POSITIVE EMOTIONS	**Pleasure providing** - Enjoyment - Love of music - Wants to attend **Sense of anticipation** - Looking forward/ forward planning - Performances and concerts **Emotional support** - Feelings/ mood - Positive attitude of staff - Emotional experiences/ grief support	**Pleasure providing** - Enjoyment - Love of music - Wants to attend **Sense of anticipation** - Looking forward/forward planning/career planning - Performances and concerts **Emotional support** - Feelings/mood - Positive attitude of staff - Emotional experiences/grief support	**Pleasure providing** - Enjoyment - Love of music/conducting - Positive experience **Sense of anticipation** - Looking forward/forward planning - Performances and concerts **Emotional support** - Feelings/mood - Positive attitude of staff - Emotional experiences/grief support
EDUCATIONAL DEVELOPMENT	**Learning through music** - Musical education - Role modelling	**Learning through music** - Musical education - Role modelling	**Learning through music** - Musical education - Role modelling - Additional learning opportunities

	Focus development - Concent-ration encourage-ment	**Focus development** - Concentration encouragement	**Focus development** - Concentration encouragement/ creates sensible attitude - Ability to focus in different environments
	Social development - Friendships - Relationships with staff - Social skill development - Social activities and opportunities	**Social development** - Friendships - Relationships with staff - Social skill development - Social activities and opportunities/ dating	**Social development** - Friendships - Relationships with staff - Social skill development/ talking with public - Social activities and opportunities
MEANING	**Significant to life** - Importance of MMP - Life changing experience	**Significant to life of P1** - Importance of MMP - Life changing experiences **Significant to family** - Positive impact on family - Negative impact on family	**Significant to life** - Importance of MMP - Life changing experiences **Significant to family** - Positive impact on family - Negative impact on family
ACCOMP-LISHMENT	**Sense of achievement** - Satisfaction and pride - Parental and family pride	**Sense of achievement** - Parental and family pride	**Sense of achievement** - Satisfaction and pride

	Sense of self-confidence - Confidence improvement **Practical support** - Support given to others - Support given to staff	**Sense of self-confidence** - Confidence improvement **Practical support** - Support given to others - Support given to staff	**Sense of self-confidence** - Confidence improvement - Confident in new surroundings **Practical support** - Support given to others - Support given to staff - Support given to other groups

Summary table for participant 2

OVERARCHING THEMES	RESEARCHER INTERVIEW WITH P2	RESEARCHER INTERVIEW WITH MOTHER OF P2	RESEARCHER FIELD NOTES FOR P2
POSITIVE EMOTIONS	**Pleasure providing** - Enjoyment - Love of music - Wants to attend - Positive experience **Sense of anticipation** - Looking forward/ forward planning - Perform-ances and concerts **Emotional support** - Feelings/ mood - Positive attitude of staff - Emotional experiences/ grief support	**Pleasure providing** - Enjoyment - Wants to attend - Positive experience **Sense of anticipation** - Looking forward/ forward planning - Perform-ances and concerts **Emotional support** - Feelings/ mood - Positive attitude of staff - Emotional experiences/ grief support	**Pleasure providing** - Enjoyment - Love of music - Positive experience **Sense of anticipation** - Looking forward/forward planning - Performances and concerts **Emotional support** - Feelings/mood - Positive attitude of staff - Emotional experiences/grief support

EDUCATIONAL DEVELOPMENT	**Learning through music** - Musical education - Role modelling **Social development** - Friendships - Relationships with staff - Social activities and opportunities	**Learning through music** - Musical education - Role modelling - Additional learning opportunities **Focus development** - Encourages concentration **Social development** - Friendships - Relationship with staff - Social skill development - Social activities and opportunities	**Learning through music** - Musical education - Additional learning opportunities **Focus development** - Encourages concentration/ creates sensible attitude **Social development** - Friendships - Relationships with staff - Social skill development - Social activities and opportunities
MEANING	**Significant to life** - Importance of MMP - Life changing experiences	**Significant to life of P2** - Importance of MMP - Life changing experiences **Significant to family** - Positive impact on family	**Significant to life** - Importance of MMP - Life changing experiences
ACCOMP-LISHMENT	**Sense of achievement** - Satisfaction and pride - Parental and family pride	**Sense of achievement** - Parental and family pride	**Sense of achievement** - Satisfaction and pride

| | | **Sense of self-confidence**
- Confidence improve-ment | **Sense of self-confidence**
- Confidence improvement
- Confident in new surroundings |
| | **Practical support**
- Support given to others
- Support given to staff | | **Practical support**
- Support given to others |

Summary table for participant 3

OVERARCHING THEMES	RESEARCHER INTERVEIW WITH P3	RESEARCHER INTERVIEW WITH FATHER OF P3	RESERACHER FIELD NOTES FOR P3
POSITIVE EMOTIONS	**Pleasure providing** - Enjoyment - Love of music - Wants to attend - Positive experience **Sense of anticipation** - Looking forward/ forward planning/ career planning - Performances and concerts **Emotional support** - Feelings/mood - Emotional experiences/ grief support	**Pleasure providing** - Enjoyment - Love of music - Wants to attend - Positive experience **Sense of anticipation** - Looking forward/forward planning/career planning - Performances **Emotional support** - Feelings/mood - Positive attitude of staff - Emotional experiences/ grief support	**Pleasure providing** - Enjoyment - Love of music - Positive experience **Sense of anticipation** - Looks forwards to performances - Looks forwards to visits to new groups **Emotional support** - Feelings/ mood - Positive attitude of staff - Emotional experiences/ grief support
EDUCATIONAL DEVELOPMENT	**Learning through music** - Musical education - Role modelling	**Learning through music** - Musical education - Role modelling	**Learning through music** - Musical education - Role modelling - Additional learning opportunities

	Social development - Friendships - Relationships with staff - Social skill development - Social activities and opportunities	**Focus development** - Encourages concentration **Social development** - Friendships - Relationships with staff - Social skill development - Social activities and opportunities/ dating	**Focus development** - Encourages concentration **Social development** - Friendships - Relationships with staff - Social skill development
MEANING	**Significant to life** - Importance of MMP - Life changing experiences	**Significant to life of P3** - Importance of MMP - Life changing experiences - **Significant to family** - Positive impact on family	**Significant to life** - Importance of MMP - Life changing experiences
ACCOMP-LISHMENT	**Sense of achievement** - Satisfaction and pride **Sense of self-confidence** - Confidence improvement	**Sense of achievement** - Parental and family pride **Sense of self-confidence** - Confidence improvement - Returning confidence **Practical support** - Support given to others - Support given to staff	**Sense of achievement** - Satisfaction and pride **Sense of self-confidence** - Confidence improvement **Practical support** - Support given to others - Support given to staff

Summary table for Participant 4

OVERARCHING THEMES	RESEARCHER INTERVIEW WITH P4	RESEARCHER INTERVIEW WITH SISTER OF P4	RESEARCHER FIELD NOTES FOR P4
POSITIVE EMOTIONS	**Pleasure providing** - Enjoyment - Love of music - Wants to attend - Positive experience **Sense of anticipation** - Performances and concerts **Emotional support** - Feelings/ mood - Emotional experiences/ grief support	**Pleasure providing** - Enjoyment - Love of music - Wants to attend - Positive experience **Sense of anticipation** - Looking forward/ forward planning - Performances and concerts **Emotional support** - Emotional experiences/ grief support	**Pleasure providing** - Enjoyment - Love of music - Wants to attend - Positive experience **Sense of anticipation** - Looking forward/ forward planning - Performances and concerts **Emotional support** - Feelings/mood - Emotional experiences/ grief support
EDUCATIONAL DEVELOPMENT	**Learning through music** - Musical education - Role modelling	**Learning through music** - Musical education - Role modelling **Focus development** - Encourages concentration	**Learning through music** - Musical education - Role modelling - Additional learning opportunities **Focus development** - Encourages concentration

	Social development - Friendships - Relationships with staff - Social skill development	**Social development** - Friendships - Relationships with staff - Social skill development - Social activities and opportunities	**Social development** - Friendships - Relationships with staff - Social skill development - Social activities and opportunities
MEANING	**Significant to life** - Importance of MMP - Life changing experiences	**Significant to life of P4** - Importance of MMP - Life changing experiences **Significant to family** - Positive impact on family - Negative impact on family	**Significant to life** - Importance of MMP - Life changing experiences
ACCOMP-LISHMENT	**Sense of achievement** - Satisfaction and pride **Sense of self-confidence** - Confidence improvement **Practical support** - Support given to others	**Sense of achievement** - Parental and family pride **Sense of self-confidence** - Maintains confidence **Practical support** - Support given to others	**Sense of achievement** - Satisfaction and pride **Sense of self-confidence** - Confidence improvement - Creates independence **Practical support** - Support given to others

List of Mencap Network Partners

1. Abbeyfield
2. ABC group
3. Abergavenny g
4. Abergwaun Social g
5. Abertillery
6. Aberystwyth g
7. Abingdon Monday Club
8. Alexander house
9. All Saints g
10. Alnwich and district
11. Amman Valley
12. Andover and district
13. Ashford
14. Ashton-under-Lyne and district
15. Atherstone district g
16. Attleborough g
17. Autism Together
18. Aylesbury g
19. Aylestone g
20. Ayrshire Enable
21. Balham g
22. Barnet
23. Barnet Monday Club
24. Barnsley
25. Basingstoke
26. Basingstoke g
27. Basingstoke g award
28. Bath g
29. Bath g out and about
30. Bath and district
31. Bath Junior g
32. Batley and district
33. Beckenham and Penge g
34. Bedford
35. Bexhill g
36. Bexley
37. Bishops Stortford
38. Bishops Waltham g
39. Blackpool
40. Bolton

41. Boston and district
42. Bourne g
43. Bournemouth g
44. Bradford disability sport and leisure
45. Braintree
46. Braintree district
47. Brent
48. Brickkiln Dunstall g
49. Bridgnorth and district
50. Bridgwater and district
51. Bridport Busy Bees
52. Brigg and district g
53. Bright Lives
54. Brighton Hove and district
55. Bromley
56. Buckingham and district
57. Burnley Colne and Nelson
58. Burntwood g
59. Burnham and Highbridge g
60. Burton upon Trent
61. Bury People First
62. Bushey Back-Up g
63. Calderdale g
64. Camberley and district
65. Cambridge Road Day Centre
66. Cardiff
67. Cardiff Chameleons
68. Care with a difference
69. Caremark Barnsley
70. Careplace
71. Carlisle
72. Carmarthen Breakthro
73. Causeway Prospects
74. Ceredigion
75. Chase g
76. Cheddar Vale g
77. Cheltenham and North Gloucestershire
78. Chepstow and district
79. Chesham Amersham and district
80. Chester
81. Chilterns (Amersham)
82. Chippenham g
83. Chipping Norton g
84. Chorley and district
85. Chorley Newtrees g
86. Chrysalis Day Service

87. Cleddau Warriors
88. Clifton (Bristol) g
89. Colchester
90. Colchester g
91. Colwyn g
92. Conwy County g
93. Cookstown g
94. Corby Steel g
95. Coventry and Wayfarers
96. Creative support
97. CREST
98. Croydon
99. Cunliffe Tuesday club
100. D and H g
101. Dacorum
102. Daisy Bank g
103. Dame Emily g
104. Darlington
105. Denbigh g
106. Derby Shield
107. DGSM Your Choice (Dartford)
108. Discovery SVS Swansea
109. Doncaster
110. Downpatrick g
111. Downpatrick sports and recreation
112. Droitwich Challengers g
113. Dundonald (family support) g
114. Dungannon Senior g
115. Dunstable
116. Durham otters SC
117. Ealing
118. Eastbourne and district
119. East Kent
120. East Surrey
121. East Wiltshire
122. Eastleigh Borough and Romsey
123. Eccles and district
124. ECHO – Extra choices in Herefordshire Ltd
125. Eden society
126. Edgcumbe g
127. Elmbridge
128. Ely Aquarius g
129. Enfield
130. Equal People (Kensington)
131. Essex
132. Everybody's g

133.	Evesham g
134.	Evesham Pershore and district
135.	Exeter g
136.	Exeter and district
137.	Exmouth g
138.	Fakenham g
139.	Feltwell Thetford and district
140.	Fermanagh
141.	Ferndown and West Moors g
142.	Folkestone Hythe and district
143.	Friday Fun Club
144.	Frome and district
145.	Gateshead
146.	Gateway wheelers
147.	GL11 community hub
148.	Glastonbury and district
149.	Glossop and Hadfield
150.	Gorseinon g
151.	Grantham and district
152.	Gravesend and district
153.	Great Yarmouth and district
154.	Great Yarmouth g
155.	Greenlight g
156.	Greenwich
157.	Guernsey
158.	Guernsey g
159.	Hailsham and district
160.	Hammersmith and Fulham
161.	Haringey
162.	Harpenden
163.	Harpenden g
164.	Harrow
165.	Harrow g
166.	Harrowgate and district
167.	Hastings and Bexhill
168.	Hastings g
169.	Haswell and district
170.	Hatfield g
171.	Havant and district
172.	Haverhill and district
173.	Heads of the Valley g
174.	Heart of England
175.	Herefordshire
176.	Hertsmere
177.	Hesley group
178.	Higham Ferrers

179.	High Wycombe g
180.	Hillingdon North
181.	Hillingdon South
182.	Hinckley and district
183.	Hitchin Letchworth and district
184.	Holyhead g
185.	Honiton 729 g
186.	Horncastle Louth and Spilsby g
187.	Huntingdon
188.	Invicta (Maidstone)
189.	Isle of Wight
190.	Jersey
191.	John's club Isle of Wight
192.	Jubilee Day Centre
193.	Keady g
194.	KEEN Oxford
195.	Kennet g
196.	Kettering g
197.	Keynsham and district
198.	Kingsbridge g
199.	Kingsley Organisation
200.	Kingston
201.	Kirklees
202.	Lambeth and Southwark
203.	Leeds
204.	Leek g
205.	Leighton Buzzard and district
206.	Lewisham
207.	Lichfield and Tamworth g
208.	Lisburn Senior g
209.	Llanelli g
210.	Lowestoft
211.	Lowton Golborne and Ashton
212.	Mencap Liverpool
213.	London
214.	Long Eaton and district
215.	Lurgan Junior g
216.	Luton
217.	Luton 21 club
218.	Maesteg and Afan g
219.	Magherafelt and district g
220.	Maidenhead
221.	Maidstone
222.	Malvern
223.	Maplewood house
224.	Market Drayton

225.	Matlock and district
226.	Melksham and Corsham g
227.	Melton
228.	Melton Mowbray
229.	Merseyside and Lancashire
230.	Merthyr
231.	Merton
232.	Middlesbrough g
233.	Midland
234.	Mid Dorset
235.	Mid Norfolk
236.	Mid Surrey
237.	Mid Sussex
238.	Milton Keynes
239.	Mon
240.	Morecombe and Lancaster
241.	Mowbray g
242.	Multi sports club
243.	Neasden g
244.	Nemo swimming and recreation club
245.	New Forest
246.	Newark and district
247.	Newforge Taggers
248.	Newhaven Lewis and district
249.	Newmarket g
250.	Newry and district
251.	Newton g
252.	Newtonabbey
253.	Norman Laud
254.	Northallerton and the Dales
255.	Northbourne g
256.	Northampton
257.	Northwich g
258.	North East
259.	North Somerset
260.	North West Walsall g
261.	Nottingham
262.	Nuneaton Bedworth district
263.	Oldham g
264.	Olympus care services
265.	Omagh g
266.	Options for life
267.	Orchard Hill College
268.	Orpington and Bromley g
269.	Orwell
270.	Oundle School

271.	Oxford and district
272.	Penarth g
273.	Penguin club (Derby)
274.	Penistone g
275.	Pennine
276.	Penny Meadow
277.	Penrose club
278.	Penwith g
279.	Pinetree Court
280.	Plympton and Plymstock
281.	Pontypridd and district g
282.	Pudsey g
283.	Purbeck g
284.	Rainbow g (Carrickmore)
285.	Raw 4 youth
286.	Reading
287.	Redbridge
288.	Redlands g
289.	Richmond
290.	Richmond upon Thames
291.	Rickmansworth g
292.	Riversiders trust
293.	Romsey g
294.	Rossendale valley
295.	Roundabout Rotherham g
296.	Royston and district
297.	Rugby g
298.	Runcorn Frodsham and district
299.	Runnymede and Spelthorne
300.	Ryedale and district
301.	Ryes college
302.	Saffron Walden and district
303.	Saturday Club (Omagh)
304.	Scarborough and district
305.	Scope in Colchester and Tendering
306.	Scunthorpe g
307.	Shrewsbury
308.	Selby and district
309.	Sevenoaks
310.	Sheffield
311.	Sheffield Mencap and g
312.	Shrewsbury
313.	Side by Side theatre company Stourbridge
314.	SKY club
315.	Skyzdalimit
316.	Slough

317. Smethwick
318. Smiley g
319. Snap club Verwood
320. Solihull g
321. Solo (Solihull life opps)
322. Southampton
323. South Leicestershire g
324. South Nothants g
325. South Oxfordshire
326. South Sefton
327. South West Oxfordshire
328. South Wilts
329. Southend
330. Spalding
331. St Albans and district
332. St Andrews healthcare
333. St Edmondsbury g
334. Mencap St Helens
335. Stepping Stones
336. Stockport
337. Stockport g
338. Strule Buzz Group
339. Sudbury g
340. Sunrise (Weymouth) g
341. Sutton
342. Sutton g
343. Swadlincote and district and g
344. Swansea
345. Swinton and Worsley
346. Syston and district g
347. TAG The Active Group
348. Taunton and district
349. Teignbridge SN youth group
350. Telford and district
351. Tenby g
352. Terrence O'Grady social club
353. The Camden Society
354. The Friendship Club
355. The Hive Avon
356. The Rockin' Roadrunner club
357. The Squad Club
358. Thursday Activities Club (TAC)
359. Thurrock and district
360. Tiverton g
361. TOAD (Trips, outings and activities for LD)
362. TODYS Teasdale

363.   Torbay
364.   Tower Hamlets
365.   Tower Project
366.   Trafford
367.   Tree Tops g
368.   Truro college
369.   Tuesday Treg g
370.   Tynemouth
371.   Ulverston and district mental health
372.   Uttoxeter g
373.   Vision in People
374.   Walsall g
375.   Warrington Mencap local society
376.   Waterside g
377.   Watford and district
378.   Waverley g
379.   West Berkshire
380.   West Dorset
381.   West Leeds g
382.   West Norfolk
383.   West Wiltshire
384.   Westmorland
385.   Whorton Hall hospital
386.   Windmill g
387.   Windsor
388.   Wirral
389.   Witney and district
390.   Woking and district
391.   Wokingham Bracknell and districts
392.   Wolverhampton
393.   Woodlands school Blackpool
394.   Worthing
395.   Worthing Scope
396.   YMCA East Surrey
397.   Yorvik g
398.   Young Ones (Durham) youth club
399.   Youth plus (Ongar)
400.   Zero Three Care

(g = gateway club)

ROYAL
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London

Mencap and music

Introduction

Dear Mencap group,

I am a PhD candidate studying at the Royal College of Music in London. My research is concerned with the potential benefits of music participation on well-being for adults with learning disabilities. I am also a music teacher specialising in students with learning disabilities and a regional director of the Music Man Project (Southend Mencap). The Music Man Project is a full-time music education service dedicated specifically to children and adults with learning disabilities.

This questionnaire concerns the use of music and other activities at your Mencap centre, whether they be regular weekly activities, one off sessions, or none at all. This will provide valuable information regarding the current usage of musical interventions for people with learning disabilities throughout the UK Mencap centres.

I would be very grateful if a member of staff at your Mencap centre who knows, manages or oversees the activity programme would take a few minutes to complete and return this questionnaire. Your responses will be anonymous and not traced back to your specific Mencap centre.

If you have any queries concerning this questionnaire, or the research being carried out, please do not hesitate to contact me via email on natalie.bradford@rcm.ac.uk. This research has been reviewed and approved by the CUK Ethics commitee.

Thank you very much for your time.

* 1. Please confirm that you have read the information above before you continue

- ☐ I consent that I have read the above information

- ☐ I agree to take part

1

ROYAL COLLEGE OF MUSIC *London*

Mencap and music

Mencap details

Please note the details below will not be linked to your responses. They are merely to keep track of which Mencap Centres have taken part.

* 2. Which Mencap group are you?

* 3. What is your job title within the organisation?

ROYAL COLLEGE OF MUSIC *London*

Mencap and music

Geographical location

2

* 4. Which part of the country is your Mencap centre located in?

- ( ) South East
- ( ) London
- ( ) North West
- ( ) East of England
- ( ) West Midlands
- ( ) East Midlands
- ( ) South West
- ( ) Yorkshire and Humber
- ( ) North East

Other (please specify)

```
[                                    ]
```

* 5. How many adult service users do you currently have?

```
[                                    ]
```

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Mencap and music

Activities

3

* 6. Which of the following activities do you currently provide?

	Daily	Weekly	Monthly	One-off	Never
Cookery	○	○	○	○	○
Arts/crafts	○	○	○	○	○
Exercise/sport e.g. football	○	○	○	○	○
Drama	○	○	○	○	○
Gardening	○	○	○	○	○
Dance classes	○	○	○	○	○
Photography/film making	○	○	○	○	○
Dating evening	○	○	○	○	○
Friendship/social club	○	○	○	○	○
Lunch club	○	○	○	○	○
Trips/outings	○	○	○	○	○
Money skills	○	○	○	○	○
Life skills	○	○	○	○	○
DIY skills	○	○	○	○	○
Volunteering club	○	○	○	○	○
Disco	○	○	○	○	○
Work/employment skills	○	○	○	○	○
Numeracy/literacy skills	○	○	○	○	○
Computer skills	○	○	○	○	○
Keeping safe classes	○	○	○	○	○
Other	○	○	○	○	○

Other (please specify activity)

[   ]

* 7. Do you currently provide any sort of music activities, music therapy, concerts or other music within your Mencap organisation?

○ Yes

○ No, nothing at all

4

ROYAL COLLEGE OF MUSIC London

Mencap and music

Music activities

* 8. Which of these music activities do you provide?

	Daily	Weekly	Monthly	One-off	Never
Choir/group singing	○	○	○	○	○
Karaoke singing	○	○	○	○	○
Group music listening	○	○	○	○	○
Attending concerts	○	○	○	○	○
Performing to others	○	○	○	○	○
Musical instrument playing	○	○	○	○	○
Music therapy	○	○	○	○	○
Other (please specify activity below)	○	○	○	○	○

Other

[   ]

5

* 9. Below are some reasons why your organisation may provide music activities. Please can you rate how important each reason is to your Mencap organisation as a reason for providing music:

	1 (most important)	2	3	4 (least important)
To help people develop skills and self-esteem	○	○	○	○
To support well-being and emotion regulation	○	○	○	○
To help people develop socially and connect with people	○	○	○	○
To support or provide a physical activity	○	○	○	○

10. Please could you provide an indication of the annual budget available for music provision?

○ No specified amount

○ Up to £250

○ Between £250-£500

○ Between £500-£1000

○ Between £1000-£2000

○ Between £2000-£5000

○ Over £5000

11. How are you music activities funded? (You can select more than one answer)

☐ Core funds

☐ Volunteer tutors

☐ Fundraising

☐ Grants

☐ Specific donors

☐ Self-funding

☐ Other (please specify)

[   ]

6

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London

Mencap and music

Funding details

* 12. Below are some reasons why your organisation may**NOT** provide **MORE** music activities. Please can you rate how important each reason is to your Mencap organisation as a reason for not providing music:

	1 (most important)	2	3	4	5	6 (least important)
Lack of available funds	○	○	○	○	○	○
Not enough staff	○	○	○	○	○	○
Not enough experience amongst available staff in music teaching	○	○	○	○	○	○
There is already felt to be enough music	○	○	○	○	○	○
Lack of interest from service users	○	○	○	○	○	○
Lack of evidence to support the benefits for people with learning disabilities	○	○	○	○	○	○

Thank you very much for taking the time to complete this questionnaire. A report of the findings will be sent to you once the project is completed.

7

APPENDIX 8

STUDY 2 ANALYSIS

STEP 3: [11/9/19]

MUSIC + GROUPSIZE + OTHER + BARRIERS

```
LOGISTIC REGRESSION VARIABLES Music
  /METHOD=ENTER Size_Number
  /METHOD=ENTER Other
  /METHOD=ENTER Barrier_Fund Barrier_Staff Barrier_Exp Barrier_Enough Barri
er_Interest
    Barrier_Evidence
  /CASEWISE OUTLIER(2)
  /PRINT=GOODFIT CI(95)
  /CRITERIA=PIN(0.05) POUT(0.10) ITERATE(20) CUT(0.5).
```

Logistic Regression

Warnings

Due to redundancies, degrees of freedom have been reduced for one or more variables.

— cells with too few cases

Case Processing Summary

Unweighted Cases[a]		N	Percent
Selected Cases	Included in Analysis	100	50.3
	Missing Cases	99	49.7
	Total	199	100.0
Unselected Cases		0	.0
Total		199	100.0

a. If weight is in effect, see classification table for the total number of cases.

Dependent Variable Encoding

Original Value	Internal Value
0	0
1	1

Block 0: Beginning Block

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Classification Table[a,b]

	Observed			Predicted		
				Music present or not		Percentage Correct
				0	1	
Step 0	Music present or not		0	0	10	.0
			1	0	90	100.0
	Overall Percentage					90.0

a. Constant is included in the model.

b. The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 0	Constant	2.197	.333	43.450	1	.000	9.000

Variables not in the Equation

			Score	df	Sig.
Step 0	Variables	Size_Number	2.133	1	.144
	Overall Statistics		2.133	1	.144

Block 1: Method = Enter

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	4.244	1	.039
	Block	4.244	1	.039
	Model	4.244	1	.039

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	60.773[a]	.042	.087

a. Estimation terminated at iteration number 7 because parameter estimates changed by less than .001.

Hosmer and Lemeshow Test

Step	Chi-square	df	Sig.
1	17.286	8	.027

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Contingency Table for Hosmer and Lemeshow Test

		Music present or not = 0		Music present or not = 1		
		Observed	Expected	Observed	Expected	Total
Step 1	1	5	1.919	6	9.081	11
	2	1	1.997	12	11.003	13
	3	1	1.244	8	7.756	9
	4	0	1.504	12	10.496	12
	5	0	1.134	10	8.866	10
	6	0	.952	10	9.048	10
	7	1	.737	9	9.263	10
	8	2	.411	8	9.589	10
	9	0	.097	10	9.903	10
	10	0	.005	5	4.995	5

Classification Table[a]

			Predicted		
			Music present or not		Percentage
	Observed		0	1	Correct
Step 1	Music present or not	0	0	10	.0
		1	0	90	100.0
	Overall Percentage				90.0

a. The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1[a]	Size_Number	.010	.007	2.028	1	.154	1.010
	Constant	1.442	.511	7.972	1	.005	4.228

Variables in the Equation

		95% C.I.for EXP(B)	
		Lower	Upper
Step 1[a]	Size_Number	.996	1.025
	Constant		

a. Variable(s) entered on step 1: Size_Number.

Block 2: Method = Enter

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	2.372	1	.124
	Block	2.372	1	.124
	Model	6.616	2	.037

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	58.401[a]	.064	.134

a. Estimation terminated at iteration number 7 because parameter estimates changed by less than .001.

Hosmer and Lemeshow Test

Step	Chi-square	df	Sig.
1	10.648	8	.222

Contingency Table for Hosmer and Lemeshow Test

		Music present or not = 0		Music present or not = 1		
		Observed	Expected	Observed	Expected	Total
Step 1	1	4	2.928	6	7.072	10
	2	2	1.753	9	9.247	11
	3	1	1.346	11	10.654	12
	4	0	.992	10	9.008	10
	5	0	.826	9	8.174	9
	6	0	.822	10	9.178	10
	7	1	.666	9	9.334	10
	8	2	.404	7	8.596	9
	9	0	.241	12	11.759	12
	10	0	.020	7	6.980	7

Classification Table[a]

	Observed		Predicted		
			Music present or not		Percentage Correct
			0	1	
Step 1	Music present or not	0	0	10	.0
		1	0	90	100.0
	Overall Percentage				90.0

a. The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1[a]	Size_Number	.009	.007	1.674	1	.196	1.009
	Other activities	1.168	.732	2.546	1	.111	3.217
	Constant	.680	.655	1.076	1	.300	1.973

Variables in the Equation

		95% C.I.for EXP(B)	
		Lower	Upper
Step 1[a]	Size_Number	.996	1.022
	Other activities	.766	13.512
	Constant		

a. Variable(s) entered on step 1: Other activities.

Block 3: Method = Enter

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	11.359	5	.045
	Block	11.359	5	.045
	Model	17.974	7	.012

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	47.042[a]	.165	.344

a. Estimation terminated at iteration number 8 because parameter estimates changed by less than .001.

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Hosmer and Lemeshow Test

Step	Chi-square	df	Sig.
1	5.151	8	.741

Contingency Table for Hosmer and Lemeshow Test

		Music present or not = 0		Music present or not = 1		
		Observed	Expected	Observed	Expected	Total
Step 1	1	4	4.400	6	5.600	10
	2	1	2.163	9	7.837	10
	3	3	1.418	7	8.582	10
	4	2	.987	8	9.013	10
	5	0	.597	10	9.403	10
	6	0	.255	10	9.745	10
	7	0	.117	10	9.883	10
	8	0	.044	10	9.956	10
	9	0	.015	10	9.985	10
	10	0	.004	10	9.996	10

Classification Table[a]

			Predicted		
			Music present or not		Percentage Correct
	Observed		0	1	
Step 1	Music present or not	0	2	8	20.0
		1	0	90	100.0
	Overall Percentage				92.0

a. The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1[a]	Size_Number	.008	.007	1.112	1	.292	1.008
	Other activities	1.400	.888	2.485	1	.115	4.057
	Barrier_Fund	.561	.585	.922	1	.337	1.753
	Barrier_Staff	.503	.570	.778	1	.378	1.653
	Barrier_Exp	1.415	.711	3.965	1	.046	4.118
	Barrier_Enough	-.081	.470	.030	1	.864	.922
	Barrier_Interest	.370	.554	.445	1	.505	1.447
	Constant	-6.603	7.489	.777	1	.378	.001

Variables in the Equation

		95% C.I.for EXP(B)	
		Lower	Upper
Step 1[a]	Size_Number	.993	1.022
	Other activities	.711	23.145
	Barrier_Fund	.557	5.513
	Barrier_Staff	.541	5.055
	Barrier_Exp	1.023	16.582
	Barrier_Enough	.367	2.316
	Barrier_Interest	.488	4.289
	Constant		

a. Variable(s) entered on step 1: Barrier_Fund, Barrier_Staff, Barrier_Exp, Barrier_Enough, Barrier_Interest.

Casewise List[b]

	Selected Status[a]	Observed		Predicted	Temporary Variable	
Case		Music present or not	Predicted	Group	Resid	ZResid
38	S	0**	.874	1	-.874	-2.639
122	S	0**	.911	1	-.911	-3.209
128	S	0**	.861	1	-.861	-2.489
129	S	0**	.828	1	-.828	-2.193
156	S	0**	.903	1	-.903	-3.046
159	S	0**	.868	1	-.868	-2.563

Casewise List[b]

	Temporary ..
Case	SResid
38	-2.255
122	-2.294
128	-2.066
129	-2.014
156	-2.257
159	-2.141

a. S = Selected, U = Unselected cases, and ** = Misclassified cases.

b. Cases with studentized residuals greater than 2.000 are listed.

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APPENDIX 9

Attendance records of the participants throughout the intervention period

P No.	Wk -10	Wk 1	Wk 2	Wk 3	Wk 4	Wk 5	Wk 6	Wk 7	Wk 8	Wk 9	Wk 10	Week non-music	Total sessions attended (12)
1	✓	✓	✓	✓	A	✓	✓	✓	✓	✓	✓	✓	11
2	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
3	✓	✓	✓	A	✓	✓	A	A	A	A	A	✓	6
4	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	A	11
5	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
6	✓	✓	✓	✓	✓	✓	✓	A	A	✓	✓	✓	10
7	✓	A	A	✓	A	A	A	A	A	A	A	✓	3
8	✓	✓	✓	A	✓	✓	✓	✓	✓	✓	✓	✓	11
9	✓	✓	✓	✓	✓	A	✓	✓	✓	✓	✓	✓	11
10	✓	✓	✓	✓	✓	✓	A	A	✓	✓	✓	✓	10
11	✓	✓	✓	✓	✓	✓	✓	A	A	✓	✓	✓	10
12	✓	A	A	A	A	A	A	✓	A	A	✓	✓	4
13	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
14	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
15	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
16	✓	✓	✓	A	✓	✓	✓	✓	✓	✓	✓	✓	11
17	✓	✓	✓	✓	A	A	A	✓	✓	✓	✓	✓	9
18	✓	A	✓	✓	✓	A	✓	✓	A	A	✓	✓	8
19	✓	A	✓	A	✓	✓	✓	✓	A	A	✓	✓	8
20	✓	✓	✓	A	✓	A	✓	A	✓	A	✓	✓	8
21	✓	✓	✓	A	A	A	A	A	A	A	A	A	3
22	✓	✓	✓	✓	A	A	✓	✓	✓	✓	✓	✓	10
23	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	12
24	✓	✓	✓	✓	✓	✓	✓	A	✓	✓	✓	✓	11

STUDY 3A ANALYSIS

SWEMWBS

```
GET
  FILE='C:\Users\natal\OneDrive\Documents\SWEMWBS DATA.sav'.
DATASET NAME DataSet1 WINDOW=FRONT.
EXAMINE VARIABLES=SWEMWBSB SWEMWBS1 SWEMWBS6 SWEMWBS10
  /PLOT BOXPLOT HISTOGRAM
  /COMPARE VARIABLES
  /STATISTICS DESCRIPTIVES
  /CINTERVAL 95
  /MISSING PAIRWISE
  /NOTOTAL.
```

Case Processing Summary

	Cases
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
SWEMWBS -10	24	100.0%	0	0.0%	24	100.0%
SWEMWBS 1	24	100.0%	0	0.0%	24	100.0%
SWEMWBS 6	20	83.3%	4	16.7%	24	100.0%
SWEMWBS 10	21	87.5%	3	12.5%	24	100.0%

Descriptives

			Statistic	Std. Error
SWEMWBS -10	Mean		21.9125	.72850
	95% Confidence Interval for Mean	Lower Bound	20.4055	
		Upper Bound	23.4195	
	5% Trimmed Mean		21.9460	
	Median		22.3500	
	Variance		12.737	
	Std. Deviation		3.56892	
	Minimum		14.08	
	Maximum		29.31	
	Range		15.23	
	Interquartile Range		5.37	
	Skewness		-.260	.472
	Kurtosis		-.059	.918
SWEMWBS 1	Mean		21.0850	.78768
	95% Confidence Interval for Mean	Lower Bound	19.4556	
		Upper Bound	22.7144	

	5% Trimmed Mean		21.2633	
	Median		20.7300	
	Variance		14.891	
	Std. Deviation		3.85885	
	Minimum		9.51	
	Maximum		28.13	
	Range		18.62	
	Interquartile Range		3.10	
	Skewness		-.576	.472
	Kurtosis		2.889	.918
SWEMWBS 6	Mean		29.3420	.99207
	95% Confidence Interval for Mean	Lower Bound	27.2656	
		Upper Bound	31.4184	
	5% Trimmed Mean		29.4611	
	Median		30.7000	
	Variance		19.684	
	Std. Deviation		4.43667	
	Minimum		21.54	
	Maximum		35.00	
	Range		13.46	
	Interquartile Range		8.21	
	Skewness		-.604	.512
	Kurtosis		-1.149	.992
SWEMWBS 10	Mean		31.2586	.75565
	95% Confidence Interval for Mean	Lower Bound	29.6823	
		Upper Bound	32.8348	
	5% Trimmed Mean		31.4955	
	Median		32.5500	
	Variance		11.991	
	Std. Deviation		3.46282	
	Minimum		23.21	
	Maximum		35.00	
	Range		11.79	
	Interquartile Range		3.77	
	Skewness		-1.054	.501
	Kurtosis		.564	.972

Histogram

Mean = 21.91
Std. Dev. = 3.569
N = 24

SWEMWBS -10

Histogram

Mean = 21.09
Std. Dev. = 3.859
N = 24

SWEMWBS 1

478

Histogram

Mean = 29.34
Std. Dev. = 4.437
N = 20

SWEMWBS 6

Histogram

Mean = 31.26
Std. Dev. = 3.463
N = 21

SWEMWBS 10

479

```
NPAR TESTS
  /FRIEDMAN=SWEMWBS1 SWEMWBS6 SWEMWBS10
  /MISSING LISTWISE.
```

Friedman Test

Ranks

	Mean Rank
SWEMWBS 1	1.00
SWEMWBS 6	2.20
SWEMWBS 10	2.80

Test Statistics[a]

N	20
Chi-Square	36.324
df	2
Asymp. Sig.	.000

a. Friedman Test

Test Statistics

N	20
Kendall's W[a]	.908
Chi-Square	36.324
df	2
Asymp. Sig.	.000

a. Kendall's Coefficient of

Concordance

```
NPAR TESTS
  /WILCOXON=SWEMWBSB SWEMWBS1 SWEMWBS1 WITH SWEMWBS1 SWEMWBS6 SWEMWBS10
(PAIRED)
  /MISSING ANALYSIS.
```

Wilcoxon Signed Ranks Test

Ranks

		N	Mean Rank	Sum of Ranks
SWEMWBS 1 - SWEMWBS -10	Negative Ranks	13[a]	13.31	173.00
	Positive Ranks	10[b]	10.30	103.00
	Ties	1[c]		
	Total	24		
SWEMWBS 6 - SWEMWBS 1	Negative Ranks	0[d]	.00	.00
	Positive Ranks	20[e]	10.50	210.00
	Ties	0[f]		
	Total	20		
SWEMWBS 10 - SWEMWBS 1	Negative Ranks	0[g]	.00	.00
	Positive Ranks	21[h]	11.00	231.00
	Ties	0[i]		
	Total	21		

a. SWEMWBS 1 < SWEMWBS -10

b. SWEMWBS 1 > SWEMWBS -10

c. SWEMWBS 1 = SWEMWBS -10

d. SWEMWBS 6 < SWEMWBS 1

e. SWEMWBS 6 > SWEMWBS 1

f. SWEMWBS 6 = SWEMWBS 1

g. SWEMWBS 10 < SWEMWBS 1

h. SWEMWBS 10 > SWEMWBS 1

i. SWEMWBS 10 = SWEMWBS 1

Descriptive Statistics

	N	Percentiles		
		25th	50th (Median)	75th
SWEMWBS -10	24	19.4325	22.3500	24.8000
SWEMWBS 1	24	19.2500	20.7300	22.3500
SWEMWBS 6	20	24.3400	30.7000	32.5500
SWEMWBS 10	21	30.0050	32.5500	33.7750

Test Statistics[a]

	SWEMWBS 1 - SWEMWBS -10	SWEMWBS 6 - SWEMWBS 1	SWEMWBS 10 - SWEMWBS 1
Z	-1.065[b]	-3.920[c]	-4.015[c]
Asymp. Sig. (2-tailed)	.287	.000	.000

a. Wilcoxon Signed Ranks Test

b. Based on positive ranks.

c. Based on negative ranks.

UCL POSITIVE WELLBEING UMBRELLA

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  /COMPARE VARIABLES
  /STATISTICS DESCRIPTIVES
  /CINTERVAL 95
  /MISSING PAIRWISE
  /NOTOTAL.
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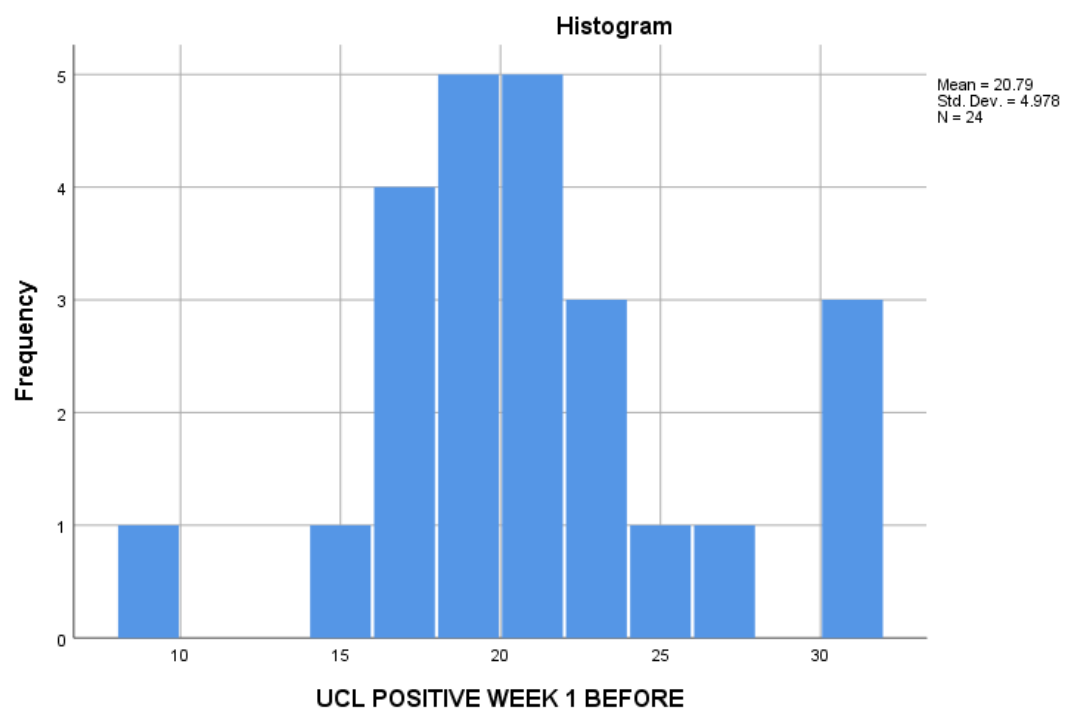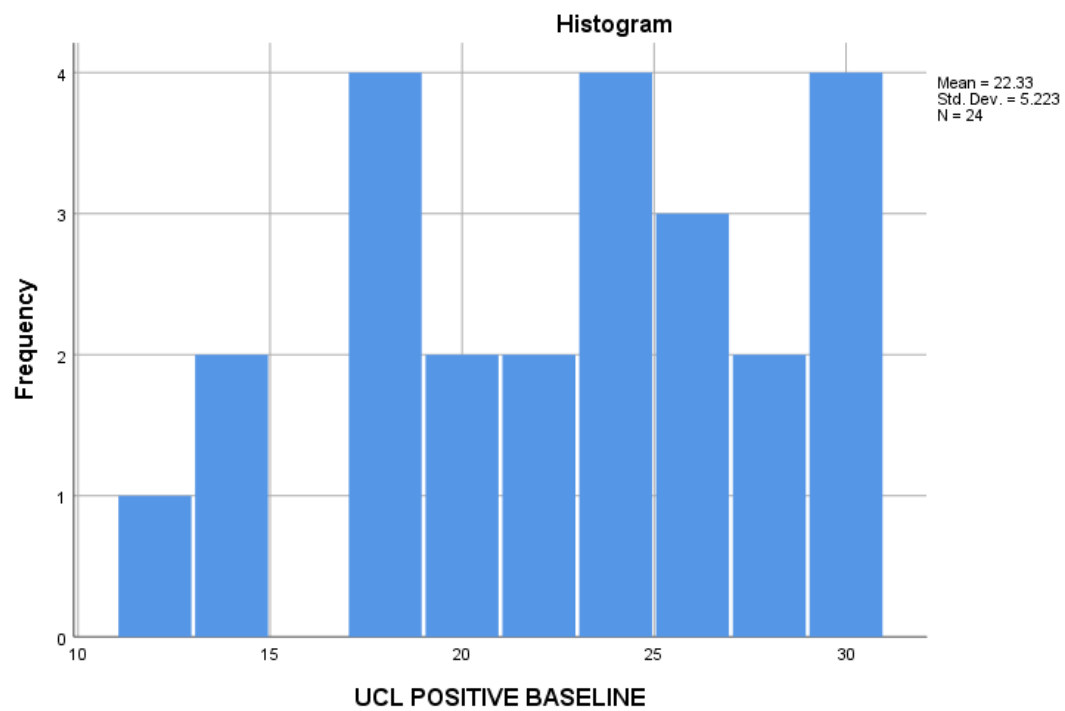
Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
UCL POSITIVE BASELINE	24	100.0%	0	0.0%	24	100.0%
UCL POSITIVE WEEK 1 BEFORE	24	100.0%	0	0.0%	24	100.0%
UCL POSITIVE WEEK 6 AFTER	20	83.3%	4	16.7%	24	100.0%
UCL POSITIVE WEEK 10 AFTER	21	87.5%	3	12.5%	24	100.0%

Descriptives

			Statistic	Std. Error
UCL POSITIVE BASELINE	Mean		22.33	1.066
	95% Confidence Interval for Mean	Lower Bound	20.13	
		Upper Bound	24.54	
	5% Trimmed Mean		22.47	
	Median		23.00	
	Variance		27.275	
	Std. Deviation		5.223	
	Minimum		12	
	Maximum		30	
	Range		18	

	Interquartile Range		9	
	Skewness		-.360	.472
	Kurtosis		-.607	.918
UCL POSITIVE WEEK 1 BEFORE	Mean		20.79	1.016
	95% Confidence Interval for Mean	Lower Bound	18.69	
		Upper Bound	22.89	
	5% Trimmed Mean		20.89	
	Median		21.00	
	Variance		24.781	
	Std. Deviation		4.978	
	Minimum		9	
	Maximum		30	
	Range		21	
	Interquartile Range		6	
	Skewness		.128	.472
	Kurtosis		.691	.918
UCL POSITIVE WEEK 6 AFTER	Mean		27.80	.610
	95% Confidence Interval for Mean	Lower Bound	26.52	
		Upper Bound	29.08	
	5% Trimmed Mean		28.11	
	Median		28.00	
	Variance		7.432	
	Std. Deviation		2.726	
	Minimum		20	
	Maximum		30	
	Range		10	
	Interquartile Range		2	
	Skewness		-2.122	.512
	Kurtosis		4.277	.992
UCL POSITIVE WEEK 10 AFTER	Mean		27.10	.804
	95% Confidence Interval for Mean	Lower Bound	25.42	
		Upper Bound	28.77	
	5% Trimmed Mean		27.38	
	Median		29.00	
	Variance		13.590	
	Std. Deviation		3.687	
	Minimum		19	
	Maximum		30	
	Range		11	
	Interquartile Range		6	

Skewness	-1.149	.501
Kurtosis	-.071	.972

Histogram

Mean = 22.33
Std. Dev. = 5.223
N = 24

UCL POSITIVE BASELINE

Histogram

Mean = 20.79
Std. Dev. = 4.978
N = 24

UCL POSITIVE WEEK 1 BEFORE

Histogram

Mean = 27.8
Std. Dev. = 2.726
N = 20

UCL POSITIVE WEEK 6 AFTER

Histogram

Mean = 27.1
Std. Dev. = 3.687
N = 21

UCL POSITIVE WEEK 10 AFTER

```
NPAR TESTS
  /FRIEDMAN=UCLP1B UCLP6A UCLP10A
  /STATISTICS DESCRIPTIVES QUARTILES
  /MISSING LISTWISE.
```

NPar Tests

Friedman Test

Ranks

	Mean Rank
UCL POSITIVE WEEK 1 BEFORE	1.20
UCL POSITIVE WEEK 6 AFTER	2.33
UCL POSITIVE WEEK 10 AFTER	2.48

Test Statistics[a]

N	20
Chi-Square	23.194
df	2
Asymp. Sig.	.000

a. Friedman Test

Test Statistics

N	20
Kendall's W[a]	.580
Chi-Square	23.194
df	2
Asymp. Sig.	.000

a. Kendall's Coefficient of

Concordance

```
NPAR TESTS
  /WILCOXON=UCLPBASE UCLP1B UCLP1B WITH UCLP1B UCLP6A UCLP10A (PAIRED)
  /STATISTICS DESCRIPTIVES QUARTILES
  /MISSING ANALYSIS.
```

Ranks

		N	Mean Rank	Sum of Ranks
UCL POSITIVE WEEK 1 BEFORE - UCL POSITIVE BASELINE	Negative Ranks	13[a]	11.54	150.00
	Positive Ranks	7[b]	8.57	60.00
	Ties	4[c]		
	Total	24		
UCL POSITIVE WEEK 6 AFTER - UCL POSITIVE WEEK 1 BEFORE	Negative Ranks	1[d]	2.00	2.00
	Positive Ranks	17[e]	9.94	169.00
	Ties	2[f]		
	Total	20		
UCL POSITIVE WEEK 10 AFTER - UCL POSITIVE WEEK 1 BEFORE	Negative Ranks	1[g]	1.00	1.00
	Positive Ranks	18[h]	10.50	189.00
	Ties	2[i]		
	Total	21		

a. UCL POSITIVE WEEK 1 BEFORE < UCL POSITIVE BASELINE

b. UCL POSITIVE WEEK 1 BEFORE > UCL POSITIVE BASELINE

c. UCL POSITIVE WEEK 1 BEFORE = UCL POSITIVE BASELINE

d. UCL POSITIVE WEEK 6 AFTER < UCL POSITIVE WEEK 1 BEFORE

e. UCL POSITIVE WEEK 6 AFTER > UCL POSITIVE WEEK 1 BEFORE

f. UCL POSITIVE WEEK 6 AFTER = UCL POSITIVE WEEK 1 BEFORE

g. UCL POSITIVE WEEK 10 AFTER < UCL POSITIVE WEEK 1 BEFORE

h. UCL POSITIVE WEEK 10 AFTER > UCL POSITIVE WEEK 1 BEFORE

i. UCL POSITIVE WEEK 10 AFTER = UCL POSITIVE WEEK 1 BEFORE

Test Statistics[a]

	UCL POSITIVE WEEK 1 BEFORE - UCL POSITIVE BASELINE	UCL POSITIVE WEEK 6 AFTER - UCL POSITIVE WEEK 1 BEFORE	UCL POSITIVE WEEK 10 AFTER - UCL POSITIVE WEEK 1 BEFORE
Z	-1.687[b]	-3.643[c]	-3.786[c]
Asymp. Sig. (2-tailed)	.092	.000	.000

a. Wilcoxon Signed Ranks Test

b. Based on positive ranks.

c. Based on negative ranks.

UCL NEGATIVE WELLBEING UMBRELLA

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  /PLOT BOXPLOT HISTOGRAM
  /COMPARE VARIABLES
  /STATISTICS DESCRIPTIVES
  /CINTERVAL 95
  /MISSING PAIRWISE
  /NOTOTAL.
```

Explore

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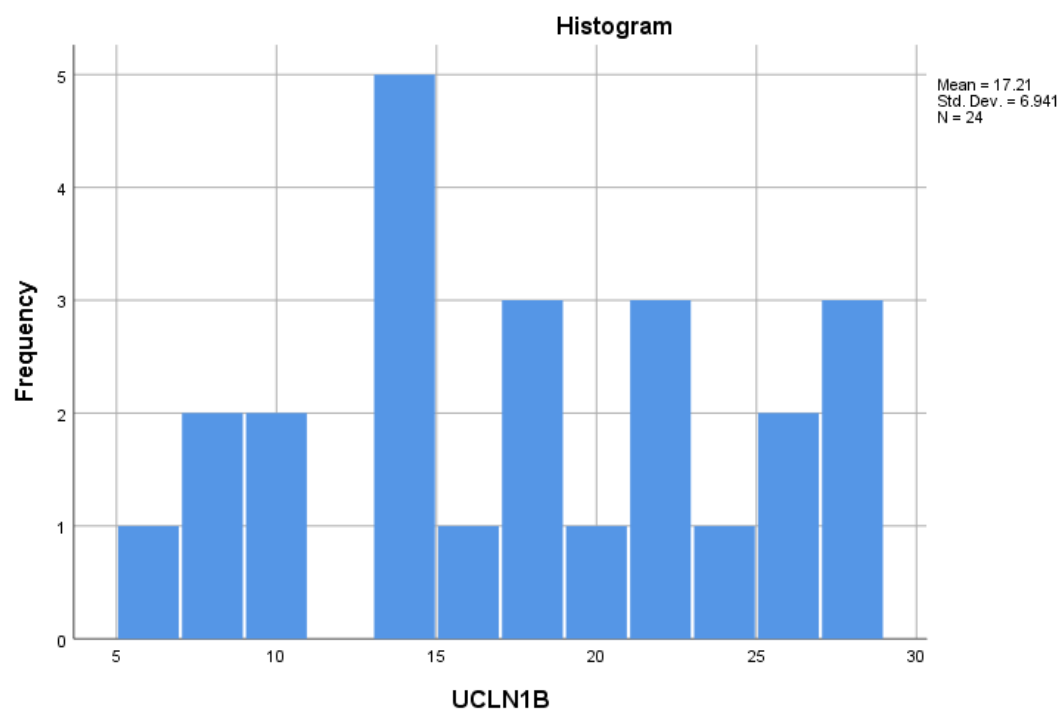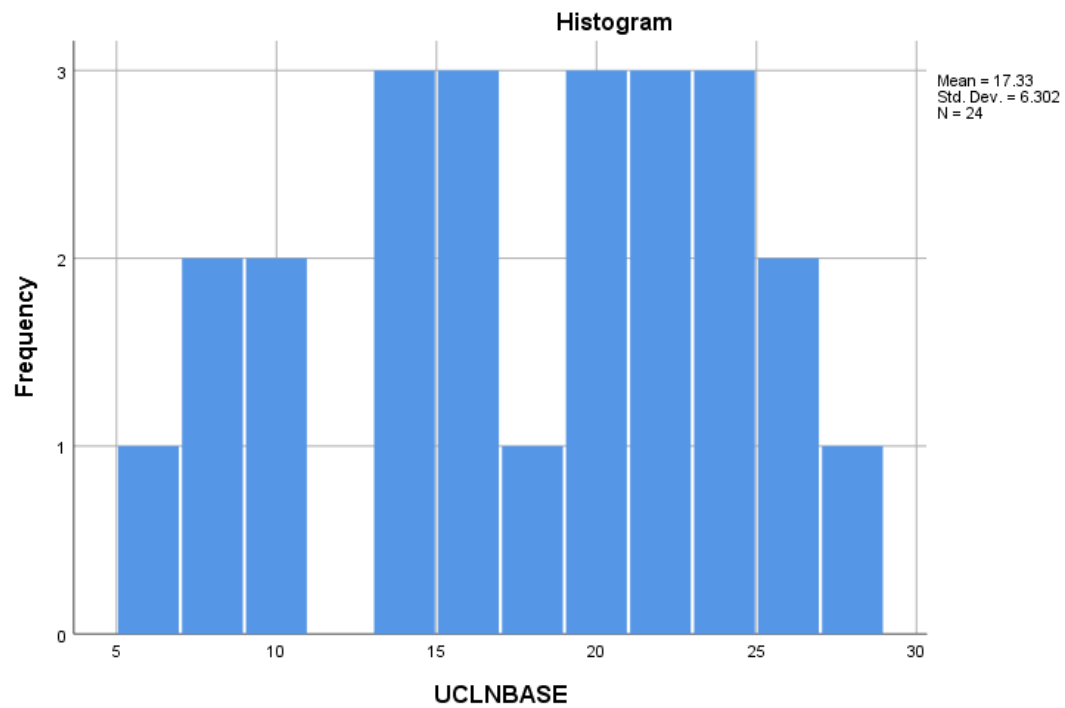
Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
UCLNBASE	24	100.0%	0	0.0%	24	100.0%
UCLN1B	24	100.0%	0	0.0%	24	100.0%
UCLN6A	20	83.3%	4	16.7%	24	100.0%
UCLN10A	21	87.5%	3	12.5%	24	100.0%

Descriptives

			Statistic	Std. Error
UCLNBASE	Mean		17.33	1.286
	95% Confidence Interval for Mean	Lower Bound	14.67	
		Upper Bound	19.99	
	5% Trimmed Mean		17.43	
	Median		18.50	
	Variance		39.710	
	Std. Deviation		6.302	
	Minimum		6	

	Maximum		27	
	Range		21	
	Interquartile Range		10	
	Skewness		-.226	.472
	Kurtosis		-.999	.918
UCLN1B	Mean		17.21	1.417
	95% Confidence Interval for Mean	Lower Bound	14.28	
		Upper Bound	20.14	
	5% Trimmed Mean		17.22	
	Median		17.00	
	Variance		48.172	
	Std. Deviation		6.941	
	Minimum		6	
	Maximum		28	
	Range		22	
	Interquartile Range		10	
	Skewness		.014	.472
	Kurtosis		-1.102	.918
UCLN6A	Mean		6.50	.170
	95% Confidence Interval for Mean	Lower Bound	6.14	
		Upper Bound	6.86	
	5% Trimmed Mean		6.44	
	Median		6.00	
	Variance		.579	
	Std. Deviation		.761	
	Minimum		6	
	Maximum		8	
	Range		2	
	Interquartile Range		1	
	Skewness		1.195	.512
	Kurtosis		-.037	.992
UCLN10A	Mean		7.29	.464
	95% Confidence Interval for Mean	Lower Bound	6.32	
		Upper Bound	8.25	
	5% Trimmed Mean		7.04	
	Median		6.00	
	Variance		4.514	
	Std. Deviation		2.125	
	Minimum		6	
	Maximum		13	

Range	7	
Interquartile Range	2	
Skewness	2.075	.501
Kurtosis	3.717	.972

Histogram

Mean = 17.33
Std. Dev. = 6.302
N = 24

Histogram

Mean = 17.21
Std. Dev. = 6.941
N = 24

Histogram

Mean = 6.5
Std. Dev. = .761
N = 20

UCLN6A

Histogram

Mean = 7.29
Std. Dev. = 2.125
N = 21

UCLN10A

```
NPAR TESTS
  /FRIEDMAN=UCLN1B UCLN6A UCLN10A
  /STATISTICS DESCRIPTIVES QUARTILES
  /MISSING LISTWISE.
```

NPar Tests

Friedman Test

Ranks

	Mean Rank
UCLN1B	2.93
UCLN6A	1.40
UCLN10A	1.68

Test Statistics[a]

N	20
Chi-Square	33.556
df	2
Asymp. Sig.	.000

a. Friedman Test

Kendall's W Test

Test Statistics

N	20
Kendall's W[a]	.839
Chi-Square	33.556
df	2
Asymp. Sig.	.000

a. Kendall's Coefficient of
Concordance

```
NPAR TESTS
  /WILCOXON=UCLNBASE UCLN1B UCLN1B WITH UCLN1B UCLN6A UCLN10A (PAIRED)
  /STATISTICS DESCRIPTIVES QUARTILES
  /MISSING ANALYSIS.
```

NPar Tests

Wilcoxon Signed Ranks Test

Descriptive Statistics

	N	Mean	Std. Deviation	25th	50th (Median)	75th
					Percentiles	
UCLNBASE	24	17.33	6.302	13.00	18.50	22.75
UCLN1B	24	17.21	6.941	13.00	17.00	22.75
UCLN6A	20	6.50	.761	6.00	6.00	7.00
UCLN10A	21	7.29	2.125	6.00	6.00	7.50

Ranks

		N	Mean Rank	Sum of Ranks
UCLN1B - UCLNBASE	Negative Ranks	11[a]	10.14	111.50
	Positive Ranks	9[b]	10.94	98.50
	Ties	4[c]		
	Total	24		
UCLN6A - UCLN1B	Negative Ranks	19[d]	10.00	190.00
	Positive Ranks	0[e]	.00	.00
	Ties	1[f]		
	Total	20		
UCLN10A - UCLN1B	Negative Ranks	19[g]	10.00	190.00
	Positive Ranks	0[h]	.00	.00
	Ties	2[i]		
	Total	21		

a. UCLN1B < UCLNBASE

b. UCLN1B > UCLNBASE

c. UCLN1B = UCLNBASE

d. UCLN6A < UCLN1B

e. UCLN6A > UCLN1B

f. UCLN6A = UCLN1B

g. UCLN10A < UCLN1B

h. UCLN10A > UCLN1B

i. UCLN10A = UCLN1B

Test Statistics[a]

	UCLN1B - UCLNBASE	UCLN6A - UCLN1B	UCLN10A - UCLN1B
Z	-.243[b]	-3.826[b]	-3.826[b]
Asymp. Sig. (2-tailed)	.808	.000	.000

a. Wilcoxon Signed Ranks Test

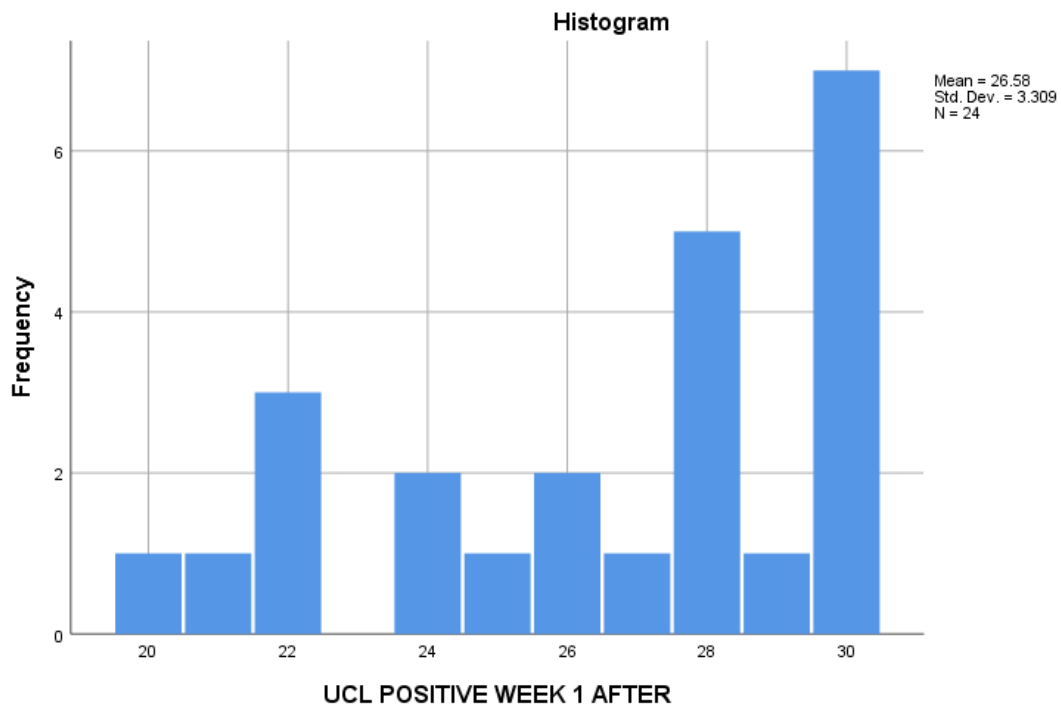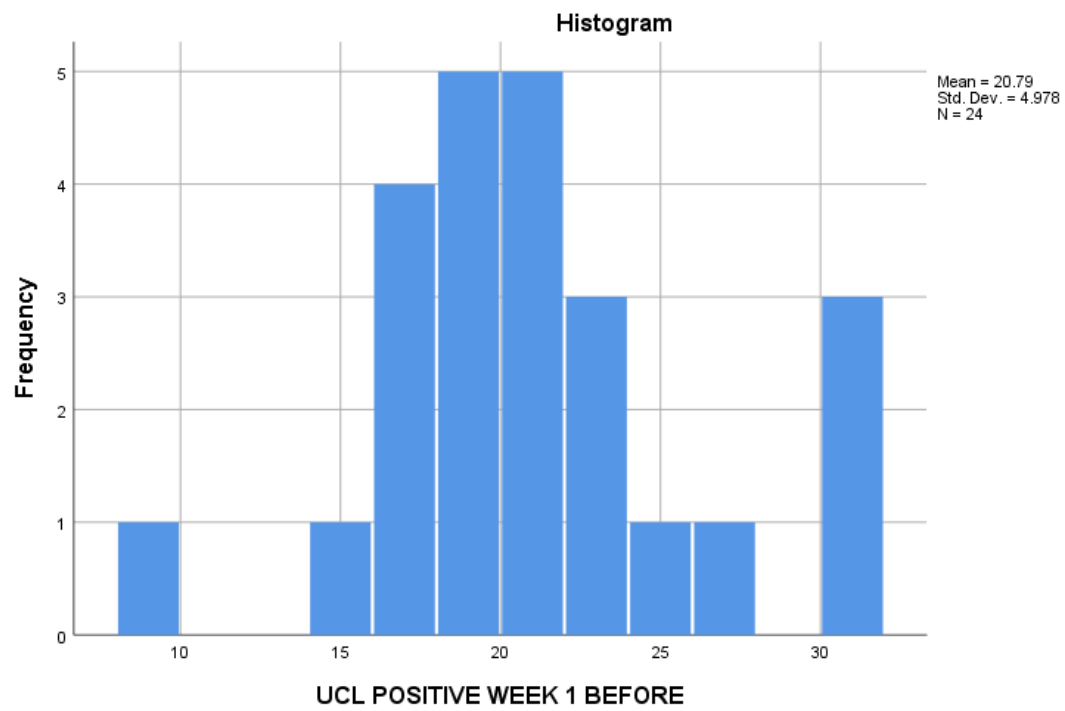b. Based on positive ranks.

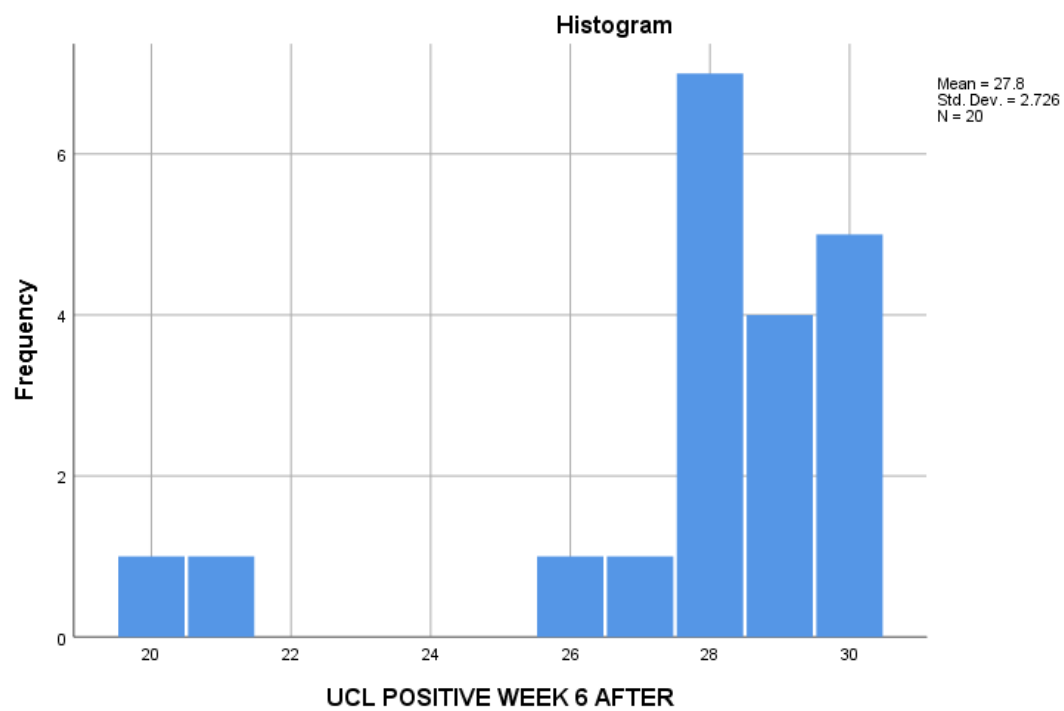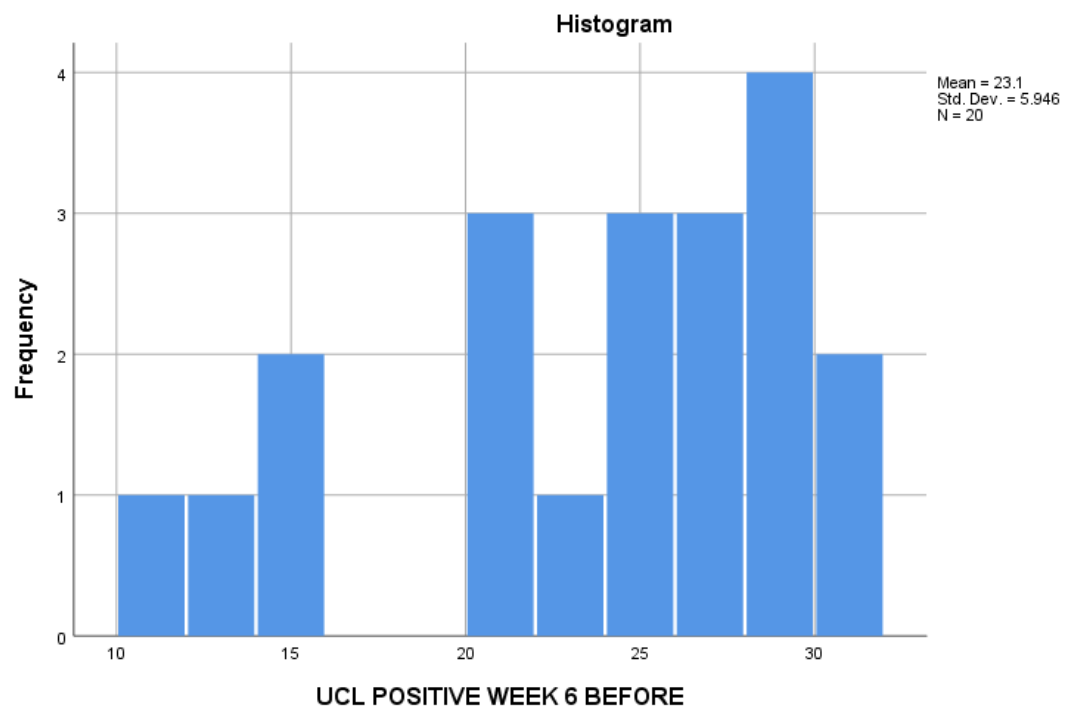# STUDY 3B ANALYSIS

UCL POSITIVE WELLBEING UMBRELLA

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NPAR TESTS
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  /STATISTICS DESCRIPTIVES QUARTILES
  /MISSING ANALYSIS.
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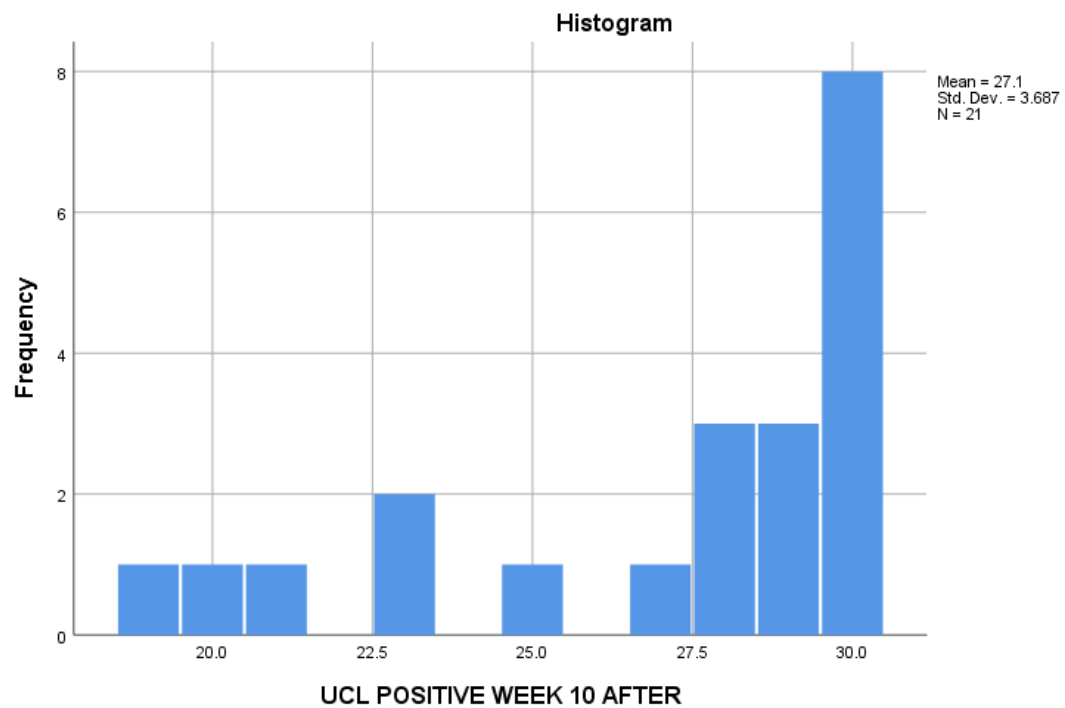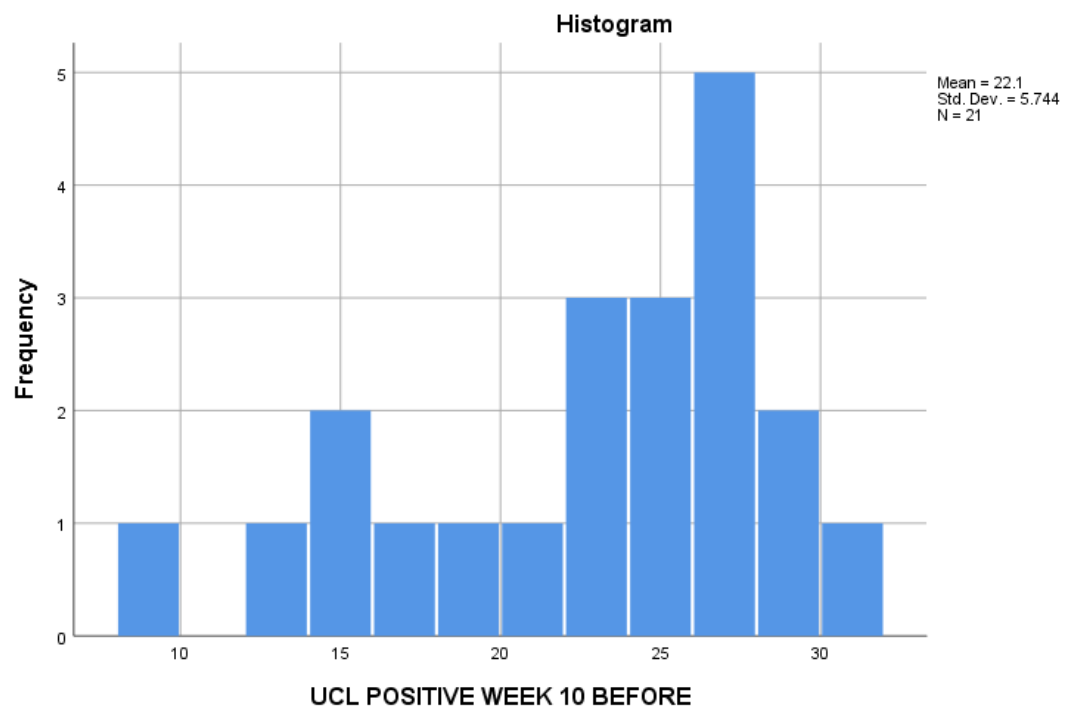
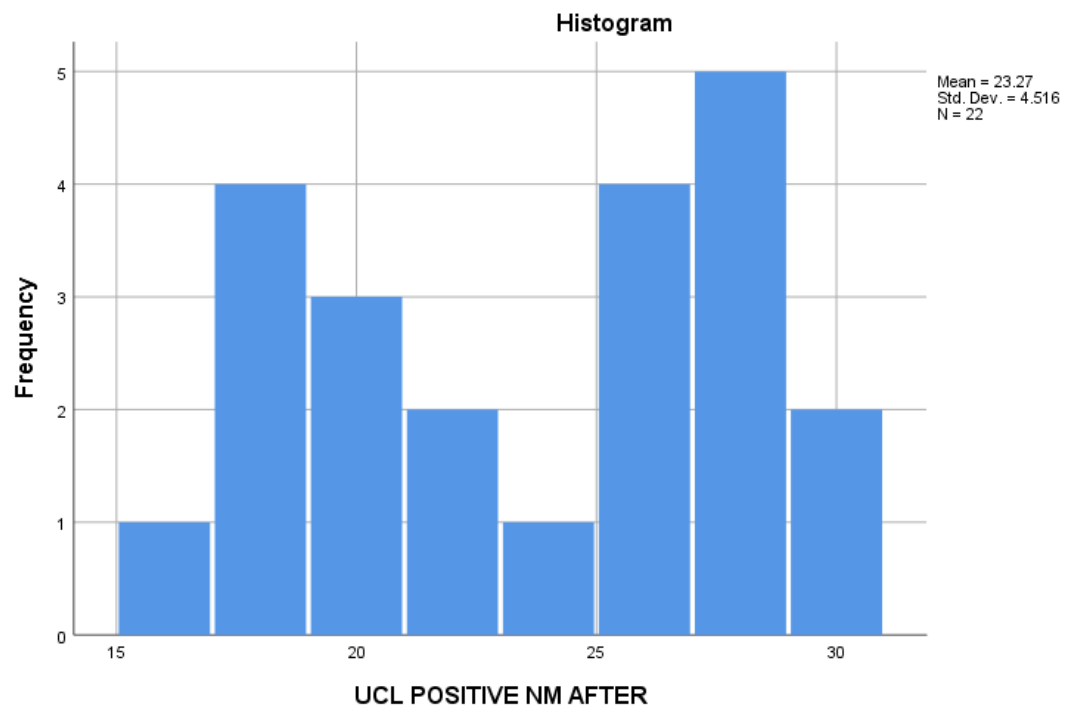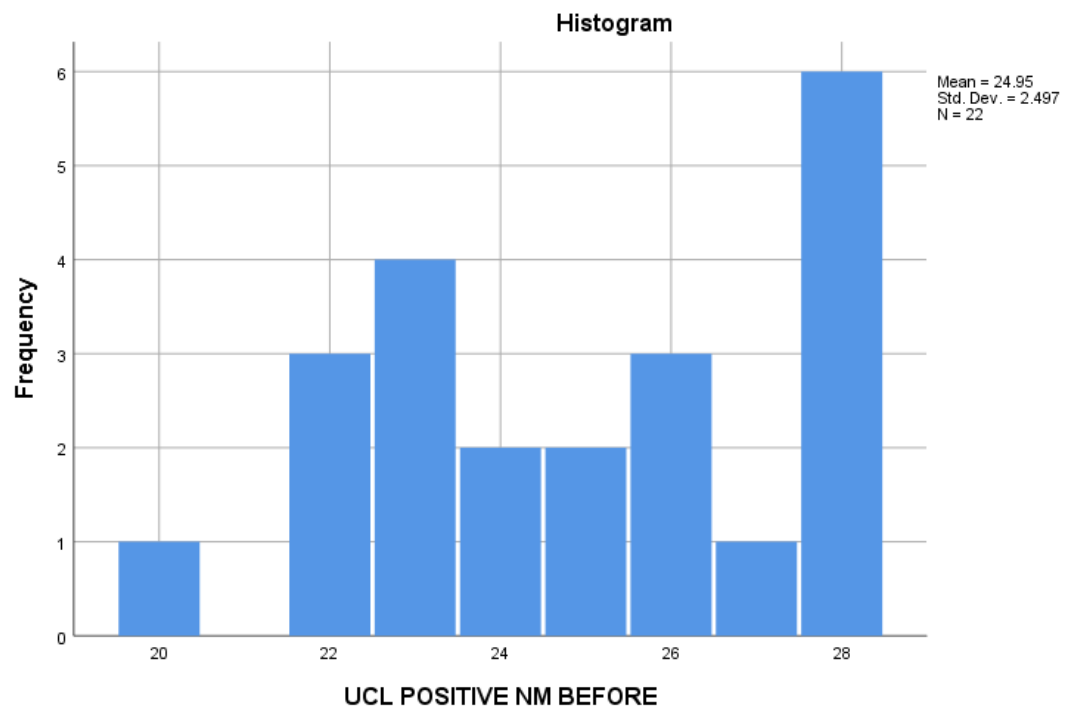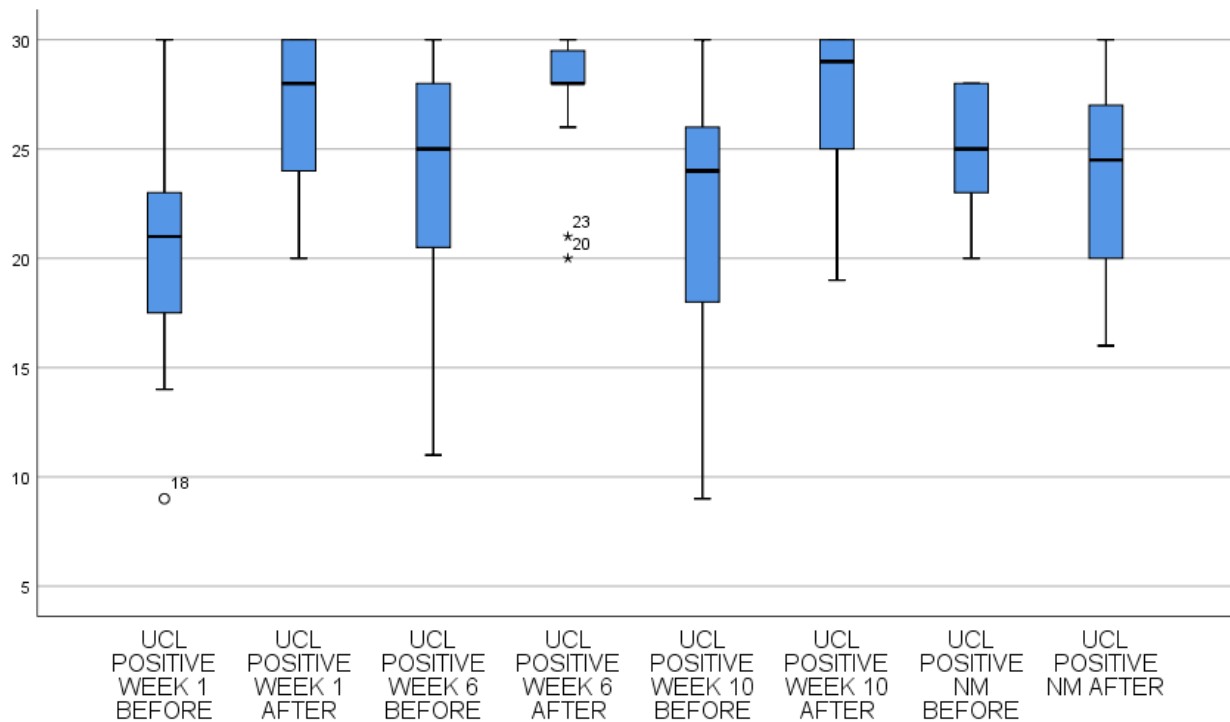[DataSet1] C:\Users\natal\OneDrive\Documents\UCL POSITIVE.sav

Descriptive Statistics

| | N | Mean | Std. Deviation | Percentiles | | |
				25th	50th (Median)	75th
UCL POSITIVE WEEK 1 BEFORE	24	20.79	4.978	17.25	21.00	23.00
UCL POSITIVE WEEK 6 BEFORE	20	23.10	5.946	20.25	25.00	28.00
UCL POSITIVE WEEK 10 BEFORE	21	22.10	5.744	17.50	24.00	26.00
UCL POSITIVE WEEK 1 AFTER	24	26.58	3.309	24.00	28.00	30.00
UCL POSITIVE WEEK 6 AFTER	20	27.80	2.726	28.00	28.00	29.75
UCL POSITIVE WEEK 10 AFTER	21	27.10	3.687	24.00	29.00	30.00

498

Histogram

Mean = 20.79
Std. Dev. = 4.978
N = 24

UCL POSITIVE WEEK 1 BEFORE

Histogram

Mean = 26.58
Std. Dev. = 3.309
N = 24

UCL POSITIVE WEEK 1 AFTER

Histogram

Mean = 23.1
Std. Dev. = 5.946
N = 20

UCL POSITIVE WEEK 6 BEFORE

Histogram

Mean = 27.8
Std. Dev. = 2.726
N = 20

UCL POSITIVE WEEK 6 AFTER

Histogram

Mean = 22.1
Std. Dev. = 5.744
N = 21

UCL POSITIVE WEEK 10 BEFORE

Histogram

Mean = 27.1
Std. Dev. = 3.687
N = 21

UCL POSITIVE WEEK 10 AFTER

501

Histogram

UCL POSITIVE NM BEFORE

Mean = 24.95
Std. Dev. = 2.497
N = 22

Histogram

UCL POSITIVE NM AFTER

Mean = 23.27
Std. Dev. = 4.516
N = 22

Wilcoxon Signed Ranks Test

Ranks

		N	Mean Rank	Sum of Ranks
UCL POSITIVE WEEK 1 AFTER - UCL POSITIVE WEEK 1 BEFORE	Negative Ranks	1[a]	11.50	11.50
	Positive Ranks	21[b]	11.50	241.50
	Ties	2[c]		
	Total	24		
UCL POSITIVE WEEK 6 AFTER - UCL POSITIVE WEEK 6 BEFORE	Negative Ranks	1[d]	5.00	5.00
	Positive Ranks	17[e]	9.76	166.00
	Ties	2[f]		
	Total	20		
UCL POSITIVE WEEK 10 AFTER - UCL POSITIVE WEEK 10 BEFORE	Negative Ranks	1[g]	5.00	5.00
	Positive Ranks	19[h]	10.79	205.00
	Ties	1[i]		
	Total	21		

a. UCL POSITIVE WEEK 1 AFTER < UCL POSITIVE WEEK 1 BEFORE

b. UCL POSITIVE WEEK 1 AFTER > UCL POSITIVE WEEK 1 BEFORE

c. UCL POSITIVE WEEK 1 AFTER = UCL POSITIVE WEEK 1 BEFORE

d. UCL POSITIVE WEEK 6 AFTER < UCL POSITIVE WEEK 6 BEFORE

e. UCL POSITIVE WEEK 6 AFTER > UCL POSITIVE WEEK 6 BEFORE

f. UCL POSITIVE WEEK 6 AFTER = UCL POSITIVE WEEK 6 BEFORE

g. UCL POSITIVE WEEK 10 AFTER < UCL POSITIVE WEEK 10 BEFORE

h. UCL POSITIVE WEEK 10 AFTER > UCL POSITIVE WEEK 10 BEFORE

i. UCL POSITIVE WEEK 10 AFTER = UCL POSITIVE WEEK 10 BEFORE

Test Statistics[a]

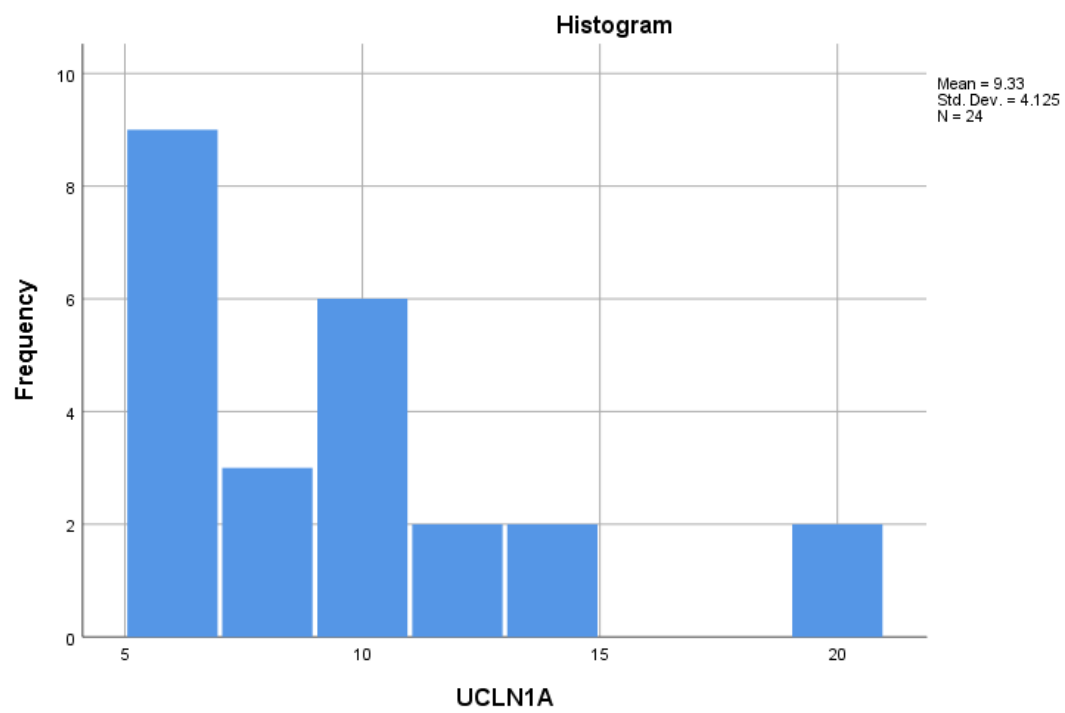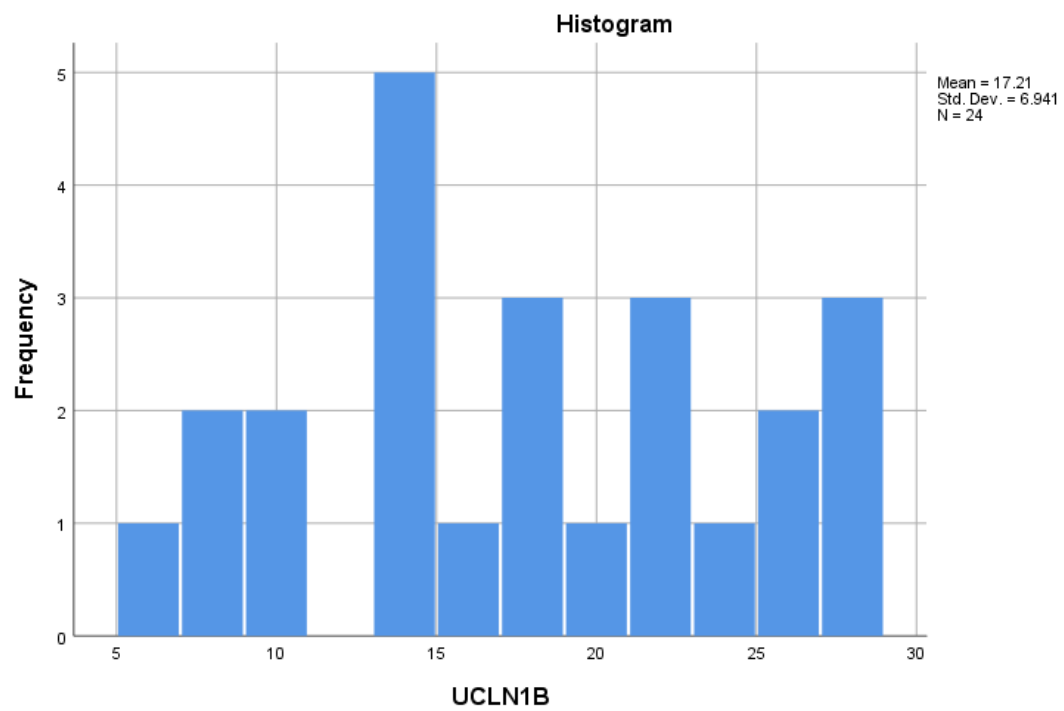|	UCL POSITIVE WEEK 1 AFTER - UCL POSITIVE WEEK 1 BEFORE	UCL POSITIVE WEEK 6 AFTER - UCL POSITIVE WEEK 6 BEFORE	UCL POSITIVE WEEK 10 AFTER - UCL POSITIVE WEEK 10 BEFORE	UCL POSITIVE NM AFTER - UCL POSITIVE NM BEFORE
Z	-3.737[b]	-3.516[b]	-3.743[b]	-1.577[c]
Asymp. Sig. (2-tailed)	.000	.000	.000	.115

a. Wilcoxon Signed Ranks Test

b. Based on negative ranks.
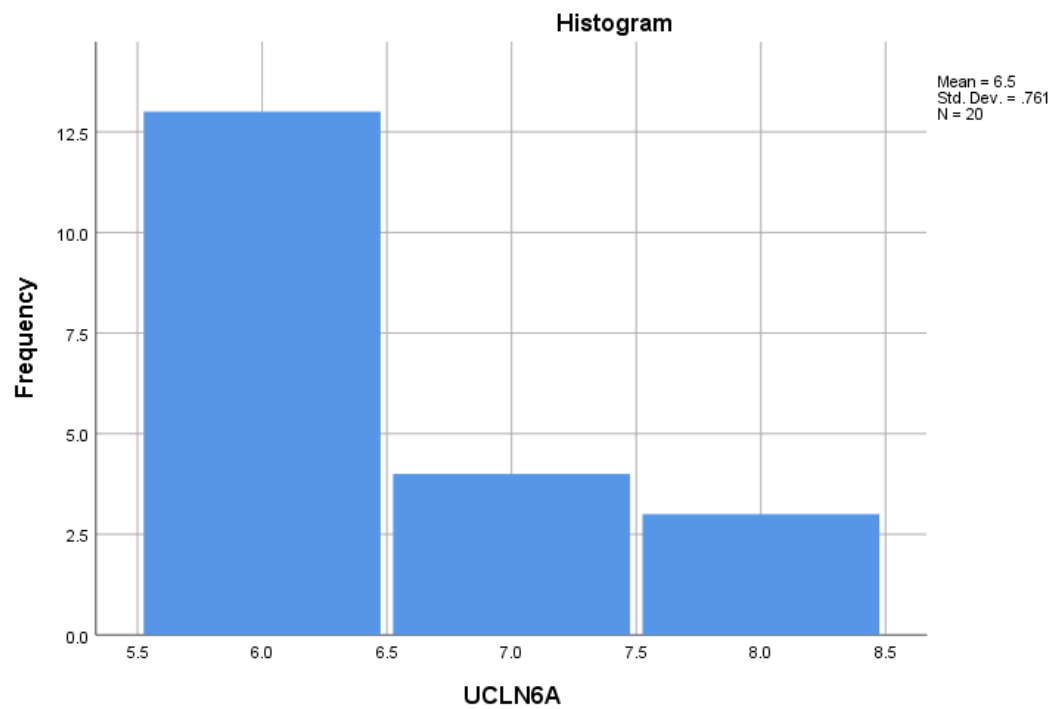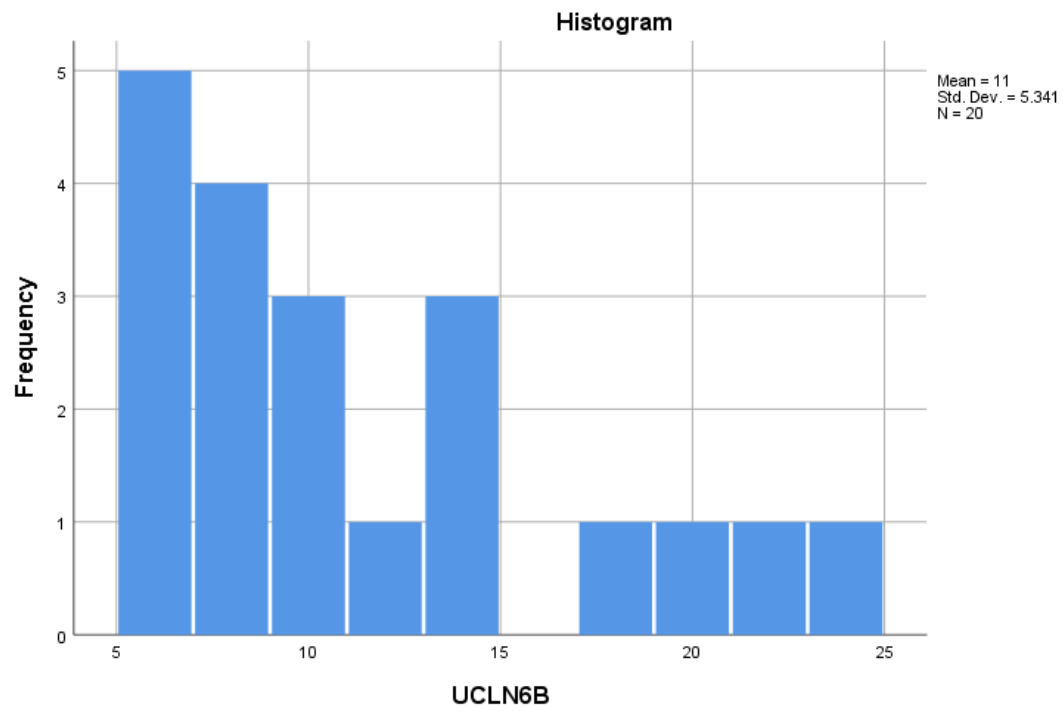
c. Based on positive ranks.
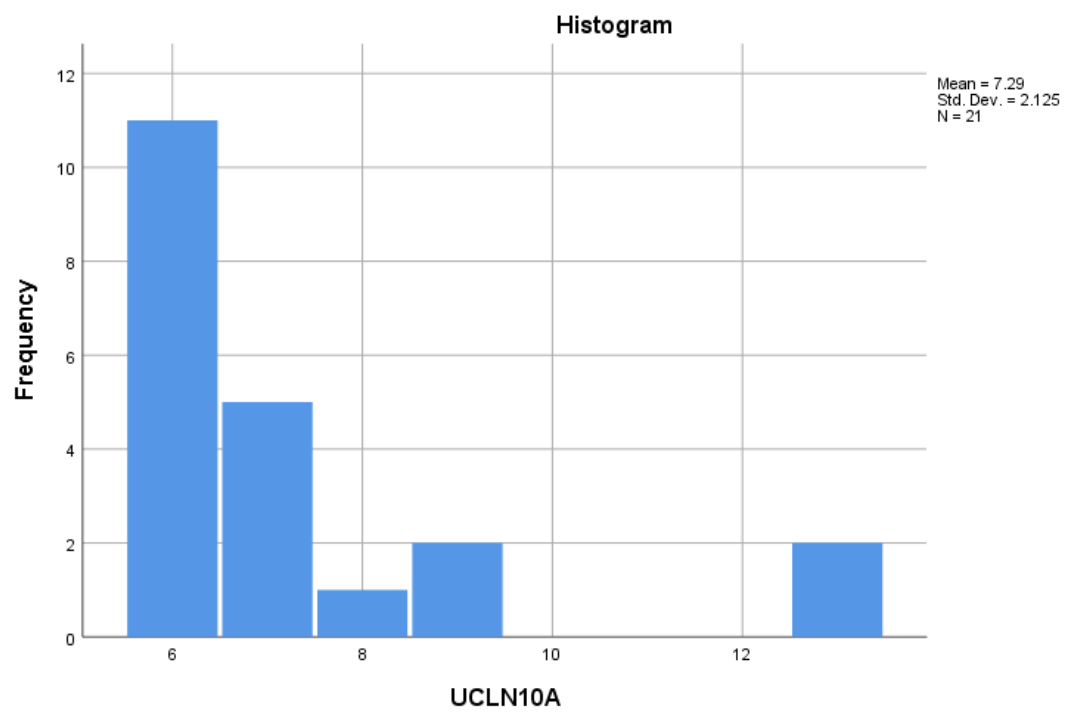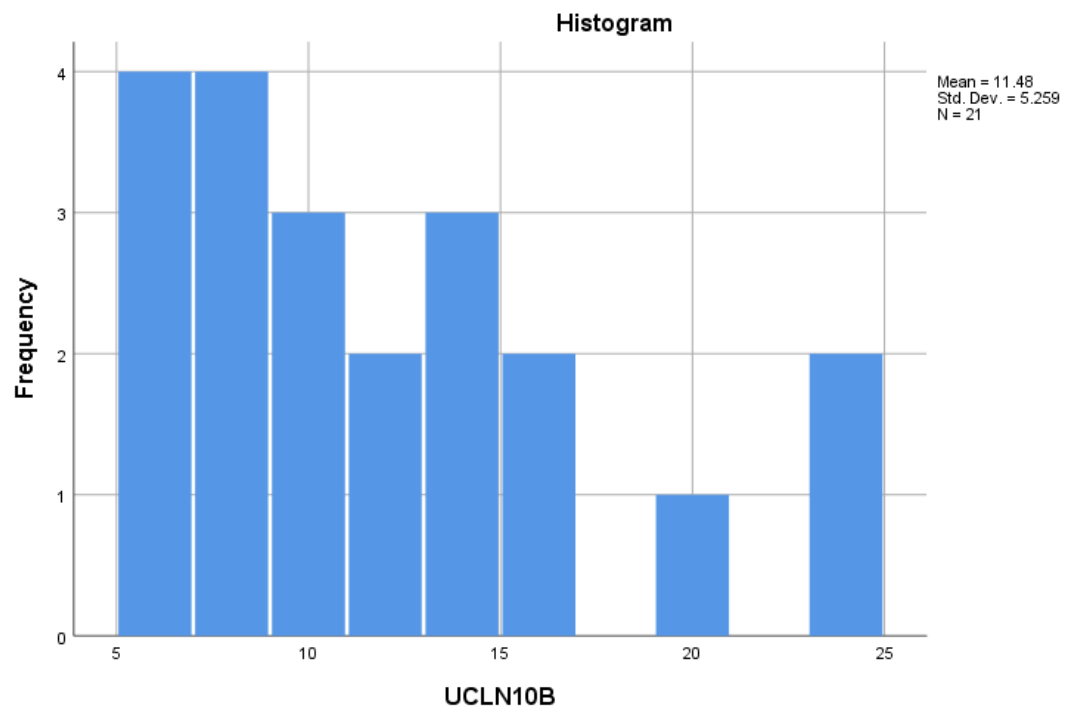
UCL GENERIC NEGATIVE WELLBEING UMBRELLA

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  /MISSING PAIRWISE
  /NOTOTAL.
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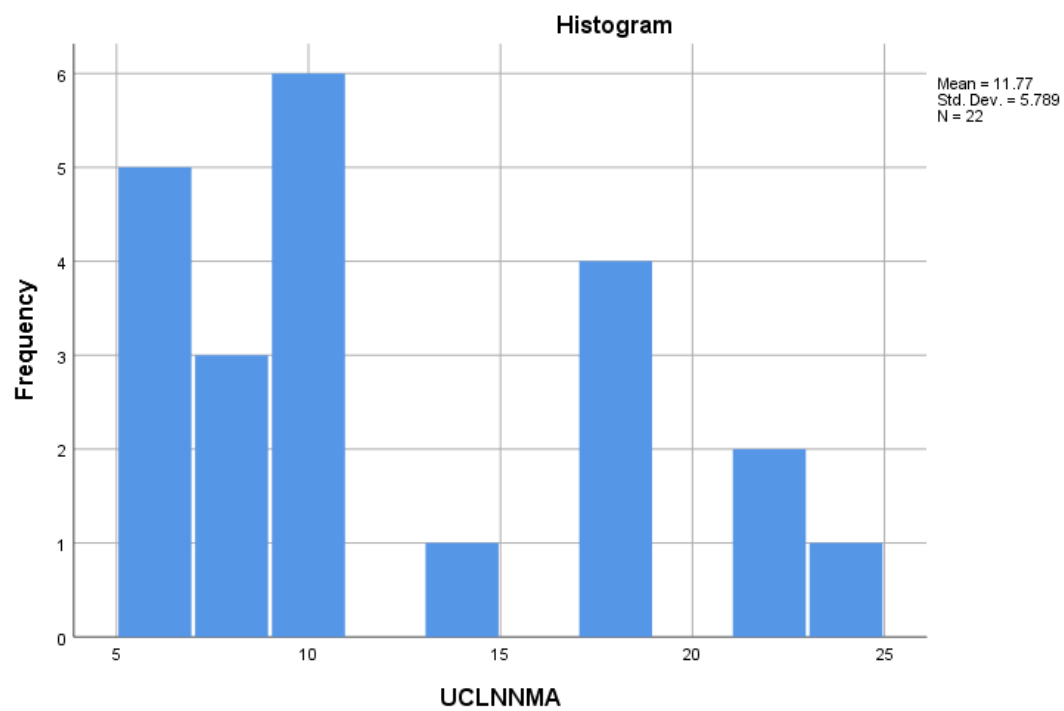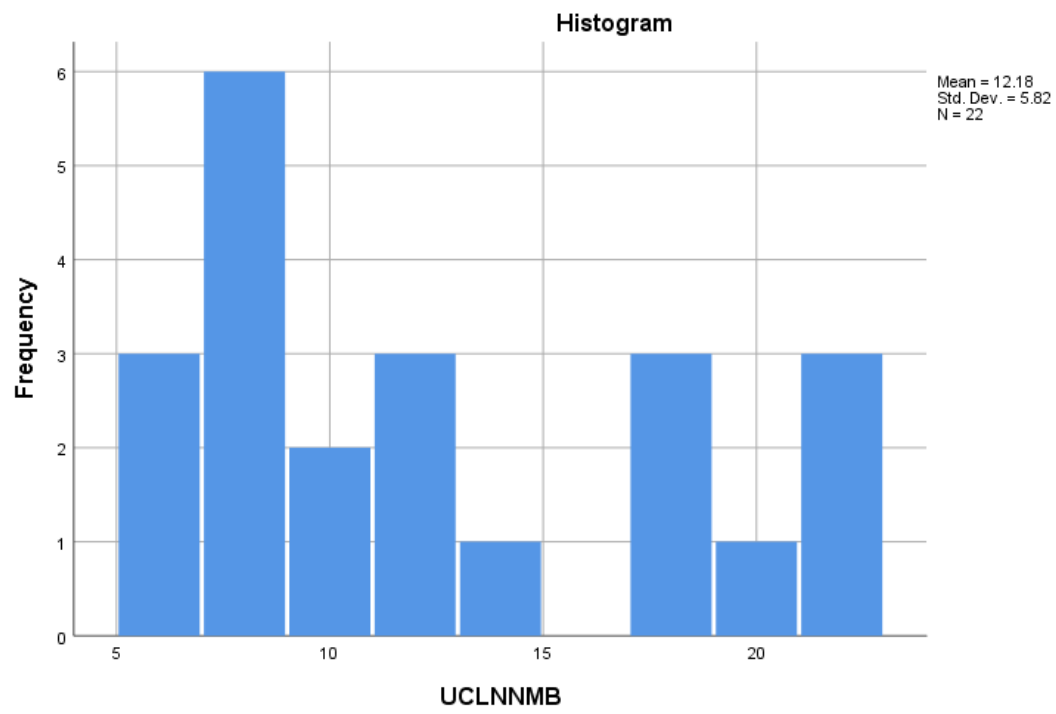
[DataSet1] C:\Users\natal\OneDrive\Documents\UCL NEGATIVE.sav

Descriptive Statistics

| | N | Mean | Std. Deviation | Minimum | Percentiles | | |
					25th	50th (Median)	75th
UCLN1B	24	17.21	6.941	6	13.00	17.00	22.75
UCLN6B	20	11.00	5.341	6	6.25	9.50	13.75
UCLN10B	21	11.48	5.259	6	7.50	10.00	14.00
UCLNNMB	22	12.18	5.820	6	7.00	10.50	18.00
UCLN1A	24	9.33	4.125	6	6.00	8.50	11.50
UCLN6A	20	6.50	.761	6	6.00	6.00	7.00
UCLN10A	21	7.29	2.125	6	6.00	6.00	7.50
UCLNNMA	22	11.77	5.789	6	6.75	9.50	18.00

Histogram

Mean = 17.21
Std. Dev. = 6.941
N = 24

UCLN1B

Histogram

Mean = 9.33
Std. Dev. = 4.125
N = 24

UCLN1A

Histogram

Mean = 11
Std. Dev. = 5.341
N = 20

UCLN6B

Histogram

Mean = 6.5
Std. Dev. = .761
N = 20

UCLN6A

507

Histogram

Mean = 11.48
Std. Dev. = 5.259
N = 21

UCLN10B

Histogram

Mean = 7.29
Std. Dev. = 2.125
N = 21

UCLN10A

508

Histogram

Mean = 12.18
Std. Dev. = 5.82
N = 22

Histogram

Mean = 11.77
Std. Dev. = 5.789
N = 22

509

NPar Tests

Wilcoxon Signed Ranks Test

Ranks

		N	Mean Rank	Sum of Ranks
UCLN1A - UCLN1B	Negative Ranks	22[a]	12.91	284.00
	Positive Ranks	2[b]	8.00	16.00
	Ties	0[c]		
	Total	24		
UCLN6A - UCLN6B	Negative Ranks	14[d]	8.43	118.00
	Positive Ranks	1[e]	2.00	2.00
	Ties	5[f]		
	Total	20		
UCLN10A - UCLN10B	Negative Ranks	16[g]	9.44	151.00
	Positive Ranks	1[h]	2.00	2.00
	Ties	4[i]		

	Total	21		
UCLNNMA - UCLNNMB	Negative Ranks	11[j]	6.55	72.00
	Positive Ranks	3[k]	11.00	33.00
	Ties	8[l]		
	Total	22		

a. UCLN1A < UCLN1B

b. UCLN1A > UCLN1B

c. UCLN1A = UCLN1B

d. UCLN6A < UCLN6B

e. UCLN6A > UCLN6B

f. UCLN6A = UCLN6B

g. UCLN10A < UCLN10B

h. UCLN10A > UCLN10B

i. UCLN10A = UCLN10B

j. UCLNNMA < UCLNNMB

k. UCLNNMA > UCLNNMB

l. UCLNNMA = UCLNNMB

Test Statistics[a]

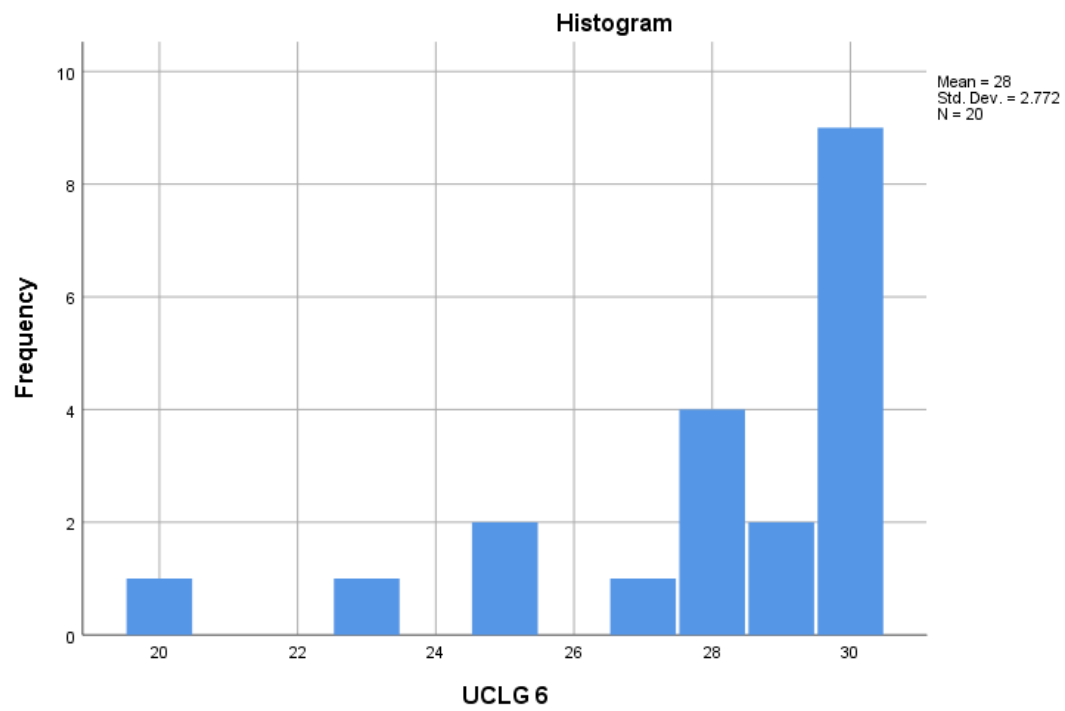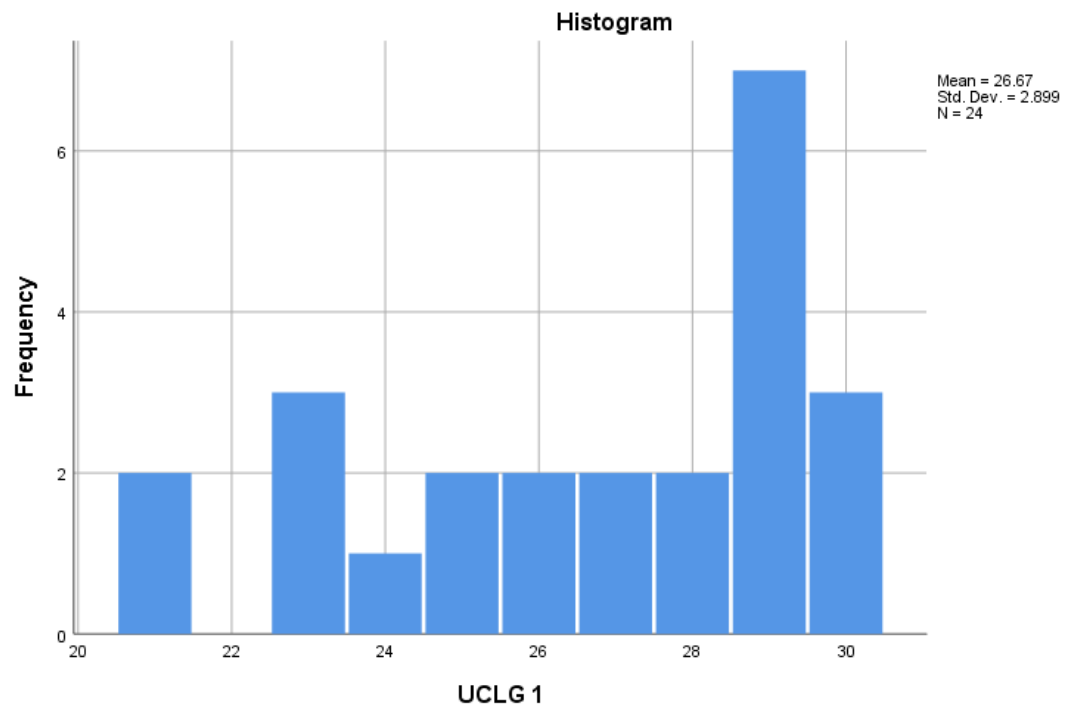|	UCLN1A - UCLN1B	UCLN6A - UCLN6B	UCLN10A - UCLN10B	UCLNNMA - UCLNNMB
Z	-3.833[b]	-3.298[b]	-3.534[b]	-1.259[b]
Asymp. Sig. (2-tailed)	.000	.001	.000	.208

a. Wilcoxon Signed Ranks Test
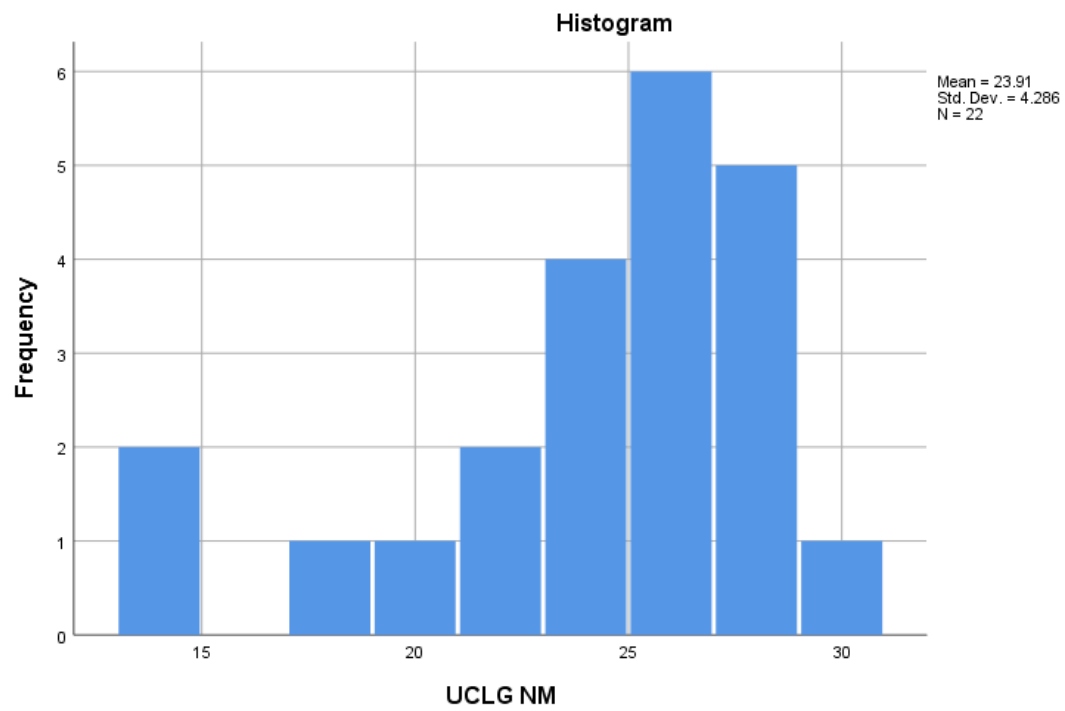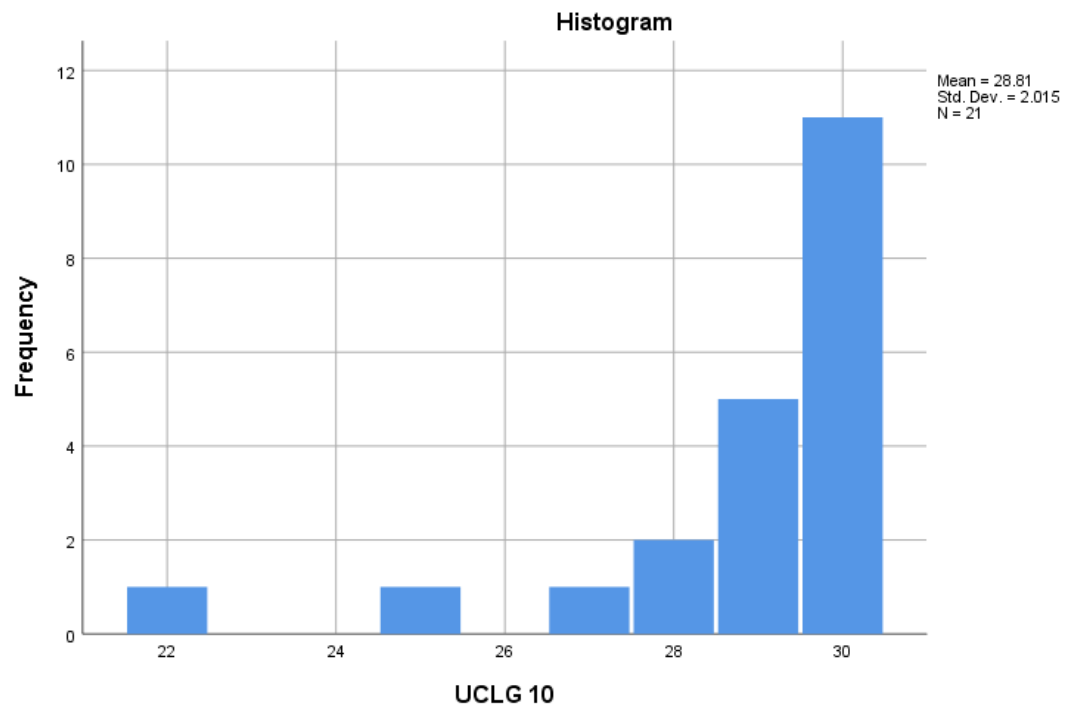
b. Based on positive ranks.
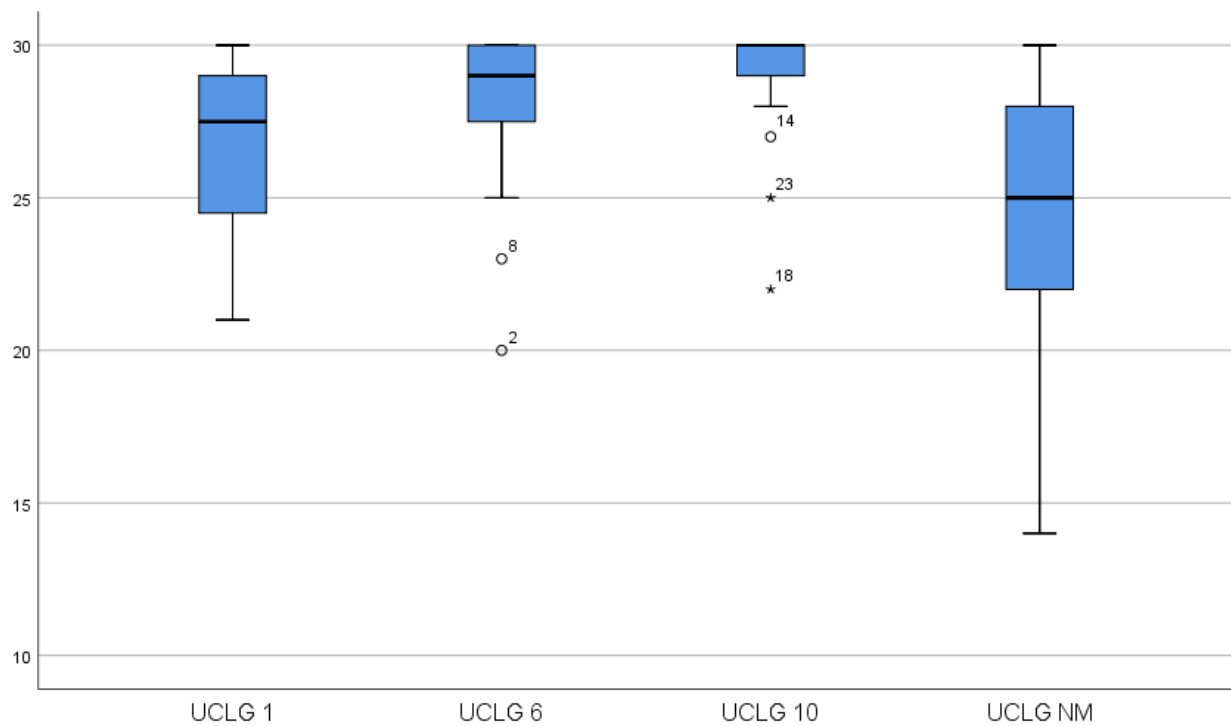
UCL GENERIC WELLBEING QUESTIONNAIRE

```
GET
  FILE='C:\Users\natal\OneDrive\Documents\UCL Generic data.sav'.
DATASET NAME DataSet1 WINDOW=FRONT.
NPAR TESTS
  /WILCOXON=UCLG1 UCLG6 UCLG10 WITH UCLGNM UCLGNM UCLGNM (PAIRED)
  /MISSING ANALYSIS.
```

[DataSet1] C:\Users\natal\OneDrive\Documents\UCL Generic data.sav

Descriptive Statistics

| | N | Mean | Std. Deviation | Minimum | Maximum | Percentiles | | |
						25th	50th (Median)	75th
UCLG 1	24	26.67	2.899	21	30	24.25	27.50	29.0
UCLG 6	20	28.00	2.772	20	30	27.25	29.00	30.0
UCLG 10	21	28.81	2.015	22	30	28.50	30.00	30.0
UCLG NM	22	23.91	4.286	14	30	22.00	25.00	28.0

Histogram

Mean = 26.67
Std. Dev. = 2.899
N = 24

UCLG 1

Histogram

Mean = 28
Std. Dev. = 2.772
N = 20

UCLG 6

513

Histogram

Mean = 28.81
Std. Dev. = 2.015
N = 21

UCLG 10

Histogram

Mean = 23.91
Std. Dev. = 4.286
N = 22

UCLG NM

514

NPar Tests

Wilcoxon signed ranks test

Ranks

		N	Mean Rank	Sum of Ranks
UCLG NM - UCLG 1	Negative Ranks	15[a]	9.73	146.00
	Positive Ranks	3[b]	8.33	25.00
	Ties	4[c]		
	Total	22		
UCLG NM - UCLG 6	Negative Ranks	16[d]	8.84	141.50
	Positive Ranks	1[e]	11.50	11.50
	Ties	2[f]		
	Total	19		
UCLG NM - UCLG 10	Negative Ranks	18[g]	11.50	207.00
	Positive Ranks	2[h]	1.50	3.00

	Ties	0[i]			
	Total	20			

a. UCLG NM < UCLG 1

b. UCLG NM > UCLG 1

c. UCLG NM = UCLG 1

d. UCLG NM < UCLG 6

e. UCLG NM > UCLG 6

f. UCLG NM = UCLG 6

g. UCLG NM < UCLG 10

h. UCLG NM > UCLG 10

i. UCLG NM = UCLG 10

Test Statistics[a]

	UCLG NM - UCLG 1	UCLG NM - UCLG 6	UCLG NM - UCLG 10
Z	-2.648[b]	-3.087[b]	-3.814[b]
Asymp. Sig. (2-tailed)	.008	.002	.000

a. Wilcoxon Signed Ranks Test

b. Based on positive ranks.