

**Exploring the dimensions of disability and
leisure: an examination of disabled
individuals' social worlds and leisure
experiences**

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A thesis submitted in partial fulfilment of the
requirements of Bournemouth University for the
degree of Masters by Research

August 2016

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Abstract

Disability and the importance of making leisure accessible and inclusive for people with disabilities has been an issue within leisure studies over the years. However, evidence suggests that researchers and society still needs to develop an understanding of the different aspects of disabled individuals' lives, in particular their leisure experiences. Therefore, this research aimed to critically explore and assess disabled individuals' social worlds and leisure experiences. The research methodology adopted a constructivist-interpretivist approach involving interviews to gather data from individuals about their disabilities, lives and leisure experiences. Five participants were interviewed (2 males and 3 females, who were aged between 18 and 57). They all had different physical disabilities. Two major themes were identified, *“Living and experiencing a disability”* and *“The leisure experience”*.

The first theme related to living and experiencing a disability. It was seen that each disability is different and that having a disability does not affect the personal characteristics of the individual, but does require the individual to manage and experience the implications of his/her medical condition(s). The second theme was about the participants' leisure experiences where it was found that leisure is a personal activity which could be meaningful, enjoyable and could be beneficial to disabled individuals. However, it was also found that if the participants experience any access problems, or negative attitudes from others within society, this meaningful, enjoyable and beneficial experience could get interrupted. This interruption means that the leisure experience becomes less personal and has less of a positive impact upon the participants' lives.

Overall, it was found that different medical condition(s) can affect different individuals on different levels. It was also found that individuals with disabilities need to be seen as individuals. In addition, the leisure experience of individuals with a disability is not just about access and inclusion, but also about the individual experiencing leisure and having the ability to feel the positive effects of leisure. Consequently, the thesis contributes to knowledge

of the social realities of the disabled individual's life and how his/her disability affects his/her world. The thesis also contributes an understanding of the disabled individual's leisure experiences and how leisure is a meaningful element of his/her time.

TABLE OF CONTENTS

Abstract	ii
List of Figures	vii
List of Tables	viii
Acknowledgements	ix
CHAPTER ONE – INTRODUCTION	1
Introducing the thesis	1
Background and rationale	2
My role within the research: going beyond just creating knowledge	6
Aim and objectives of the research	8
The structure of the thesis	9
CHAPTER TWO – LITERATURE REVIEW	10
Introduction	10
Laying the foundations to understanding disability and leisure	10
Understanding disability	11
The International Classification of Functioning, Disability and Health: a United Nations (UN) approach	13
Models of disability: criticisms and the weaknesses	15
Thinking about disability critically	19
Understanding the scope of knowledge on disability and leisure	20
Understanding the basics of leisure	21
Current knowledge and approaches to understanding disability and leisure	22
Conclusion	26

CHAPTER THREE - METHODOLOGY	29
Introduction	29
Research philosophy	29
Adopting a qualitative research methodology	32
Embracing semi-structured interviews	32
The pilot interview	34
Sampling and participants' profile	35
The data collection process: conducting the interviews	38
Data analysis	39
Being reflexive and keeping a research diary	40
Ethical considerations	42
The trustworthiness of the research	43
The transferability of the research	44
Limitations of the research	45
Summary	47
CHAPTER FOUR – LIVING AND EXPERIENCING A DISABILITY	49
Introduction	49
Being disabled	50
Living with a disability	55
The disabled person as an individual and managing life with a disability	56
Being resilient: thinking 'I can'	64
Conclusion	68
CHAPTER FIVE – THE LEISURE EXPERIENCE	71
Introduction	71
Making leisure choices	73
The participants' leisure choices and the personalisation of their leisure	73
The enhanced meaning of socialising within leisure	79
The benefits of leisure	82

Breaking away from experiencing the disability and gaining a sense of self and control	83
Learning through leisure and developing abilities	88
Access and inclusion within the leisure experience	93
The importance of physical access and social inclusion	93
Creating an inclusive environment	97
Conclusion	101
CHAPTER SIX – CONCLUSION	104
Introduction	104
The contributory themes: insights to the participants’ social worlds and leisure experiences	104
Contribution to knowledge	106
Reinforcing and expanding the current knowledge of disability	106
Reinforcing and expanding the current knowledge of disability and leisure	107
Challenging the current understanding of disability and leisure	108
Conceptual framework	110
Recommendations for future research	113
Reflecting on me and my research	114
REFERENCES	116
APPENDIX A - INTERVIEW SCHEDULE	147
APPENDIX B - CONSENT FORM	149
APPENDIX C - PARTICIPANT INFORMATION SHEET	151
APPENDIX D - EXEMPLAR REFLECTIVE DIARY	155

LIST OF FIGURES

Figure 2.1 – World Health Organisation’s International Classification of Functioning, Disability and Health	14
Figure 3.1 - Areas of questioning within the interviews	34
Figure 4.1 - Discussion chapter one themes and sub-themes	50
Figure 5.1 - Discussion chapter two themes and sub-themes	72
Figure 5.2 - Classifications of leisure	76
Figure 6.1 – The individual, his/her leisure experience and his/her social world: a conceptual framework	112

LIST OF TABLES

Table 1.1 - Push and pull motivations of physically disabled peoples' motivations to undertake leisure travel	4
Table 3.1 - Interview participants and their disabilities	38
Table 3.3 - Discussion chapters and sub-themes	48
Table 4.1 - Examples of situations which cause stress and difficulty	63

ACKNOWLEDGEMENTS

Within the process of doing this research, there have been several people which have given me support and guidance.

Firstly, are my supervisors Dr Emma Kavanagh and Professor Roger Vaughan. They have been invaluable in this process and have taught me much about research as well as how to conduct and write about it. They have always been willing to give me feedback, advice and the flexibility which I sometimes needed. Particularly, I wanted to thank Emma for encouraging and supporting me in becoming critical in how disability is examined within society and by researchers. I also want to thank Roger for encouraging me to understand about research methods more effectively and giving me advice in how I think about and report my research. Both Emma and Roger have given me so much feedback and support, it has really helped me in doing my research. I would also like to thank Denise George and The Graduate School for their advice, assistance and patience over the years.

I also want to thank John, Kathy, Liz and Carolyn from Bournemouth University's Additional Learning Support service. They have been important in giving me the practical support with my study when I was living in Bournemouth during my first year. Additionally, I want to thank Professor Simon Darcy (University of Technology Sydney) and Dr Shane Pegg (The University of Queensland). From a request for one of their journal articles, they have kindly given me a couple of their other papers on the topic of disability and leisure and on Therapeutic Recreation. Together with their encouragement, their donated journal articles have assisted me and my understanding of the relationship between disability and leisure.

I want to thank all of my PGR friends for their support over the years, in particular Kim who has gone out of her way at different times in order to provide me with encouragement, support and advice when I needed it. I also

want to thank Sandra, Kathryn and Janice for kindly acting as proof-readers in the latter stages of the research.

As I am disabled myself, I have met numerous of friends who have also got disabilities and organisations that have (and still do) provide support and opportunities for individuals with disabilities. They have inspired me to apply for, and to complete, this research, where I will never forget the support and the good times which they have given me over the years. I would also want to pay a huge thank you to my very good friend Joe who has supported and encouraged me a great deal. He has been there through the high and low, given me advice when needed it (sometimes whilst over pizza!) and has been an ear when needed.

Finally, I want to say thank you to my family who have supported and encouraged me over the years, both whilst I have been at Bournemouth as well as the time prior to Bournemouth. I want to thank Andrew, David, Carrie, Kathryn and Chris for their support but, especially, my Mum and Dad. They have helped me a lot over the years and have been much needed ears. Without them, I probably would not be where I am today. Last but not least, I want to thank my nephew Nathan. Whilst he is only very young, he has helped me to understand the importance of leisure and how leisure aids human development, through watching him enjoy playing with his toys, smiling and giving me reasons for taking breaks during the day.

CHAPTER ONE – INTRODUCTION

Introducing the thesis

The focus of this Masters by Research thesis is to critically assess and explore the social worlds and leisure experiences of physically disabled individuals. The research was conducted through interviewing 5 participants with disabilities. The thesis contributes to knowledge by highlighting that different medical condition(s) can have different effects on each individual's functional abilities but also a personal effect on each of his/her feelings, influencing how he/she manage his/her condition(s) and feelings about themselves within everyday life. Therefore, this thesis contributes towards the understanding that there are a number of different dimensions to each disabled individual's social worlds and that there is no one way of understanding disability. The thesis also contributes to knowledge that disabled individuals' leisure experiences are not always about access and inclusion, but about how leisure is a personal part of the individual's own time during which leisure can help them further to manage and overcome different challenges within their lives. Consequently, the thesis gives a broader understanding of leisure experienced by individuals with a disability, not only by explaining the importance of access and inclusion from an individual's perspective, but also how leisure behaviours are centred around the individual's wants and desires.

The main aim of this chapter is to provide the reader with an introduction to the research and its underpinnings. It will start by discussing the background and rationale for the study. It will then present the research aim and objectives. This is followed by the researcher presenting his place within the research. The chapter will finish by setting out the structure of the thesis.

Background and rationale

Both disability and leisure are fields of study in own right, which have evolved over time (Goodley 2011b, 2013; Thomas 2007, 2008; Spracklen 2013b), and have looked at disability and leisure in everyday life (Aitchison 2010; Barnes and Mercer 2010; Thomas 2007; Spracklen 2013b). However, different researchers have discussed these subjects from a variety of different angles and have argued that they should be seen from certain positions (Aitchison 2003, 2015; Shakespeare 2008; Spracklen 2013a; Stebbins 2011; Thomas 2007). Therefore, this section aims to provide a background to leisure, disability and research relating to the leisure activities of individuals with a disability.

Traditionally, leisure has been understood and seen as being the opposite to work (Blackshaw 2010), whereby Rojek (1995, 2013b) suggested that leisure was (and to some extent, still is) an experience of self-pleasure, that individuals control, in order to help them to break away and 'escape' from the pressures of work. Rojek (1995) has additionally argued that as a country's economy can affect different people through the need to pay household bills and taxes, leisure was also traditionally seen as a breakaway and rest from the different economic issues which impacted on people's everyday lives. However, Page and Connell (2010) noted that leisure is more than the opposite of work and paying bills and taxes. It is a personal activity of enjoyment whereby leisure helps individuals to create pleasure and enjoyment within their lives (Page and Connell, 2010).

From their book "*A Social Psychology of Leisure*", Kleiber et al. (2011) illustrated that whilst leisure is dependent upon individuals' work, money and access to different places, leisure should not always be associated as being the opposite to work. This is because Kleiber et al. (2011) explained that the concept of leisure is about the individual choosing to do any activity in order to avoid boredom and to help them to characterise their lives with meaning, purpose, pleasure and/or entertainment. In fact, research has shown that the pleasure of a leisure activity lifts individuals' enjoyment of life (Fullagar 2008;

Henderson 2007; Hutchinson and Kleiber 2005; Iwasaki and Mannell 2000; Iwasaki and Schneider 2003; Kleiber 2001; Kleiber et al. 2002, 2011; Sivan and Stebbins 2011). Therefore, Spracklen (2009) has expressed that leisure is not a thing or an item, but a social and personal phenomenon that is sometimes cultural and is something that the individual decides to undertake.

Whilst leisure studies is concerned with how leisure is used in society (Kleiber et al. 2011), disability studies is concerned with the concept of disability and its place within society (Thomas 2007). At a basic level, disability is a phenomenological concept of how an illness(es), medical condition(s), medical abnormality(ies) or an injury(es), causes a difficulty and/or a lack of ability (Darcy and Buhalis 2011). Accordingly, over the years, disability studies have witnessed many debates about how disabled individuals should be seen, understood and supported in society (Barnes and Mercer 2010; Goodley 2014; Hughes and Paterson 1997; Read 1998; Swain and French 2000). This is because historically disabled individuals have been oppressed and overlooked due to their differences to people without medical condition(s) (Barnes 2012; Thomas 2008). Since the disability political movements that happened during the 1970s, that opposed the oppression of disabled individuals (Barnes 2012), social approaches to understanding disability have increased in order to move research on from just looking at individuals' 'inabilities' to looking at their rights and possibilities (Barnes 2012; Darcy and Buhalis 2010; Huang 2005; Thomas 2007, 2008). This positive shift in studying and understanding disability has also encouraged some researchers to see an individual's medical condition(s) as being no longer relevant in understanding disability (Thomas 2007). However, this has limited the full understanding of disabled individuals' social worlds (Goodley 2013; Hughes and Paterson 1997).

Even though leisure and disability studies are complex subjects, Aitchison (2003, 2009) sees the study of disability *and* leisure as being important in making leisure inclusive. Over the last decade, the understanding of disabled individuals, their needs and the importance of social inclusion has become the focus of various scholars (Aitchison 2000, 2003; Buhalis and Darcy 2011;

McCabe 2009; Minneart et al. 2009; Shaw et al. 2005). Gaining an understanding of the disabled individual and his/her needs is seen as being crucial to ensure effective social inclusion (Ambrose et al. 2012a, 2012b; Dattilo 2012), and in helping the design of accessible facilities and services (Blichfeldt and Nicolaisen 2011; Darcy et al. 2011). However, Shi et al. (2012) illustrated that accessibility is not the only dimension of disabled individuals' social 'leisure' worlds.

From interviewing two groups of people with disabilities about their leisure travel motivations, Shi et al. (2012) identified that, whilst accessibility did influence individuals' leisure choices, it is the experience of different activities themselves which can also appeal to disabled individuals. Similarly, as their findings in Table 1.1 indicated, Shi et al. (2012) found that even though individuals may have disabilities, they still have the ability to connect with, and enjoy, different leisure activities.

<i>The Disabled Person</i>	
Push Motivations	Pull Motivations
<i>The escape from a perceived mundane environment</i>	<i>The novelty within an experience/the love of the experience</i>
<i>The exploration and evaluation of self</i>	<i>The educational opportunities offered within different leisure and tourism experiences</i>
<i>The ability to relax</i>	<i>Accessibility</i>
<i>Facilitation of social interaction</i>	
<i>Independence</i>	
<i>The desire of being in a natural environment</i>	
<i>Adventure/risk</i>	
<i>'Do it today'/'time is to little' motivation</i>	

(Adapted from Shi et al. 2012: 228-229)

Table 1.1 – Push and pull motivations of physically disabled peoples' motivations to undertake leisure travel

Therefore, whilst this study wanted to explore and increase the knowledge concerning disability and disabled individuals' leisure experiences, Shi's et al. (2012) study highlighted that disabled individuals' experiences of leisure are not always about access or inclusion, but also about experiencing the enjoyment and pleasure of an activity. However, as Shi et al. (2012) explained that disabled individuals' experiences of leisure can be more than just about access, it highlights that academic and societal understanding of leisure for individuals with a disability needs to reflect the non-accessibility elements of this phenomenon.

When reviewing the different types of leisure research on disabled individuals' leisure experiences which has been conducted globally (such as Buhalis and Darcy 2011; Darcy 2010; Eichhorn et al. 2008; Veitch and Shaw 2011), it can be seen that research has looked at the non-accessible aspects of disabled individuals' leisure experiences (such as Cook and Shinen 2014; Henderson et al. 1994; Smith and Hughes 1999; Stumbo and Pegg 2004). While these studies have helped to enhance academic and societal understanding of disabled individuals' leisure experiences, it is clear that there has been limited knowledge exchanges between different studies to collectively provide an understanding of disabled individuals' leisure experiences and lives. Additionally, research into Social Tourism (McCabe 2009; Minnaert 2014; Minnaert et al. 2006, 2009, 2011), Accessible Tourism (Buhalis and Darcy 2011), Leisure Education (Dattilo 2012; Kleiber 2012; Sivan and Stebbins 2011), Therapeutic Recreation (Robertson and Long 2008) and Disability Sport (Frossard et al. 2010; Hassan et al. 2012; Luiselli et al. 2013), demonstrates that there have been attempts to conceptualise different disabled individuals' leisure experiences and to provide theoretical underpinnings to the relationship between disability and leisure. However, even though tourism, events and sports can be all classed as leisure activities (Aitchison 2010; Hall and Page 2014; Henderson 2010; Roberts 2011), the maturing of leisure studies into tourism, events and sports studies in some countries seems to have created knowledge boundaries which has limited different ideas of disability and leisure being transferred across the leisure studies spectrum. Internationally there are even differing philosophies

concerning the study of disability and leisure, which seem to discourage the actual understanding of disability and leisure (Aitchison 2003, 2009, 2010; Coalter 1997; Dieser 2011).

Despite the knowledge boundaries between leisure, tourism, sport and events, when looking at leisure which is experienced and available to individuals with a disability in a non-academic way, from a UK perspective there are many 'real-life' examples of disabled individuals participating within leisure. Such participation includes sporting competitions, drama groups, outdoor recreation activities, arts and crafts activities, specialised recreational weekends and holidays with family and/or friends (Bennett et al. 2014; CP Sport ca. 2015; Schänzel 2012a; Smith and Hughes 1999; Treloar Trust 2015). As a result, Aitchison (2007, 2009) has argued that academia should become more open minded and critical about the different dimensions of disability and leisure. Furthermore, Coles (2015) has argued that in order to act on, and become aware of different disability issues, we need to understand them within their real-life contexts. Therefore, it is important to acknowledge and understand all of the aspects of disabled individuals' social worlds and leisure experiences in order to fully understand and appreciate their lives and leisure experiences (Aitchison 2009; Aitchison et al. 2000; Page and Connell 2010; Smith and Sparkes 2008).

My role within the research: going beyond just creating knowledge

Jones et al. (2013) have explained that in qualitative research it is common for the researcher to include themselves within the research by writing in the first person. Consequently, within this thesis, I will be writing in the first person. Additionally, as understanding a phenomenon in qualitative research involves the researcher interpreting and exploring the phenomenon (Denzin and Lincoln 2011), it is important to understand the position of the researcher and his/her relationship with the phenomenon (both within and outside academia) (Denzin and Lincoln 2011; Etherington 2004; Johnson 2009; Tribe 2007).

My position is that I am physically disabled myself and have experienced life and leisure with a disability. My brain was starved of oxygen at birth and as a result the doctors diagnosed me with Cerebral Palsy. My Cerebral Palsy affects my limbs, muscles, speech and coordination. I received specialist play sessions at home, baby physio and hydrotherapy until I was three years old. After that, I went to a special needs school in Newcastle Upon Tyne, UK, until I was 16. I had Physiotherapy, Speech and Language Therapy and Occupational Therapy, together with support workers and teachers, all on one site. The school supported me (and my family) in finding ways for me to communicate, to increase my range of movements and to help me to walk and improve my coordination. The school also helped me to increase my confidence, numeracy and literacy skills, as well as my independence and social skills. After I left school I went to a special needs residential college in Alton in Hampshire, UK, where I was encouraged to develop my academic abilities, social skills, physical abilities, independence and confidence further. Even outside of school and college, my parents got me involved in different drama groups, social clubs and sports clubs, which all assisted me to develop as a person. However, even now, I felt frustrations, annoyances and even sometimes a feeling of being lost when people pay no attention to me just because I have impairments or when people are 'pretending' to understand me either verbally (due to my speech impediment) or as a person. It felt like that I have been told that I 'was not entitled'.

Due to my inner motivation to stand on my own two feet, I began researching master's programmes in the middle of my undergraduate degree. However, when I searched for 'disability and leisure based masters' or 'disability and leisure based research degrees' (in order to do a mixture of leisure, sport and tourism, with an application to disability), it surprised me that most of the courses were at USA universities. I started seeing references to Therapeutic Recreation and how some in North America look at disability and leisure from a number of different perspectives, and not just from the common one of access. The concept of Therapeutic Recreation seemed to promote a philosophy that had aided me and my friends when I was young, that leisure can be a beneficial activity for disabled individuals. Accordingly, I remember

that I used to look forward to doing leisure activities (such as cooking, sport, physical education, going out with carers and going to drama club), because it felt that I was a bit more independent, free and able to experience life as me. I felt that I could be independent later on in life and that I did not need to be 'protected' or be treated like a 'baby'. With this in mind, in order to help other disabled individuals and their families, friends and carers, I wanted to use my experiences to broaden the understanding of disability and of disability and leisure.

Aim and objectives of the research

The aim and objectives of this research were designed around the disabled individual, his/her world, and his/her experiences of leisure. However, as disabilities are wide ranging, I decided to only focus on individuals with a physical disability. Therefore, my overall research aim was:

To critically explore the social worlds of individuals with a physical disability and their leisure experiences

Furthermore, my objectives were:

- 1. To understand disability from an individual person's perspective*
- 2. To examine the 'individual' behind the disability, their 'social' world and leisure experiences*
- 3. To explain the connections between leisure and the individual, in order to discuss physically disabled people's leisure choices and how leisure can allow physically disabled people to experience their 'free time' and enjoyment of life*
- 4. To critically discuss whether physically disabled people gain any benefits from participating within leisure*

My research strategy adopted an interpretivist-constructivist approach which was implemented through a qualitative research approach based on interviews with physically disabled individuals. A qualitative approach was used so that I could ask the participants first-hand about their everyday lives and leisure experiences. The interpretivist-constructivist approach was adopted so that I could re-construct their worlds and explore how the

participants' accounts explain more about their social worlds and leisure experiences.

The structure of the thesis

This thesis is formed of six chapters. Chapter 2 reviews the current literature and provides an introduction to disability and leisure. Chapter 3 explains the methodological approach behind this research, exploring the methodological underpinnings and the method adopted. Chapters 4 and 5 will critically assess my findings and discuss them in relation to relevant literature. Chapter 6 will conclude my research, by explaining the contribution(s) I have made to our knowledge and by identifying ideas for future research.

CHAPTER TWO - LITERATURE REVIEW

Introduction

This chapter will provide an examination of the current knowledge of disability, leisure and of disability and leisure. The chapter is constructed in two major parts. The first part will provide an introduction and examination to the academic concepts and debates relating to disability. Secondly, the chapter will provide an introduction to the concept of leisure and will then evaluate previous research on disability and leisure.

Laying the foundations to understanding disability and leisure

The focus on disabled individuals within leisure studies is crucial as it encourages researchers, lecturers and students to understand that leisure is for everyone and not just for a few (Aitchison 2009; Henderson 2014; Parry et al. 2013). However, Aitchison (2009) has explained that research on disability and leisure has been limited and lacks the exploration of leisure from a disabled individual's perspective. Therefore, Aitchison (2009) has warned that the limited amount of understanding and research on disability and leisure can influence society to become exclusive. In addition, the lack of research and understanding could limit the awareness of disabled individuals' rights to experience and enjoy leisure (Aitchison 2009).

Hannam and Knox (2010) noted that when understanding the individual and his/her behaviours, it is important to understand the individual's social world and why his/her world may differ to someone else's. This is because in knowledge, there is a need to appreciate different groups within society and the reasons why individuals perform things in different ways (Hannam and Knox, 2010). There is a need to understand, relate and appreciate the diversity of different leisure participants (Browne and Bakshi 2011; Pritchard et al. 2002), in order to understand and to reflect on the diversity of different leisure experiences and phenomena within global society (Hall 2004, 2013;

Hall and Page 2014; Shaw and Williams 2002; Spracklen 2009; Tribe 1997). Therefore, in order to understand disability and leisure, and how physically disabled people may experience leisure, it is important to firstly understand the complexities of a disability (Aitchison 2009; Shakespeare 2006; Small and Darcy 2011).

Understanding disability

At the simplest level, disability has its connections with the medical phenomenon of when an illness(es), medical condition(s), medical abnormality(ies) or an injury(ies) has contributed towards an alteration or a loss in someone's body and capabilities (Foose and Ardovino 2008; Long and Robertson 2008; Thomas 2007). The individual's abilities and level of function will depend on how the individual and his/her body has been affected by his/her medical condition (Fegan 2011; Foose and Ardovino 2008; Kelly 2011; Liederman 2005; Long and Robertson 2008; Porretta 2005a, 2005b; Winnick and Lavay 2005). However, trying to define and explain disability is complex as there have been many philosophical and academic arguments about how disability should be seen and understood within society (Goodley et al. 2012; Thomas 2007, 2008).

The reasons why disability is complex to define and explain is not only because individuals have a range of different conditions (Fegan 2011; Kelly 2011; Liederman 2005; Long and Robertson 2008; Porretta 2005a, 2005b), but also because different researchers and individuals within society have argued that different ways of seeing and understanding disability could influence people to have certain attitudes about disability and even the basis of how they treat disabled individuals within society (Barnes 2012; Thomas 2004c). For example, Davis (2013) proposed that the concept of being disabled has been influenced through the idea of 'normality', where within society, it is sometimes viewed that individuals have to have a 'normal' body, with 'normal' capabilities, to be considered as a 'normal' person. Hence, Davis (2013) illustrated that such a perspective can encourage people to

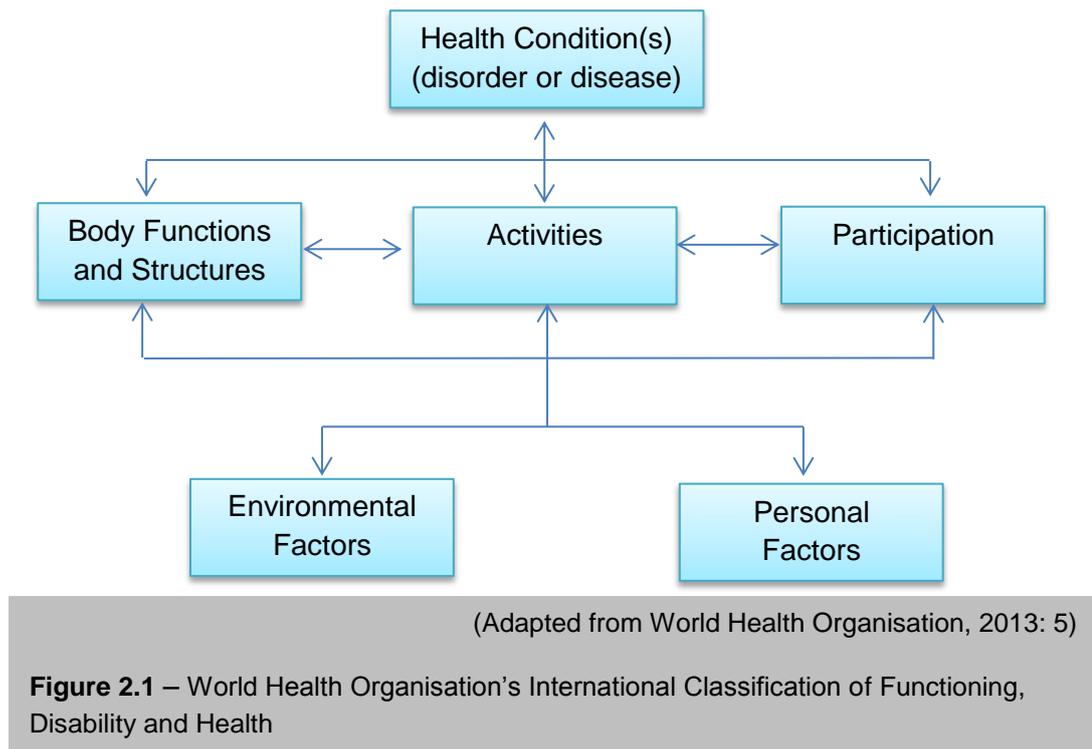
think that there is only one way to be 'normal' (i.e. straight, white and able-bodied) and that anyone else is different and is 'unable' to be normal. In addition, McRuer (2006) proposed the concept of 'Crip Theory' and suggested that there is a 'Heterosexual Compulsory Able-Bodiedness' culture within society where queer and disabled ideas of the world would 'interrupt' the social fabrics of the world. Equally, these sort of philosophical arguments are important as they question 'what is normal?' and remind society and academia that there are people and cultures in global society which are not heterosexual, straight, able-bodied and/or white (Barounis 2009). Therefore, they encourage equality, respect and the fair treatment of all citizens (Barounis 2009; Davis 2013; Goodley 2014; McRuer 2006). However, they also provide complexity in defining and explaining disability as they encourage society and researchers to think deeply about other individuals' worlds and see that all people are still human (Barounis 2009).

On top of the philosophical arguments, which argue for equality within society and the recognition of all communities regardless of gender, sexuality, race and/or disability, some researchers (such as Aitchison, 2003; Fullagar and Darcy, 2004) have also proposed that society and academia should not look at the medical implications on the disabled individual's body. This is because they argue that in doing so it will encourage people to look at the functional problems which an individual has and create the idea that individuals are, as a result, 'unable' because they have 'difficulties', which consequently means that they are 'different' and lack the capabilities in doing certain tasks (Aitchison 2003, 2009; Fullagar and Darcy 2004). However, other researchers (such as, Goodley 2011a, 2012; Smith and Sparkes 2005, 2008; Sparkes and Smith 2008; Thomas 2007) have expressed that the impairment(s) and the body cannot be ignored. This is because the both have the potential to impact upon individuals' lives and how they go about their lives (Hughes 2004, 2007; Thomas 2004b). They argue that the impairment(s) and the body may also have a psychological effect on how the individual feels in everyday life (Goodley 2011a, 2012; Smith and Sparkes 2005, 2008; Sparkes and Smith 2008; Thomas 2007).

Overall, the different ideas to how disability should be seen and understood within society make the task of defining and explaining disability complex. To provide a universal, international, way of defining and explaining the United Nations' World Health Organisation (2013) has developed a classification model which aims to help the understanding of disability. Similarly, the classification model provides a multidimensional perspective on disability, trying to encourage global society to see disability from more than one perspective (Goodley 2014; Howard 2008; Howard et al. 2008; Oliver and Barnes 2012).

The International Classification of Functioning, Disability and Health: a United Nations (UN) approach

In order to understand the complexities of disabilities, the World Health Organisation (2013: 5) constructed a simple yet detailed guide to understanding disability called "*The International Classification of Functioning, Disability and Health...*" (as shown in Figure 2.1 (p 14)). The classification aims to provide a neutral, but international, way of understanding disability through illustrating that there are six components to understanding disability (the health condition(s), the body, what activities the individual does, how participation rates of daily activities are affected by his/her disability and the environmental and personal factors that challenge the individual) (Goodley 2014; Howard 2008; World Health Organisation, 2013). The classification helps to create an understanding of how social, environmental and medical factors (such as people's attitudes, a lack of access, or a hearing loss), may affect the individual's life, coping strategies or general well-being (Howard et al. 2008). Therefore, Azaiza et al. (2012) noted that classification model encourages thinking about what provisions and opportunities need to be put into place to support, enable and increase the quality of life of disabled individuals.



While some favour the international classification model (Azaiza et al. 2012; Burnett 2013; Howard et al. 2008; Shakespeare 2006), other academics have found weaknesses with the classification. Singleton and Darcy (2013) suggested that it still has the potential to encourage society and professionals to focus more on the medical dynamics of an individual’s condition(s) rather than on the individual as a whole. Sylvester (2014) proposed that the model may also encourage some to assume that a disability is the individual’s problem, whereby wider society does not need to assist (or worry about) a disabled individual. Furthermore, Barnes and Mercer (2010) proposed that the model places very little emphasis on how societal issues (such as welfare cuts and abuse within care homes), can affect an individual’s life or well-being.

Oliver and Barnes (2012) argued that what divides opinion is that disability can be seen as a medical and an individual’s problem in the model, whereby individuals have problems and lack certain abilities which make them ‘able’. However, other academics would argue against this proposal as they state that the model is not aiming to look at disability solely from a medical perspective, but is trying to give people a multidimensional perspective on

disability (Burnett 2013; Howard et al. 2008; Shakespeare 2006). Thus, this debate on the United Nations' classification model demonstrates further that defining and explaining disability is an ideological and academic problem. With the diverse perspectives in understanding disability, there is therefore a range of other disability models (Henderson and Bryan 2011; Roush and Sharby 2011; Swain and French 2000). These different models of disability aim to represent different schools of thought when understanding disability (Henderson and Bryan 2011; Thomas 2004c). However, each of them do have weaknesses which affect societal and academic knowledge on what is a disability (Goodley 2011b, 2013; Kavanagh 2012; Shakespeare 2006; Swain and French 2000).

Models of disability: criticisms and the weaknesses

Henderson and Bryan (2011) stated that there are different models of disability. These models explain the advantages and implications of seeing disability in different ways (Thomas 2004c). Compared to the universal, international, view on disability in the World Health Organisation's model, these disability models are built on individuals' beliefs of how disability should be seen and understood in society (Henderson and Bryan 2011; Oliver 2013; Shakespeare 2006). However, only having one or two beliefs on disability also limits the ability to see the range of the different dimensions of disabled individuals' lives fully (Goodley 2013; Oliver 2013).

Roush and Sharby (2011) stated that the well-known disability models are 'the medical model' and 'the social model' of disability. From a theoretical perspective, the underpinnings of these models provide opposing views on how disability should be understood within society (Darcy and Buhalis 2011; Shakespeare 2006; Sylvester 2014). The medical model looks at disability from a medical perspective and compares a disabled individual's function with a person without a medical condition(s), in order to identify how the disabled individual's condition(s) have affected his/her health and capabilities (Darcy and Buhalis 2011). Additionally, the medical model encourages users

to identify ways of helping the disabled individual (Darcy and Buhalis, 2011). For example, the medical model promotes the use of different therapies (such as physiotherapy) and medical interventions (such as operations) in order to try and enhance the individual's overall quality of life (Barnes and Mercer 2010; Green and McAdory-Coogan 2008; Oliver 2009). Although, Darcy and Buhalis (2011: 25) have suggested that the medical model plays on the 'in-capabilities' of the person, where anyone "*...who cannot be modified or changed by professional intervention, remains deficient...*", a view which provides a negative and discriminative description of a disabled person.

In contrast, the social model of disability "*...defines disability as a product of...disabling environment[s] and prevailing hostile social attitudes...*" (Darcy and Buhalis 2011: 27). The social model suggests that while disabled individuals do have impairments, it is society that makes individuals 'disabled' due to society not creating enough accessible and inclusive provisions for them to be included or integrated (Barnes 2012; Barnes and Mercer 2010; Sylvester 2014). Therefore, Barnes (2012) proposed that the social model of disability helps to provide protection for disabled individuals as it promotes a philosophy that disabled individuals should not be judged, suppressed or have their rights taken away from them just because they have a disability. However, the social model risks overlooking the effect of the medical condition(s) and may make society responsible for the disabled individual's negative experiences when it is inappropriate (Goodley 2011b, 2013; Shakespeare 2006; Thomas 2004b). For example, when thinking about a mainstream school which can cater for disabled children who have minor to mild impairments, and a child who may have more complex physical and learning needs, it might be inappropriate to criticise the school for not doing more if; (a) the school has not got the appropriate resources to support the needs of the child fully, and (b) the child's development will be a risk if he/she cannot get the appropriate support that is needed (Read 1998). Likewise, the child may benefit and enjoy his/her childhood more with a higher level, and individual-focused, support package at a more specialise school (Read, 1998). Therefore, the social model of disability does limit

society's ability to understand the needs of the individual through focusing too much on society and not enough on the disabled individual (Read 1998; Shakespeare 2006; Swain and French 2000).

In addition to the medical and social models, there are two other models which aim to enhance and deepen the understanding of disability (Swain and French 2000; Thomas 2004a). Firstly there is Swain and French's (2000) idea of the affirmation model. Swain and French (2000) have explained, that while having a disability can have negative implications for the individual's functioning and well-being, empowering the individual can enable him/her to become more positive and can help him/her to develop his/her own identity. Therefore, the idea of the affirmation model is about looking at the individual more, the functional and psychological effects of the impairment(s), and how the disabled individual's life can be improved through them having the chance to control of some/all parts of his/her life (Kavanagh 2012; Swain and French 2000). The negative aspect of this model is that it risks overlooking how negative aspects of being disabled (such as feeling pain or feeling discriminated against) can effect and alter the individual's world.

The second model is Thomas' social-relational model. Thomas (2004c) stated that because society and the disability of the individual can limit and/or alter an individual's world, it is important to understand how society and the disability affects what the individual needs, feels and thinks within everyday life. Whilst the model rejects the idea that the impairment is the individual's problem, it tries to consolidate all of the factors which might affect the individual's life and any possible medical (such as physiotherapy) and non-medical strategies (such as carers or better access into buildings) which could help the individual (Thomas 2004a, 2004c).

Whilst the affirmation and social-relational models seem to encourage society and academia to look at the finer details of disability (Swain and French 2000; Thomas 2004a, 2004c), the idea of modelling disability can be argued as still being an ideological problem. Goodley (2001) has explained that this is not only because modelling disability may miss out (or overlook)

different issues, such as that impairments may not just be physical but can also be intellectual, but that modelling disability may also provide too much of a structure to the idea of disability, limiting the ability to think about different issues which the individual faces. Accordingly, in reference to the social model, Oliver (who came up with the social model) stressed with Barnes that:

“...we have constantly stated that the social model is a tool to...produce changes in society and is not and was never intended to be a theory” (Oliver and Barnes 2012, p 7)

Where Oliver (2013, p 1024) later said:

“At no point did I suggest that the individual model [or the medical model] should be abandoned, and neither did I claim that the social model was an all-encompassing framework within which everything that happens to disabled people could be understood or explained”

Therefore, whilst there are mixed messages about the basis of different disability models, confining oneself to one school of thought about disability creates difficulty in understanding all of the aspects of an individual's world fully (Goodley 2001; Oliver 2013). Imrie (1997) advocated that too much theorising has been happening on how a disability should be understood. Oliver (2013, p 1026), for example, has also pointed to the implications of theorising too much on disability and how with the 2010-2015 UK Government aiming to reduce UK spending, too much academic theorising has left:

“...disabled people at the mercy of an ideologically driven government with no-one to defend us except the big charities who are driven by self-interest”

Hence, Goodley (2013, 2014) has suggested that disability cannot be understood through one structured lens. Therefore, the next part of this section aims to examine disability through a more critical lens, aiming to define and explain disability fully and clearly.

Thinking about disability critically

Goodley (2013) stated that when looking at disability it is important to understand the relationship between the individual, his/her human body, his/her medical condition(s) and his/her experiences of the wider world. Shildrick (2012) has stated that it is important to be critical about disability and see it through a postmodern lens, whereby society does not just confine itself to a particular aspect of the disabled world (such as treatments or accessibility). Devine (2008) also suggested that looking at disability from a multiplicity of different perspectives enables a better understanding of the individual's needs and abilities.

With the idea that disability cannot be seen through one structural lens, it is clear that when trying to understand disability, there needs to be an understanding of how different factors interconnect with each other (as seen within the World Health Organisation's classification model). As such, Henderson et al. (1994) and Smith and Sparkes (2002, 2008) have each stated that the individual, his/her condition(s) and his/her wider world, can influence the dynamics of the individual's social world. This is not just because access, inclusion and societal acceptance are crucially important in creating equality and fairness (Dattilo 2012; Darcy and Buhalis 2011; Darcy et al. 2011; Patterson et al. 2012; Singleton and Darcy 2013), but also the individual's own emotions, thinking and confidence play an important role in either enabling or limiting their ability to think positively (Henderson et al. 1994; Kleiber et al. 1995; Smith and Sparkes 2008; Shakespeare 2006).

Overall, in attempting to define and explain disability clearly, it can be said that disability is a phenomenon in which an individual has a medical condition(s) that can affect his/her everyday experiences, and where society also has a role in assisting the individual when appropriate in order to make society accessible and inclusive (Goodley 2011b; Hughes 2004; Oliver and Barnes 2012; Smith and Sparkes 2005; Stumbo et al. 2015; Thomas 2004a, 2004c; Winnick and Lavay 2005). It can also be said that the reality of having and living with a disability is a complex phenomenon of managing oneself,

one's feelings, one's condition(s) and one's hopes and desires, within a world where the individual is presented with opportunities and challenges (Dattilo 2012; Goodley 2013; Henderson et al. 1994; Kleiber et al. 1995; Smith and Sparkes 2002, 2008; Sparkes and Smith 2005). However, it can also be expressed that human life has a number of layers to it, such as the geography and access of different places, the sociology of how people live their lives, the psychology of different emotions and behaviours, as well as the political and economic climates of different societies (Boniface et al. 2012; Goodley 2014; Kleiber et al. 2011; Thomas 2007). As a result, disability should be studied in a multidimensional way, from the disabled individual's perspective (Goodley 2001, 2013; Oliver and Barnes 2012; Thomas 2004a, 2004c). Accordingly, when looking at the knowledge of disability and leisure, there is a diverse interpretation on how academia and society should look at the relationship of disability and leisure and what it is.

Understanding the scope of knowledge on disability and leisure

Devine (2003, 2004, 2008, 2013) argued that apart from the need to treat the disabled individual as an individual, there is no one side to disability and leisure as, apart from access, the concept of disability and leisure also has a social, personal and emotional side. This is because overall leisure is an experience of enjoyment and fun where the individual occupies his/her own 'free time' with a pleasurable activity (Dattilo 2012; Elkington and Stebbins 2014). Therefore, this means that disability and leisure are not just about access but also about the personal experience of enjoyment and fun (Stumbo et al. 2011). However, before assessing the current knowledge of disability and leisure, it is important to have a basic understanding of leisure.

Understanding the basics of leisure

Similar to disability, the concept of leisure is multidimensional and complex (Chick 1998; Page and Connell 2010; Spracklen 2009, 2013a), where different academics have different ideas and ways of studying leisure (Dieser 2011; Henderson 2010; Page and Connell 2010). Traditionally, leisure has been defined as the individual's own 'free time' where individuals decide to do enjoyable activities outside of their work time or their other obligations (such as doing the school run or paying bills) (Blackshaw 2010; Boniface et al. 2012; Rojek 1995, 2013b). However, over time, the concept of leisure has changed.

Whilst people's income and access to different things still do affect what leisure activities they can do (Page and Connell 2010), it can be argued that over the years leisure has become more than just 'free time' or even pleasure (Crouch 1999; Fox and Leipine 2012; Hannam and Knox 2010; Kleiber et al. 2011). This is because, as Spracklen (2013a) explained, with technological advances and the beginnings of most liberal societies, society has entered an age of postmodernity. Within the age of postmodernity, the idea of leisure has changed from simply individuals experiencing something fun and pleasurable outside of their work and other obligations, to the aspect that they can satisfy themselves through leisure, do an activity which is meaningful and do an activity which can contribute towards their identity (Browne and Bakshi 2011; Fox and Leipine 2012; Spracklen 2013a). For example, using different activities and spaces (such as girls weekends or gyms), can help people to feel a specific gender or sexual identity (Berdychevsky et al. 2013; Blanco and Robinett 2014; Browne and Bakshi 2011; Kleiber et al. 2011 Norman et al. 2011). Consequently, today leisure practices are seen as activities and experiences which are personally shaped by the identity of a person or a group in order to help them to express themselves, to experience enjoyment and to help them to avoid the feelings suppression as well as to find different meanings within life (Chick 1998, 2009; Kleiber et al. 2011; Spracklen 2013a).

It can be argued that understanding how individuals use their leisure time also plays a significant role in the understanding of sports, events and tourism (Hall et al. 2014; Spracklen 2009). This is because sports, events and tourism can be perceived as a form of leisure, only being differentiated by the context and type of activity (Aitchison 2010; Hall and Page 2014; Page and Connell 2010). However, whether or not an individual's leisure time is placed within a sports, events or tourism context, Kleiber and colleagues stated that, as a whole, the study of leisure is an important scholarly pursuit. This is because it not only allows the understanding of leisure within modern society, but also allows the understanding of whether/how leisure can influence individuals' everyday feelings, emotions, health and behaviours (Hutchinson and Kleiber 2005; Kleiber 2001, 2012; Kleiber et al. 2002, 2011). Therefore, leisure can be argued as not only being about the individual and his/her leisure experience, but also about the individual experiencing an activity in order to bring happiness, joy and/or meaning into his/her everyday life in order to avoid boredom (Caldwell 2005; Kleiber et al. 2011; Page and Connell 2010). Accordingly, the next subsection will examine current knowledge of disability and leisure.

Current knowledge and approaches to understanding disability and leisure

The study of disability and leisure has been a research theme for scholars across the leisure studies spectrum over the years, with issues such as accessibility (Eichhorn and Buhalis 2011; Eichhorn et al. 2008), disability sport development (Hassan et al. 2012; Luiselli et al. 2013) and the beneficial aspects of leisure participation for disabled individuals (Kleiber et al. 2008; Mayer and Anderson 2014), being on academics' research agendas. However, despite such scholarly activities, there has been limited overall understanding and recognition of disability and leisure (Aitchison 2009). This is not just because there are differing ideas on disability which have influenced how disability is researched in a leisure context (Aitchison 2003), but also because of how the study of leisure has developed differently

across the world, which has then created knowledge barriers for different ideas and concepts to be used across the leisure studies spectrum (Elkington 2013; Henderson 2010; Roberts 2011; Sylvester 2015b). Additionally, such ontological, epistemological and methodological issues have created problems in understanding disabled individuals' leisure time, experiences and the world of disability and leisure (Mobily 2015a; Sylvester 2015b). Although, in order to fully understand the scope of disability and leisure knowledge fully and the ontological, epistemological and methodological issues, there needs to be a basic understanding of what research there is.

Across the leisure studies spectrum, leisure research internationally has engaged with the concepts of disability and social inclusion. For example, Social Tourism research has looked at the relationship between social capital, tourism, disadvantaged groups and the positive effects of having a break (McCabe 2009; Minnaert et al. 2009, 2011). Accessible Tourism has examined how to make tourism more accessible and inclusive (Buhalis and Darcy 2011). Sports disability research has focused on sport, disability and social inclusion (Brittain and Green 2012; Brittain et al. 2013; Bush and Silk, 2012; Collins and Kay 2014; Hassan et al. 2012; Howe 2011). Additionally, sports research has demonstrated how sport can be a vehicle for human development and increased social capital (Adams 2011; Gould and Carson, 2008).

There are also two additional leisure orientated concepts related to disability, but these have received limited attention in the UK. The first concept, with its roots within North American scholarship, is Therapeutic Recreation. Therapeutic Recreation is about helping individuals mostly with health problems and medical condition(s) to overcome their difficulties by using their leisure interests to empower them through offering them the opportunity to experience something different to their condition(s) and/or possible everyday challenges (Jennings and Guerin 2014; Kleiber et al. 2002, 2008; Kunstler and Daly 2010; Mayer and Anderson 2014). The second concept is Leisure Education which is about helping individuals, with and without condition(s), to

self-develop naturally as human beings and to gain different life skills (such as confidence, social skills, autonomy and independence skills), through leisure participation (Dattilo 2012; Sivan and Stebbins 2011). Both of these concepts are not specific to sports, events or tourism, but see leisure generally as a good way of assisting disabled individuals to increase their well-being (Dattilo 2012; Kleiber 2012; Kunstler and Daly 2010; Robertson and Long 2008).

In addition to the concepts above, when comparing UK research on disability and leisure with overseas research, particularly from the USA, Canada and Australia, the comparison reveals that research on disability and leisure can be moved beyond the perspective of rights and equality, and can be further focussed on the embodied, personal and/or beneficial nature of the leisure of individuals with disabilities (Bennett et al. 2014; Cook and Shinew 2014; Kleiber et al. 2008; Mayer and Anderson 2014; Patterson 2001). For example, Patterson (2000) noted that leisure helps disabled individuals to form their own identity. Therefore, these authors showcase the ability to understand disability and leisure from a social, personal and non-policy based perspective.

Overall, all of these different theories and explanations of disability and leisure have made a real contribution to knowledge, although they have not been used collectively to understand all of the dimensions of disabled individuals' leisure behaviours and experiences. Academic research suggests that this is because leisure studies have matured and that certain countries (such as the UK and Australia) and researchers have become more specialised in either tourism, sport and/or events (Rojek 2013a; Spracklen 2013b). Thus, creating academic and knowledge boundaries based on whether something can be classed as tourism knowledge, sport knowledge and/or event knowledge, therefore making it harder for researchers to become aware of the different ideas of disability and leisure (Elkington 2013; Henderson 2010; Parr and Lashua 2004). Equally, whilst leisure studies has not diversified so much within the USA (Aitchison 2003, 2009; Coalter, 1997; Dieser 2011), the USA's approach sees more

similarities between leisure, sport, events and tourism and sees leisure as a meaningful activity which can create empowerment and identity opportunities as well as experiences of escape and enrichment for individuals (Coalter, 1997; Henderson 2010). Within the USA, the ideas of Therapeutic Recreation and Leisure Education have therefore naturally developed through the philosophy that they help to empower and enrich disabled individuals' lives, as well as creating accessible and inclusive opportunities for individuals with a disability to experience leisure (Dattilo 2012; Kunstler and Daly 2010). However, whilst both Therapeutic Recreation and Leisure Education have been proposed and advocated as ways of opening up different leisure experiences to disabled individuals and to individuals who have experience personal and physical barriers in experiencing leisure (Kleiber 2012; Kunstler and Daly 2010; Robertson and Long 2008; Stumbo et al. 2004), Therapeutic Recreation and Leisure Education appears to have little acknowledged by the international leisure studies (including sports, events and tourism community) (Stebbins 2011; Sylvester 2015b). Consequently, it can be argued that this has also affected the understanding of disability and leisure. This is because, by researchers and society focusing more on access and inclusion, and less on the personal and meaningful aspects of leisure, it could have encouraged researchers and society to be less appreciative of the personal and meaningful aspects of leisure which can be experienced by someone with a disability (Kleiber 2012; Mobily et al. 2015; Sylvester 2015a).

Even though there has been research conducted concerning disability and leisure internationally, some of which is not always orientated around the concept of access, it can be seen that knowledge boundaries and the maturity of leisure studies in places have played a significant role in academics' full understanding of disability and leisure. Although, as academics have illustrated attitudes towards disability can also affect how/whether they conduct research on disability and leisure (Aitchison 2003, 2009; Fullagar and Darcy 2004; Sylvester 2015b), it is also clear that the issue of how disability is be seen within society affects the direction of research on disability and leisure. For example, Aitchison (2009) explained

that because research on disability and leisure has historically been dominated by a medical perspective of disability, this has led to limited social construction of disabled individuals' experiences of leisure and limited attempts to explore disabled individuals' everyday and leisure experiences. This is due to how being disabled has been perceived as being 'different' to the everyday, able-bodied, leisure participant and how the disabled individual's leisure experience will be different to 'normal' way of studying leisure (Aitchison 2009). Additionally, Howe (2009), who has a mild form of Cerebral Palsy himself, has suggested that leisure researchers have not acknowledged individuals' impairments and bodies enough, or the dimensions of individuals' social worlds and leisure experiences, within research. Howe (2009) therefore has illustrated that, in doing so, this has provided a lack of context and understanding of how the individual experiences the world and subjectively experiences leisure.

Conclusion

The aim of this literature review was to provide a foundation to the understanding of disability, leisure and disability and leisure, and to critically assess the current state of research within these fields. Overall, the literature review demonstrated that both disability and leisure, as concepts, are complex and multidimensional phenomena, and that academics have different ideas about how both concepts should be seen and researched. Similarly, the literature review identified that research on disability and leisure has been conducted internationally and provides different pieces of knowledge that can benefit disabled individuals and help leisure to be accessible and inclusive to disabled individuals. However, despite different ideas and concepts being conducted internationally, there has been limited knowledge exchange between them to jointly create a full and detailed understanding of disability and leisure.

In essence, it is clear that academics cannot overlook the individual when looking at disability or individuals' with disabilities experiences of

leisure/leisure behaviours. Therefore, researchers need to engage with the individual and his/her social world more. Research has suggested that sometimes (more so in the UK), academics have not considered all of the elements within the individual's world (including the individual, his/her emotions, his/her impairments and his/her experiences of leisure), that provide a detailed picture of the disabled individual, his/her leisure experiences and his/her life (Howe 2009; Macbeth 2010). This is likely because the agenda has been overshadowed by disability models and academic theorising about different models rather than looking at the individual, seeing life through his/her eyes and, at the same time, acknowledging them as a person (Imrie 1997; Oliver 2013). In order to address this, this research has not adopted any specific model of disability but just views the research participants as people and listened to their words.

Another issue which was raised in this chapter was the divides in disability and leisure scholarship. Whilst subject boundaries and approaches internationally have affected this, such divides have made the understanding of disability and leisure disjointed. Whilst maturity, academic development and diversifications of studies (such as studies on sustainable tourism, the economic impact of mega events and high performance sports training), are good in enhancing societal and academic knowledge; this has no doubt affected the ability to broaden the multidimensional understanding of disabled individuals' leisure choices, behaviours and experiences. Therefore, through this study focusing on leisure (acknowledging its associated studies of tourism, sports and events), and from listening to the participants, this research aimed to contribute to knowledge more understanding of disabled individuals' social worlds and leisure experiences.

Finally, as Dixon (2008) noted, when looking at the disability and leisure, there is a need to see the individual's leisure experience through the individual's eyes, and to identify how different elements of his/her experiences explain more about his/her social worlds and leisure experiences. Therefore, even though there are a range of attitudes to how disability and the leisure choices, behaviours and experiences of individuals

with disabilities should be researched, in this research, the sole focus was on the understanding of the participants, their worlds and leisure experiences, whereby their words and accounts would influence the direction of the discussion. This 'attitude' towards how the research was conducted was important in telling the full picture of disability and of disabled individuals' leisure choices, behaviours and experiences, as it did not turn the research to having a 'particular' attitude about disability or disability and leisure. Equally, by examining in detail the relationship between the disability, the individual and leisure, there is a real opportunity to understand and appreciate the in depth and specific dimensions of disabled individuals' leisure choices, behaviours and experiences (Stumbo and Pegg 2004; Stumbo et al. 2004, 2011). Consequently, from the study being led by the participants own accounts and experiences, there was the ability to have a greater and in-depth understanding of disabled individuals' social worlds and leisure experiences, something of which that is not very well acknowledged across the international leisure community.

CHAPTER THREE – METHODOLOGY

Introduction

The aim of this research was to explore physically disabled individuals' social worlds and leisure experiences. As human experiences are subjective and differ depending upon how each person thinks and feels (Cutler and Carmichael 2009; Kleiber et al. 2011), there was the need to adopt an approach that captured disabled individuals' 'lived' experiences. Accordingly, this research utilised an interpretivist-constructivist approach, through the collection of semi-structured interviews enquiring about the everyday lives and leisure experiences of people with disabilities. This chapter explores the research methodology and explains how participants' voices were captured and analysed.

Research philosophy

The art of research has been referred to as examining and answering a research question, as well as addressing a gap in knowledge, in order to enhance understanding, awareness and knowledge about a phenomenon (Ayikoru 2009; Bryman and Bell 2011; Henderson 2014; Johnson 2014; Jones 2015; Pritchard and Morgan 2007; Sparkes and Smith 2014). Due to research being able to be conducted in different ways (Bryman and Bell 2010; Tribe 2006), Sparkes and Smith (2014) explained that differing research philosophies and methods can result in different ways through which a research question can be answered or a gap in knowledge can be filled. Consequently, this affects how phenomena are understood and interpreted in real-life (Bryman and Bell 2011; Henderson 2011; Jones 2015). This section aims to explain the philosophy of the study and the reasons why this research adopted an interpretivist-constructivist approach.

Before adopting a paradigmatic approach, it was important to think about what current research there was concerning disability and leisure and how

my research could contribute towards current knowledge. Additionally, there were three questions of research philosophy which needed to be asked: the ontological question (what was known and unknown), the epistemological question (what was the relationship between the researcher(s) and the known) and the methodological question (what research methods were needed to help the unknown to be known) (Ayikoru 2009).

When asking 'what do people know about disability and disabled individuals' leisure choices, behaviours and experiences?' (the ontological question), it can be argued that disability, as well as the concept of disability and leisure, is known within leisure studies. However, the presence of disability and the leisure choices, behaviours and experiences of individuals with a disability within leisure research, differs throughout the world dependent on how different researchers and academic communities see disability and disabled individuals' leisure choices, behaviours and experiences as concepts and the matter of how they should be researched (Aitchison 2003, 2009). Similarly, when asking 'how do researchers see disability within leisure studies?' (the epistemological question), it can be argued that this varies as well as depending on the position of the researcher, what sub-field of leisure studies they are in and/or what country the researcher is in. This has meant that the research and engagement in disability and disabled individuals' leisure choices, behaviours and experiences has been different amongst the international academic community and have influenced a disjointed overall understanding of disability and leisure (Aitchison 2003; Dieser 2011; Fullagar and Darcy 2004; Mobily 2015a; Sylvester 2015b). Based on these answers, the answer to the methodological question was that there should be an approach that did not objectify the research participant's social world and leisure experiences, and did not adopt a specific attitude to how disability or disabled individuals' leisure choices, behaviours and experiences should be understood. It should be a methodological approach that allowed for subjectivity, flexibility and exploration. Equally, whilst this research would not have been the only piece of research to examine disabled individuals' lives and leisure experiences (Devine 2004; Henderson et al. 1994, 1995; Hutchinson et al. 2003; Kleiber et al. 1995; Pattinson, 2000, 2001), this

research project would contribute towards the understanding of disabled individuals' social worlds and leisure experiences.

Research philosophy is about certain beliefs and ideas (Tribe 2009), and Tribe (2006) has noted that different philosophies and ideas result in different ways of seeing the world. Equally, Creswell (2009) has stated that paradigms (or paradigmatic philosophies) are different beliefs that the researcher has on how research should be conducted and assessed. Additionally, Lincoln et al. (2011) have expressed that the relationship between ontological, epistemological and methodological questioning and the different paradigmatic philosophies, is of one adopting a paradigmatic philosophy that suits the methodological requirements of a research question. The reason for this argument is that, because different paradigms represent different views and ideas on how different things should be researched and reported, they influence the use of specific research methods and how the researcher sees the phenomenon (Ayikoru 2009; Goodson and Phillimore 2004; Henderson 2011; Parry et al. 2013). For example, by adopting a paradigm which is less subjective and more scientific (such as positivism), which upholds a belief that research is conducted through tests rather than subjectively interpreting the world, it can be argued that methodologies will be quantitative based (Ayikoru 2009; Henderson 2011). However, as paradigmatic philosophies can encourage the researcher to look at a phenomenon in a certain way (Ayikoru 2009; Goodson and Phillimore 2004; Ren et al. 2010), Henderson (2011) and Parry et al. (2013) stated that different ways of viewing the research can alter the impact of the research on society and future knowledge. Therefore, it was clear that this research's paradigmatic philosophy would affect how the research would be conducted.

To explore disabled individuals' social worlds and leisure experiences, an interpretivist-constructivist approach was adopted. With this paradigmatic approach, it was seen that there was an ability to look at disabled individuals' social worlds and leisure experiences from a subjective, flexible and explorative perspective. Bryman and Bell (2011) explained that interpretivism is about looking at the world from a social and subjective perspective,

making sense of why different things happen through looking between the lines. Jones (2015) has also explained that constructivism is the art of reconstructing different aspects of the world in order to make sense of different aspects of reality. Consequently, the relationship between interpretivism and constructionism helps in exploring and reconstructing the different dimensions of a phenomenon (Bryman and Bell 2011; Flick 2009; Goodson and Phillimore 2004; Hollinshead 2004; Lincoln et al. 2011). Given the assumptions of this approach a qualitative methodology was adopted for this study.

Adopting a qualitative research methodology

With the adoption of the paradigmatic approach, the research adopted a qualitative methodology. Qualitative research is about observing the real world and exploring different meanings of reality (Corbin and Strauss 2015; Creswell 2009; Flick 2014; Holloway 2011). Denzin and Lincoln (2011) further explained that it is a methodological approach of deconstructing different aspects of the world around us, in order to make sense of the dynamics of different phenomena. Therefore, qualitative research allows researchers to move away from objectivity and examine different meanings, behaviours and situations (Denzin and Lincoln 2011; Holloway and Brown 2012; Holloway and Wheeler 2010; Jones et al. 2013; Phillimore and Goodson 2004). Accordingly, with an adoption of a qualitative methodology, the research then decided to use a semi-structured interviewing method.

Embracing semi-structured interviewing

Semi-structured interviews were adopted as conducting interviews would enable me to listen to disabled individuals' voices and examine how their experiences are formed. Chase (2011) stated that interviewing captures people's sense of reality, by letting the participant share his/her stories, feelings and experiences with the researcher. Jones et al. (2013) and Jordan

and Gibson (2004) explained that interviewing provides a deep insight into the participant's world. Moreover, interviewing provides the opportunity to ask individuals' first-hand about their lives and experiences (Chase 2011).

Semi-structured interviewing is the process of asking the participant specific questions, in order to get more focused answers from the participant (Flick 2009; Jones et al. 2013). Such an approach further allows the researcher to focus the interview upon specific aspect(s) of the participant's world as the researcher is asking specific, yet open, questions to the participant about his/her feelings and experiences (Jones et al. 2013). Therefore, because semi-structured interviewing is about the researcher asking specific questions to a participant (Jones et al. 2013), in this study, semi-structured interviewing provided a useful way in understanding the participants' social worlds and leisure experiences. This was because semi-structured interviewing enabled the interviews to be flexible enough to allow the participants to say what they want, but also encouraged the participants to talk more about their everyday lives and leisure experiences through them being asked specific questions. Accordingly, before conducting the interviews, I prepared a list of questions (an interview schedule) related to disability and the individual's leisure time, to understand more about the participants' conditions, everyday lives and leisure experiences.

The questioning strategy was based upon asking questions about the participants' disabilities, the implications of their conditions, their leisure time, their interpretations of leisure as an experience and also whether or not they feel that they gained any benefits from participating within leisure (as seen in Figure 3.1 (p 34)). Thus, the aim of the questioning strategy was to try and get the participants to talk about themselves, their conditions, the implications of their conditions as well as their leisure experiences. This was so that from asking questions such as *"How does your disability affect your everyday life?"* or *"What do you do in your free time?"*, there was an ability to contextualise their everyday experiences and explore the different dimensions of their worlds. A pilot interview was carried out before the actual interviews were conducted. This was essential in testing the interview design

and for making any refinements necessary in ensuring that the participants were asked the right questions.

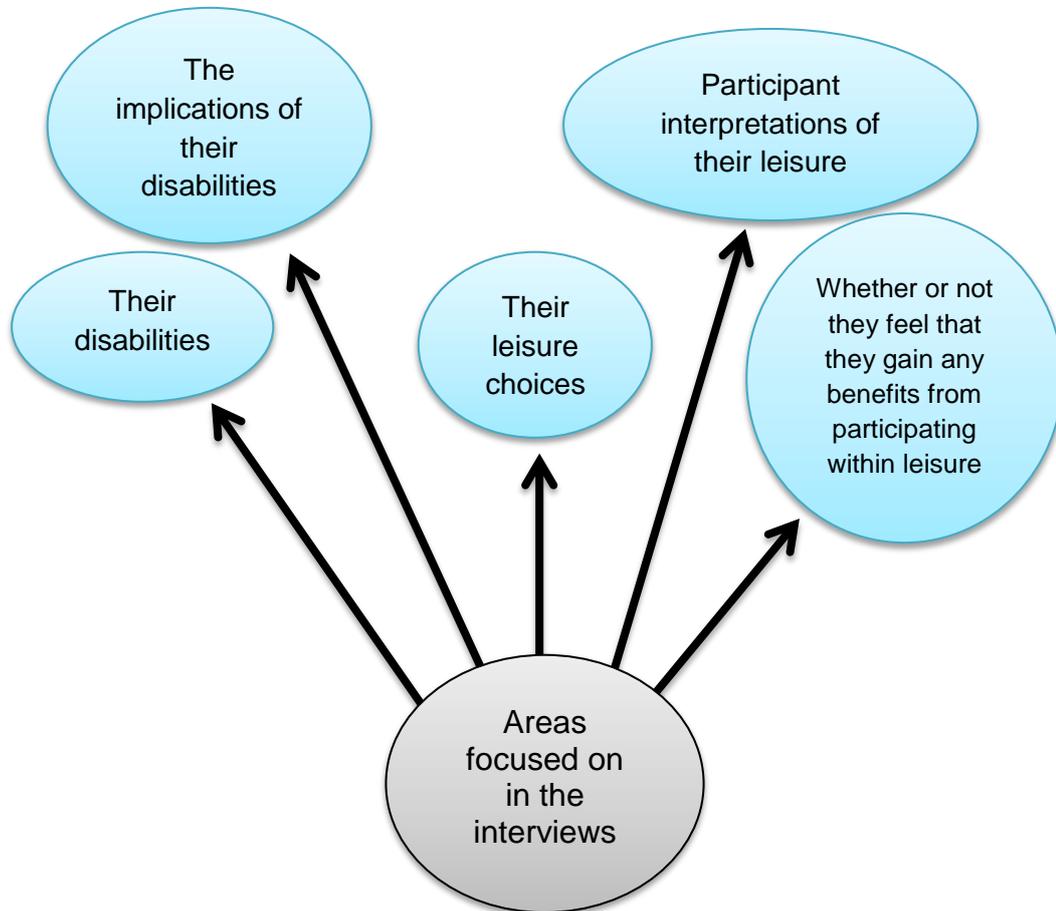


Figure 3.1 – Areas of questioning within the interviews

The pilot interview

Pilot interviews are crucially important in any research process as it helps the researcher to practice his/her interviewing technique and gives the researcher a 'dry run' (Sparkes and Smith 2014). Doing a pilot interview also helps the researcher to identify the effectiveness of the interview schedule and whether the interview approach is achieving what it meant to achieve. Similarly, Jones (2015) stated that fine tuning of the interview approach is really important as it helps to get as much out of the interview as possible.

The pilot interview was conducted with a male participant, who was in his 20s, had Cerebral Palsy, and needed a wheelchair due to limited function in his legs. The pilot interview was face-to-face and was extremely useful as whilst the interview approach got the participant talking, the questions asked, and the interview structure adopted, were not flexible enough for the participant to tell his experiences. Additionally, while I had assumed that people might choose particular leisure activities within his/her time such as visiting cafés, pubs, museums or shopping centres, the participant said that he would not generally be motivated to go to those places. This showed that I was almost assuming what the participant was going to say and was assumptive of individuals' social worlds. There was also a sense that I was too objective in the pilot interview, where I was too focussed on following the interview schedule rather than listening to the participant, which impaired the flow of the dialogue.

To improve the interview style and schedule, it was decided to keep the same areas of questioning but to have more open yet specific questions in order to encourage the participants to speak more about their social worlds and leisure experiences (the interview schedule is shown in Appendix A (p 147)). To also make sure that as much data was gained from the interviews as possible, probing questions (such as "*why is that?*") were used to encourage the participants to talk in more depth about their social worlds and leisure experiences. This was to help the participants to provide context and understanding into their lives and leisure experiences. Overall, the pilot interview helped to refine the interview style and schedule as it provided an understanding of how the questioning strategy could be more effective and how I could get the participants to say more.

Sampling and participants' profile

In designing the research, it was important for me to gain an appropriate research sample. Holloway et al. (2010) explained that qualitative research is about understanding different meanings and not different measurements.

Therefore, rather than trying to interview a specific number of people, qualitative participant selection is focussed on gaining access to the relevant people who had knowledge of the phenomenon (Holloway and Brown 2012).

A sampling strategy is the process of how and why the participants and/or objects are included in the research (Bryman and Bell 2011; Jones et al. 2013). Within this study, a combination of purposive and convenience sampling strategies were adopted. A purposive sampling strategy is about choosing individuals who have the relevant experience and knowledge about the phenomenon being explored (Jones et al. 2013). A convenience sampling strategy is about the researcher asking individuals, who are within easy reach of the researcher (geographically or online), to be involved in the study (Jones et al. 2013). These sampling strategies were used because the purposive strategy helped me to target individuals who had a disability, while the convenience strategy helped me to minimise the issue of gaining access to the participants due to geography.

Once a sampling strategy(ies) has been chosen, it is then recommended that researchers think in more detail about their sample strategy so that they have a firm idea about what type of sample they want, and that they have not created a sampling strategy that might provide negative implications for the data analysis stage (Bryman and Bell 2011; Jones et al. 2013; Sparkes and Smith 2014). For example, travelling around the country to interview people might create unnecessary pressure on the researcher if his/her research is under a time pressure (Jones et al. 2013). Therefore, when planning my research sample, there were a two more of things which I needed to consider. Firstly, as there are many different forms of disabilities, it was important to make sure that the experiences of different disabled individuals did not override my ability to be reflexive enough to explore and report the participants' lives and experiences effectively. Too many experiences of different medical conditions could run the risk of spreading the research too thinly across the disability spectrum. Therefore, a decision was made to only interview individuals with a physical disability. I also decided to only interview adult participants to minimise issues of vulnerability and parental consent.

Overall, the sampling criteria were that:

- 1) All participants needed to be over the age of 18
- 2) All participants needed to have a physical disability, or consider themselves as having a physical disability
- 3) All participants could be:
 - a. Interviewed online via a web camera
or
 - b. Be interviewed at a location which could be easily accessed by myself and my support worker (within a day) through the use of public transport

As shown within Table 3.1 (p 38), five participants were recruited. Due to having a physical disability myself, I have been fortunate to meet other disabled individuals via different organisations such as athletics sports clubs and universities' groups. The recruitment of the participants happened by informing different disabled individuals which I have made connections with and informing them about my study, what I was researching and that I was interested in interviewing physically disabled individuals about their social worlds and leisure experiences. All the participants who confirmed their willingness to be involved were aged between 18 and 57. Four of them were wheelchair users and one of them did not use a wheelchair but sometimes needed to walk with crutches. Three of the participants were females and two were males.

Pseudonym	Katie	Lisa	Jessica	John	Bart
Age of participant	21	51	23	57	19
Gender of participant	Female	Female	Female	Male	Male
Their disability	Visual impairment and severe joint condition	Incomplete spastic paraplegia	Ehlers-Danlos Syndrome	Various injuries from a road traffic accident	Duchenne Muscular Dystrophy
Wheelchair user	No but has got problems with mobility and uses crutches to aid ambulation	Yes	Yes	Yes	Yes

Table 3.1 – Interview participants and their disabilities

The data collection process: conducting the interviews

The participants who volunteered, were e-mailed and provided with a consent form (see Appendix B (p 149)) and a participant information sheet (see Appendix C, p 151). In line with recommendations that Comic Sans MS is an accessible font for everyone to read (whether or not they have dyslexia or any other reading difficulty) (Francis and Gould 2012), both the participant information sheet and the consent form were written in this font. The participant information sheet also included pictures in order to enhance understanding and to reduce any risk of anxiety amongst potential participants.

Due to the possible difficulties of arranging interview locations and times which were convenient to the participants, myself and my support worker, based on travel and accessibility issues, it was decided that the interviews could either be conducted online via virtual video link (for example, Skype) or in a face-to-face environment. Accordingly, four participants (Katie, Lisa, Bart and Jessica) were interviewed via an online video link and one participant (John) was interviewed face-to-face. The duration of each interview was

between 49 minutes and 74 minutes (1 hour 14 minutes) and all interviews were recorded using a digital voice recorder.

Data analysis

Holloway and Brown (2012) state that data analysis is one of the critical points of qualitative research, as it is the time when the data moves from being raw and flimsy, to being solid and meaningful. Therefore, the data analysis stage was important as it helped me to critically explore the meaning of the data collected (Ateljevic et al. 2005; Chambers 2007; Hollinshead 2012; Holloway 2011; Jordan and Gibson 2004; Thomas 2004d; Tribe 2001, 2007).

The data analysis process was formed of three parts: transcribing, coding (through thematic analysis), and by reflecting about the meaning of the data. This is because, apart from transcribing and coding being important for turning the participants' words into text and helping the researcher to make sense of the data (Jones 2015; Jones et al. 2013), there is a real need to think about the data from the participants' perspective. This means that the researcher has to move beyond his/her assumptions and think 'what picture(s) is the data trying to create?' (Sparkes and Smith 2014).

The first part was the transcribing process which was done by a professional transcriber, as my own disability limited my ability to complete this process. When the transcriber finished, all the transcripts were sent to me and I double checked them. This checking process also gave me the chance to get to know the data, what the data was saying, and allowed me to gain a deeper insight into the participants' stories.

Second, after the transcription process, I coded the data by using thematic analysis. In general, thematic analysis is the process of reading through the data set and identifying themes (such as "*Living with a disability*"), when the researcher then examines each theme further in order to identify any other

sub-themes or clues as to why particular things have been said (such as “*Being resilient*” (sub-theme) or “*I just think it’s important to not give in!*” (a clue)) (Flick 2009; Jones et al. 2013). Within this research, the process of thematic analysis increased my familiarisation with the data by enabling me to read through and understand more about the context of the data and the differences between different parts of the interview transcripts. There was also an ability to reconstruct the participants’ accounts according to theme from the thematic analysis process. This helped me to concentrate on specific themes one at a time (such as managing a disability or the release which leisure can give to some of the participants), why particular situations/experiences happened and how they played a part in the participants’ worlds or particular experiences.

The final part of my data analysis was reflecting about the meaning of the data. As different social realities are formed in different ways (Coles 2015; Darbellay and Stock 2012; Tribe 1997, 2009), this meant that I needed to think in a less structured way in order to try and understand the underlying pieces of the participants’ accounts (Chambers 2007; Franklin 2007; Gale 2012; Hollinshead 2012; Holloway and Brown 2012; Thomas 2004d; Tribe 1997, 2007, 2008, 2009). Reflecting about the data enabled me to extend my thinking on what the data meant and what the participants were trying to describe in their interviews. It also helped me to think about the data from a participant’s perspective and imagine how different situations happen within their world and what effects these situations had on the individual. Additionally the role of reflexivity was significant in aiding me to understand the data from the participants’ perspective.

Being reflexive and keeping a research diary

As a qualitative researcher, reflexivity was really important in capturing the participants’ stories and experiences and transferring them into text. This is because reflexivity helps to identify the details of the phenomenon by the researcher withdrawing themselves from the world of academia and of

different professions, to the world 'outside' of these professional circles where they can see the authenticity of different things and behaviours (Cohen 2013; Holloway and Brown 2012). Accordingly, Johnson (2009, 2014) explained that reflexivity encourages the researcher to see the 'blurriness' of the world. Therefore, being reflexive helped me to explore the participants' narratives in a non-academic way. This was not just through seeing things from the participants' perspectives, but also imagining the realities of their stories from using my own experiences of living with a disability as a way of setting the different scenes and imagining the context of different situations.

To help me to reflect upon my interpretations of the findings, I also kept an audio diary (an example of it is transcribed in Appendix D (p 155)). Keeping a research diary aided the research process, as it allowed me to note down any personal reflections of the data (Flick 2014; Holloway and Brown 2012). Johnson (2009) has suggested that self-reflexivity can be an emotional journey as being reflexive can require the researcher to go out of his/her comfort zone whereby they are tested on his/her own personal thinking about life, if they are able to personally relate to a specific experience(s) which a participant had mention. Similarly, being reflexive did become difficult for me personally as from personally understanding the participants' different situations, and from also using my experiences to understand their worlds, reflexivity did remind me of my life and encourage me to think about particular issues that I have come across myself. Hence, reflexivity required me to manage my own feelings and emotions. However, keeping a research diary helped me to really understand what was happening and, as a researcher and not as a person, to question why things were happening (Etherington 2004; Holloway and Brown 2012; Johnson 2009). Therefore, my research diary enabled me to see beyond some of my issues, due to allowing me to personally reflect on the participants' accounts and to ponder on why different things were said. It also enabled me to widen my mind about the meaning of the data.

Ethical considerations

To become ethically approved, the research needed to gain consent from the Ethics Board at Bournemouth University to ensure that the research followed the Research Ethics Code of Practice (Bournemouth University 2014). Bournemouth University Ethics Board approved the research after some minor adjustments to the participants' information sheet, in order to improve the clarity and to include details of an independent contact if participants wanted to contact anyone external to the research. After this, the research gained formal consent from each of the participants. However, when looking at the research as a whole, it was important to conduct the research in an ethical manner.

Ethics is important within any part of life, as it stresses the right to be respected and that fairness should occur on every level of society (Fennell 2009; Flick 2014). Additionally, ethics within research is essential in protecting someone or something from harm (Fennell 2009). However, ethics within research is also about giving justice, telling the true stories of individuals' lives so that others within wider society (such as lecturers, students and even other individuals with a disability and their families), can understand, appreciate, support and treat them as equals (Henderson 2014; Holloway and Brown 2012; Johnson 2009, 2014). Accordingly, as individuals who have a disability are considered as 'vulnerable people' under UK law (Bournemouth University 2014), it was important to design the research so that no harm was done to the participants, whilst also making sure that their stories were effectively being told.

To improve the ethical dimensions of this research project, I designed the interviews so that all of the participants had a chance to tell me about their everyday lives and leisure experiences, whilst also protecting them, their families and friends identities. This was achieved through giving the participants pseudonyms and masking the names of their family members and friends, as well as the names of places where they had a negative experience. Additionally, within the interviews, all of the participants were

made to feel comfortable and heard. They were informed that they did not need to answer certain questions if they did not want to and they could stop the interview at any time. They were also told that they could withdraw from the research at any time without giving a reason. Accordingly, there was no harm to the participants as they appeared enthusiastic and pleased that someone wanted to listen to them and learn about their lives. Furthermore, as mentioned earlier, all of the participants were given an information sheet and a consent form, and all of the forms were signed.

The trustworthiness of the research

Decrop (2004) stated that trustworthiness in qualitative research is vital in reassuring others that the research is valid, credible and transferable. Similarly, trustworthiness is connected to the process of adopting specific strategies which can increase the validity and reliability of the research (Holloway and Brown 2012; Jones et al. 2013).

To demonstrate trustworthiness within this research, there were a number of strategies which were adopted. First, was the process of being reflexive because this helped me to think upon the reasons to why the participants said particular things (Holloway and Brown 2012; Johnson 2009, 2014). My own experiences of disability helped me to contextualise my findings into an in-depth discussion, through imagining what everything meant (the participants' accounts and the literature) and thinking how all of this could be expressed within a written format. Consequently, reflexivity helped to increase the trustworthiness of the findings through encouraging me to think deeply about the data and what the data was representing.

Second, the use of thick description throughout the discussion chapters was also important. Thick description is about describing the details and context of each of the participants' accounts fully, so that the reader has a sense of why particular things were said and how they related to the research question (Holloway and Brown 2012). Therefore, thick description helped me

to illustrate the context of the participants' stories, giving the reader further information about the context of their different explanations and how particular parts of the participants' explanations related to particular parts of the discussion.

The final strategy was not to be solely reliant upon particular books, articles and journal publications, especially when there was a real need to look at the participants' accounts in a subjective light. This meant not just looking at well-known academic publications such as *Leisure Studies*, *Leisure Sciences* and *Disability and Society*, but also less well-known ones such as *Therapeutic Recreation Journal*.

The transferability of the research

The aspect of transferability helps research to be valid and interpreted positively by others (Bryman and Bell 2011). This is because if other researchers have the confidence to transfer different ideas and concepts from the study into one of their pieces of research, this demonstrates that the study has some value and is perceived as transferable (Denzin and Lincoln 2011; Jones et al. 2013).

It can be deemed that the findings of this research are transferable because, while each finding was interpreted and discussed in relation to the literature, each finding contributed towards the overall understanding of disabled individuals' social worlds and leisure experiences. Based on the nature of the findings, the overall discussion was therefore, at times, sociologically orientated, whereas at other times it was socio-psychologically orientated, health orientated and management orientated. Hence, while this research was contextualised to the experiences of the participants, the discussion also critically discussed the realities of disability and different medical conditions, as well as leisure and the leisure choices, behaviours and experiences of individuals with a disability. Therefore, different parts of the overall discussion can be transferred into different contexts. This is due to how parts

of the critical analysis of disabled individuals' social worlds and leisure experiences could be used understand similar phenomena which have a connection with the participants' social worlds and leisure experiences. For example, the coping experiences of people battling cancer, the importance of adapted physical education or the relationship between leisure and youth development. Additionally, it can be argued that ideas and concepts present within a piece of research are sometimes more valuable to scholarship than the subject matter itself. This is because some academics have illustrated that sometimes what is needed in academic scholarship is not the title or a breadth of a subject field, but the critical analysis and enhancement of ideas which can improve the understanding of a phenomenon and/or can benefit society (Jamal and Kim 2005; Mair and Reid 2007; Ren et al. 2010; Roberts 2011).

Limitations of the research

When reflecting back on the research, it can be identified that there are some limitations with the research. Despite the reasons for only interviewing individuals with certain types of disabilities, if there were more individuals with a wider range of disabilities, there could have been more scope to understand the reality of having a disability and how different medical conditions can affect people's lives.

The time and the word limit set for a Masters by Research thesis were also factors, as these limited the amount of primary research which could of been done. If the time and word count were much greater, there could been a possibility to develop and enhance the data by doing an initial thematic analysis of the interviews and then either doing some follow up interviews on the participants to understand more or specific parts about their lives, or to conduct some quantitative research in order to understand about whether specific things found within the interviews occurred in other disabled individuals' realities. Additionally, there were disadvantages in adopting a qualitative methodology and in the adoption of online interviews via webcam.

The weakness of adopting a qualitative methodology was that the research was dependent upon my own interpretations of the data and on the subjectivity of the participants' own accounts (Bryman and Bell 2011). Such weaknesses would make the research difficult to replicate and that there would also be a risk of generalising the participants' accounts in order to explain how the overall research made a contribution to knowledge (Bryman and Bell 2011). Although, with the issue of replication, academics have noted that whilst qualitative research can never be precisely replicated, researchers can imitate a similar type of study with a similar type of qualitative methodology (Bryman and Bell 2011; Holloway and Wheeler 2010). Equally, academics can avoid the issue of generalisation by firstly describing their data fully, to spell out the context of their findings, and secondly critically reflecting and evaluating what the data is trying to represent as well as whether it adds to or criticises current knowledge (Holloway and Wheeler 2010; Sparkes and Smith 2014). Consequently though, it was judged that a qualitative approach was the best, as it would allow me to go beyond the participants' answers and critically examine the underlying components of their feelings and behaviours.

The disadvantage of online interviews is that it affects the rapport between the researcher and the participant, meaning that the researcher has less of an ability to understand and identify the participant's body language (Janghorban et al. 2014; Jones et al. 2013). Consequently, this limits the potential data being gathered, as body language can give the researcher a true understanding of what the participant is feeling as they talk about a situation (Jones et al. 2013). Similarly, from not being in close proximity, a weaker rapport between the participant and the researcher can occur as the participant feels more distant from the researcher (Jones et al. 2013). However, the advantage of online interviewing is that it can overcome the issue of time and space, and as a result, can provide flexibility in conducting an interview at a time and place which is convenient to the participant and the researcher (Janghorban et al. 2014; Jones et al. 2013). Therefore, in order to avoid the issue of struggling to find an interview time and place

which was convenient to each participant, me and my support worker, online interviews were adopted as an option.

Summary

The main point of this chapter was to explain and explore the research philosophy, methodology and methods adopted in this research. The chapter aimed to explain the assumptions behind the qualitative methodology and to describe the approach taken when selecting and interviewing the participants, as well as the process of analysing and interpreting the data. The chapter also stated the trustworthiness, transferability and limitations of the data.

As qualitative research is about understanding, observing and acknowledging different behaviours, options, lives and cultures (Denzin and Lincoln 2011; Flick 2014; Holloway 2011; Jones et al. 2013), the qualitative research approach was adopted to enable this research to give justice to, and recognition of, physically disabled individuals' social worlds and leisure experiences. By using qualitative research, there was a real opportunity to listen to the participants and to understand more about their lives. Overall, as Table 3.2 shows (p 48), from analysing and interpreting the interviews, there were several different aspects found which could be themed into two major discussion chapters: *Chapter 4 - Living and experiencing a disability* and *Chapter 5 - The leisure experience*.

Chapter number	Chapter Title	Sub-themes
4	<i>Living and experiencing a disability</i>	<i>Being disabled</i>
		<i>The individual behind the disability</i>
5	<i>The leisure experience</i>	<i>Making leisure choices</i>
		<i>The benefits of leisure</i>
		<i>Access within the leisure experience</i>

Table 3.2 – Discussion chapters and sub-themes

CHAPTER FOUR - LIVING AND EXPERIENCING A DISABILITY

Introduction

The aim of the research was to understand physically disabled individuals' social worlds and leisure experiences. Accordingly, whereas the participants talked about their leisure experiences, and this is discussed in the next chapter (*Chapter 5 - The leisure experience*), the participants also shared stories about what it is like to live with a disability. The participants' descriptions all detailed different ways in which their disabilities had affected them. However, they also illustrated aspects about themselves as individuals and the phenomenon of living with a disability, which highlighted a distinction between their conditions and them as people. This chapter will therefore critically assess the experience of having and living with a disability. Two major themes were found, *being disabled* and *the individual behind the disability* (as Figure 4.1 shows on the next page (p 50)). Thus the chapter will firstly discuss the participants' disabilities and will secondly explore their experiences of living with a disability, through exploring the individual behind the disability, the participants' experiences of managing their disabilities and the importance of staying resilient.

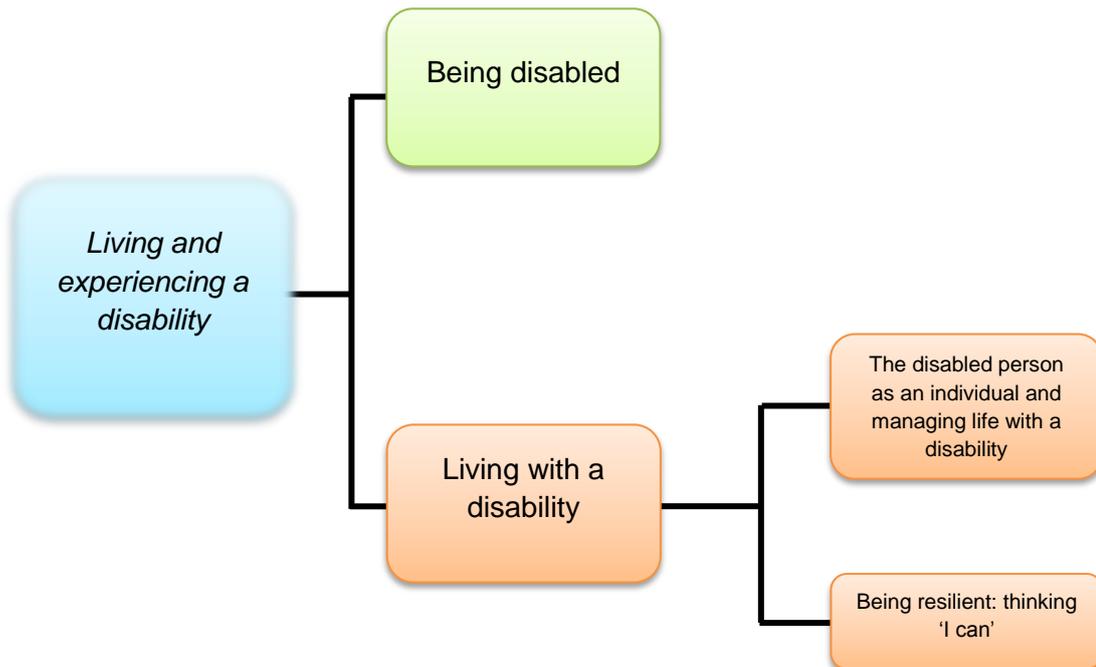


Figure 4.1 - Discussion chapter one themes and sub-themes

Being disabled

The aim of this chapter is to critically assess the experience of having and living with a disability. However, the origins of this experience is the individual's medical condition(s) or injury(ies), and how the medical condition(s)/injury(ies) have impacted upon the individual's everyday life and functional abilities (Foose and Ardovino 2008; Kelly 2011; Long and Robertson 2008; Porretta 2005a, 2005b; Sparkes and Smith 2008; Smith and Sparkes 2008; Stumbo et al. 2015; Winnick and Lavay 2005). When the participants were asked about what type of medical conditions they had and how their conditions affected their everyday lives, it could be seen that all of their conditions were different and affected them in different ways. This resulted in them having different abilities, needs and requirements, sometimes resulting in the need for different pieces of equipment and/or support packages. Therefore, the basis of this section is to provide an introduction into the participants' social worlds and what types of disabilities

each of them have. Additionally, the section will then assess how the participants' descriptions of their disabilities affected the understanding of disability.

When asked about their individual disabilities, all of the participants addressed this question with detailed answers, painting a full picture of how their conditions have affected their abilities and the consequences this had on their everyday lives. In turn, this illustrated that disabilities and conditions are diverse, affecting individuals in different ways. However, as it was clear that all of the participants had different medical conditions that affected them in different ways, it explained that by each of their conditions affecting different parts of their bodies, their conditions had altered and/or damaged different aspects of their overall function.

In her interview, Katie explained that:

"I have a severe visual impairment, so I am registered blind, and...I also have a joint condition which affects all my joints"

Katie also said that in terms of her visual impairment, she was:

"...born blind, surgery gave me good partial sight but then I lost more vision age 21"

In terms of her joint condition, it was:

"...only properly diagnosed November last year [November 2015]. This is getting worse in fact. I'm currently in the process of being assessed for a power chair... I'm actually quite excited as I broke my foot a few weeks ago - not being strong enough to use crutches is a bitch lol"

Jessica also described that she has:

"Ehlers-Danlos syndrome, so EDS...It's a connective tissue disorder, so it affects the way the proteins and things work"

Ehler-Danlos is a disorder affecting how the individual's human tissues develop, directly impacting the development of his/her skin and muscles (Ehlers-Danlos Support UK, 2014; The Ehlers-Danlos National Foundation,

2015). Jessica said the disorder affects how the proteins work in her body and this inhibits “...my muscles...and tendons, and that type of thing...”.

Bart indicated that his disability is progressive as he has:

“...Duchenne Muscular Dystrophy. So, basically, it’s a muscle wasting condition, a progressive one ...”

Porretta (2005a, 2011) has explained that people with Duchenne will become more dependent over time as the condition weakens their muscle strength and affects their ability to do everyday tasks such as walking, transferring and breathing (if the condition has affected their respiratory system). Additionally, Bart said about how people with his condition:

“...OK, the age sometimes differs - but when they are a bit older [they] have to use a ventilator system...”

However, in reference to whether he needs to use a ventilator at the moment, Bart said “...luckily, I don’t have to yet, but I probably will do in the future...”.

Lisa’s and John’s conditions also affect them in different ways. Lisa said:

“I have got incomplete spastic paraplegia, in my legs. So that means they are really, really...stiff...”

Incomplete Spastic Paraplegia is a form of spinal cord injury where the spine has been damaged (Spinal Injury Network 2015b, 2015c). John said that:

“I have a head injury, chest injury, shoulder injury, spinal injuries, hip injuries, left knee injury, left elbow injury and a right appendectomy, all caused by a road traffic accident in 1991...”

Skeletal damage affects the movement of the bones and joints, affecting what movements the individual can do (Kenney et al. 2012; Long and Robertson 2008), whereas nerve damage can lead to specific functions (such as feeling things, managing emotions and speaking) being altered or prevented from happening (Porretta 2005b; Spencer-Cavaliere et al. 2014; Winnick and Lavay 2005).

In addition to their descriptions, when looking at what affect the participants’ conditions had on their abilities and everyday lives, it was noticeable that the

effects of their conditions were diverse. For example, John explained that from being able to walk and run, he now has to:

“...use my arms! So, I have adapted from being physically able to being, if you like, physically ‘disabled’...”

Jessica said that with her condition, *“It means I am only in a chair and I am a hoist transfer”*, illustrating that her condition had affected her body’s ability to bear weight in a standing position. Bart said that his condition means that:

“...I can’t weight bare or transfer independently...it affects me in my day to day life with physical activities...and means that I am confined to a wheelchair...”

Due to the reduction of his muscle strength, Bart’s condition has influenced the way in which he experiences the world because it limits his ability to move unaided. Katie also described that *“...I have a guide dog...”* which illustrated that with her severe visual impairment, she needs help with spatial awareness. In addition, Katie said:

“...sometimes I have to use crutches...sometimes I have to walk with a stick...sometimes I can’t do steps...but other times I can”

This highlights that her joint condition impairs her ability to move around, but that any movement she does have depends on how she feels in her joints. Finally, Lisa explained:

“...I don’t walk too well and I need...well I don’t walk at all, so I rely on a wheelchair to get about, out and about...”

Therefore, the stiffness in her legs makes the walking motion hard for her to do.

Overall, what can be seen is that the participants’ conditions are diverse meaning that their needs and capabilities are diverse as well. But, what this reveals is that each of their conditions have altered (and sometimes, continue to alter) their body structures (such as their muscles, bones and nerve systems). This has meant that some of the functional parts of their bodies (such as the joints) have been affected, resulting in differing levels in their abilities. From an ethical perspective, Pegg and Darcy (2007) explained that when understanding a disabled individual, solely looking at the individual’s medical condition(s) will risk overlooking the individual, as the

focus will then be on their condition(s) rather than on them as a person and on their whole social world. Additionally, Fullagar and Darcy (2004) have indicated that any sole focus on individuals' impairments, and on how people are 'unable' to do things, dehumanises the individual as there is an immediate assumption that they are 'incapable', without actually recognising what they could possibly do. Whilst it is right that disabled individuals (such as the participants) should be seen as individuals and are not objectified, it is also seen that the participants' conditions do influence their needs and requirements greatly. Hence, when understanding their social worlds, their impairments and the effects of their impairments, their impairments cannot be ignored due to how they influence the participants' everyday lives. This agrees with Thomas' (2007, p 136) proposal of the "...*impairment effect*" where she stated that someone's impairment restricts and causes difficulty to their everyday life. Yet, when looking at the finer details of the participants' conditions, it also highlights more about their world.

Apart from Jessica, who did not want to reveal whether her condition was progressive, congenital or acquired, it can be said that Bart's condition is progressive (it get worst over time) whereas John's and Lisa's were acquired conditions. Furthermore, Katie's conditions are mixed as her visual impairment is congenital (she was born with it), her joint conditions are acquired and that both of her conditions have become worse over time. In addition to their conditions uniquely influencing the nature of their social worlds and functional abilities, the basis whether of their conditions are congenital, acquired and/or progressive, also affects the participants' worlds. This is because it is not just the implications of their conditions which have shaped their lives, but also how and why their impairments have occurred. For example, whilst both Bart and Lisa require wheelchairs, Lisa's spinal injury has caused the nerves to limit her from effectively doing a walking motion. But, because Bart's condition decreases the strength in his muscles over time, Bart's condition has affected his walking motion differently. Therefore, it can be argued that whilst different conditions affect a person's body structure in different ways (Hughes and Paterson 1997), the

participants' abilities are further affected by how their conditions have developed.

As noted in the literature review, there are multiple ways of understanding disability through using different models. However, from acknowledging the diversity of the participants' conditions, different models seem to simplify, take different 'political' or 'academic' sides, and provide limited means of understanding the realities of people's lives. Furthermore, because of the complexities within the participants' conditions, it seems that in order to appreciate the participants' worlds fully, there has to be an appreciation of how their conditions have uniquely affected their worlds and the reasons to why this is. But, as demonstrated within the next section, while it is important to note the participants' conditions and their effects, it is also important to identify that they still are individuals with personalities and feelings. This 'personal' and 'subjective' aspect of their worlds highlights that the concept of having and living with a disability is not just about the individual, physiological, aspects and effects of a condition. It is also about the individual, the individual with a personality and the individual who have desires in life.

Living with a disability

Whilst the participants were explaining their conditions, each of their accounts also told a story of who each of them were as individuals. The participants all had opinions, interpretations and experiences which were unique to them. In addition to this, the participants' stories also highlighted their need to experience and manage life with their conditions. Therefore, this section explores the participants' explanations of experiencing life with a disability. The section is broken down into two subsections. The first subsection will explore the concept of the individual behind the disability and the participants' experiences of managing and coping with a disability. The second subsection will then explore the importance of being resilient when living with a disability

The disabled person as an individual and managing life with a disability

When listening to the participants, it was easy to see that despite their disabilities and the effect of their medical conditions, they were still individuals and that they had their own personalities and characteristics. However, what was also notable was that living with a disability can be challenging, which could impact on the individual's positive feelings about life.

In his interview, John shared aspects of what he had done in his life and what he is currently doing, rather than just talking about his disability. He started:

"...when I was able bodied, I was an athlete and ran for England Schools as a kid, and I ran for the Royal Navy"

As we sat round his kitchen table, it felt like he wanted to tell 'his' story and inform me that his life is not just about his disability. John then continued:

"I ran twice for Portsmouth field gun crew which, unless you are of that era...[it was] the Royal Tournament [that] took part at Earl's Court in front of the Queen...and it was three commands, Portsmouth, Devonport and Fleet Air Arms...and you had to dismantle a gun, push it through holes, over walls, over chasms etc, so I was one of the top 300 fittest guys in the Royal Navy at the time. I have tried to keep that going, or try to!"

It was clear that John was proud of his life and that these memories were deeply meaningful to him, as these were parts of his life story. These stories provided a historical narrative of where John has been, featuring the aspect of serving his country and trying to be the best that he could be. Therefore, they provide memories of the earlier parts of his life in which he treasures. But, it was also clear that John told these stories as they drew a picture of 'him' and not of his 'disability'. Accordingly, his descriptions illustrated that his life story was/is not always about the 'road traffic accident'. By John saying "*I have tried to keep that going, or try to!*", it illustrated that he still has that motivation inside him to be like his old self, trying not to let his disability to prevent him from doing what he wants in life. Consequently, what this overall described was that even though John has a physical condition that impacts

on his functional abilities, John is still a person with feelings, which helps him to be motivated and achieve that feeling of being like his old self again.

Sparkes and Smith (2003) have explained that the different personal stories which a person tells, describe an overall picture of who people are underneath their condition(s). This is because stories of different times which an individual has been through, and the different decisions that they have made, tells an overall story of what the individual has experienced/done within his/her life, experiences/tasks which were not all about (or connected to) his/her disability (Sparkes and Smith, 2003). Consequently, with the personal aspect of a disabled individual, it can be argued that 'being disabled' is a construct of 'me and my disability' or that there is a body of the disability and a body of the self (Smith and Sparkes 2002), whereby the individual's self is still present and allows the individual to feel, think and sense (Fullagar and Owler 1998). This therefore describes that the individual is still an individual but that the individual also has a set of impairments (Fullagar and Owler 1998; Henderson et al. 1995; Sparkes 1996; Winn and Hay 2009). It also highlights that the stories a disabled person tells can act as reminders that they are still an individual, where his/her personal stories broaden out his/her overall life story from that of just having a medical condition(s) (Brock and Kleiber 1994; Sparkes and Smith 2003).

While conditions affect the human body, academics have suggested that disabled individuals' abilities to feel and experience different aspects of life is not gone (Henderson et al. 1995; Kleiber et al. 1995, 2008), as they still have the ability to experience and enjoy life (Brock and Kleiber 1994; Singleton and Darcy 2013; Smith and Sparkes 2002). The emotions and desires to do different things and to experience certain aspects of life can be seen as powerful forces within a disabled individual's life, as they help to influence the characteristics and identity of a person, what they want in life and how they want to feel as a person (Henderson et al. 1994; Hutchinson et al. 2003). Accordingly, as a sporty person, Lisa was very clear in expressing her 'self' and that, despite her paraplegia, she just wanted to live life, be with her

partner, and not believe that her life was ruined just because she has a disability. Lisa said:

“...when we went to Bath last Sunday...well we didn't go actually into Bath, we went to the sports venue because I was getting my classification [as a wheelchair racing athlete]...But that was good because we were interacting with other people, of all ages and different disabilities and it's always good to meet new people and people that I have met before; [lady's name] was there, the discus thrower, and I met up with a new lady called [lady's name]; I made Facebook friends with her. She is about in my age group as well so it was interesting to meet her. And then I met a couple of lads; they were nice young fellows; I got to know them as well...wheelchair racers. It's good fun to meet all the new people”

As Lisa described her enjoyment of meeting other people, her account gives a picture of a person who has emotions and also a person who has a personality and a joy of being sociable. Additionally, in reference to the divides between the body of the self and the body of the disability (as mentioned earlier in this subsection), it can be seen that through Lisa enjoying specific things, she has specific personal characteristics (sporty, the desire to active and to be sociable) that defines who she is as a person. Furthermore, Lisa's personality and specific characteristics (such as her openness to making friends) contribute to her identity, as her personality and characteristics influence Lisa's outlook and attitude in life. Therefore, it is clear that Lisa's personality, and her need to make personal choices, are still there despite her acquiring a disability, and that these drive her forwards in living life and becoming more than just someone who has a disability.

One of Katie's accounts also showed that she feels different things despite her conditions, and that she can see an enjoyable and fun aspect to life. Through describing a sense of adventure from being in London at night, Katie gives the insight that her 'self' is independent from the body of her disability. Katie said:

“...I think it is good to have, like, a sense of adventure. So, just a couple of months ago [I went on a] big train up to Central London, in the dark, and I lived...it was quite funny”

Katie's positive emotions of feeling happy and a sense of adventure reinforces that she is a person.

People's characteristics, desires and wants, help to formulate people's unique identities (Henderson et al. 1994; Kleiber et al. 2011). Kleiber et al. (2011) stated that identities can be formulated by a person and by the different social groups that he/she are connected to. Similarly, when looking at John's, Katie's and Lisa's explanations about their experiences, it is clear that each of their personalities and identities help them to drive forward and to do particular things in their lives according to what they desire. Their abilities to be individuals and to be who they want to be mean something to them. Henderson et al. (1994) suggested that for an individual with a disability, an identity becomes really powerful and precious as it provides a sense of self and meaning; a sense that they are more than his/her impairments. This is because identities can help to harness that sense of self as it comes from the individual being able to identify themselves with something or by a certain character that they have (such as being fun loving) (Kleiber et al. 1995, 2011). However, what can also be seen was that John, Katie and Lisa revealed specific characteristics of what they are like as people, specific identities which they have that separates them from each other, something of which Oliver and Barnes (2012) explained as being important when understanding disability and disabled individuals.

Despite their descriptions of themselves as individuals, the participants also shared their experiences of managing and coping with their disabilities. Their explanations detailed that trying to manage different issues can be challenging as the individual has to find ways and solutions around problems. In her interview, Katie talked about a situation where she faced emotional pain from a group that was threatening her:

"...I don't know how to word this properly...but I was waiting for the [Town A] ferry back over to [Town A] and a man walks into the back of my guide dog, and I told him to be careful. I pointed out that she was a guide dog and...him and his mates, who were drunk...then turned on me and started having a go at me and calling me everything under the sun and saying that they will beat me up. And, although there were people around, I was really happy to see that there were a couple of

other men there that must have stood up to these guys and everything...the people on the ferry were really helpful and one of the workers on the ferry sat with me for the entire journey, and like he was...'I wait with you until everybody else got off', and I got off myself, and he said 'if they are still up there, just come back and we'll call the police'...Everyone was really supportive with it...[however]...things like that happening, it has knocked my confidence a bit. ...I don't really want to go out in [Town B] in the evening, when it's dark - and it gets dark quite early, so...I'm just not doing it...I don't go to [Town B] in the dark very often so it's not a big problem. But it's certainly something I don't wanna do on my own. ...I should be able to go out and do things on my own without having any problem...[but] it is not all about being confident and being independent...when I'm in a place where I don't feel confident, so I don't know it as well perhaps, something like that, I get very nervous and stressed”

In telling this story, Katie explained that trying to protect herself and her guide dog was hard because the group of men did not care about standing on her guide dog and just wanted to evoke a reaction out of her by trying to frighten her physically and verbally. The incident caused Katie to feel overpowered and overwhelmed, which challenged Katie as a person. The situation of feeling overpowered, led Katie to feel vulnerable. It is also clear that trying to manage her disability and then being threatened hurt Katie. As a result, the experience lowered Katie's self-esteem through making her feel less confident in herself, which has then affected her overall confidence in going out in Town B at night again. Academically, this reflects that when people abuse and attack others based upon a difference, the individual's emotions become fragile and turn negative (Kavanagh 2014; Kleiber et al. 2002; Sparkes 1996), which can in return affect the individual negatively and lead them to think negatively about life afterwards (Smith and Sparkes 2008).

One of Jessica's stories also illustrated that she is able to feel negative about herself when experiencing something negative. When she cannot access a building, she would feel:

“...to be honest, not terribly happy! If I went to a place and I couldn't access it, it wouldn't make me feel very happy. I would....yep! Not very happy. Any feelings...um...to start with...a tiny bit of embarrassment, yeah! I will feel embarrassed about that! But other than that....I would feel slightly annoyed, but not drastically...but, I wouldn't be happy that I couldn't get in the place”

Even though being unable to access a building would not be Jessica's fault, Jessica described that she would feel embarrassed from not being able to get into the building. This is because she does not want to feel like she is the only one 'unable' to access the building and that she is holding other people back. Yet again, while this was not Jessica's fault, this is just a psychological reaction which, as Sparkes et al. (2014) have explained, appears when the individual wants to do something, but finds in reality that his/her physical body struggles to do what is wanted. This illustrates that Jessica's condition can influence how she feels when placed in a situation of facing barriers or difficulties.

On reflection of both of their accounts, Katie and Jessica have described emotional responses to both situations which shows that disabled individuals can go on an emotional journey when trying to manage themselves and their difficulties. Kleiber et al. (2008) has stated that overcoming different things tests the individual, as they need to go through a process of finding different ways of overcoming specific difficulties, whilst also knowing that they do not have those specific functional abilities to help them to do so. Therefore, this can challenge the individual further emotionally and personally, making things even harder for them (Iwasaki and Schneider 2003; Kleiber et al. 2002, 2008; Smith and Sparkes 2008; Sparkes and Smith 2003, 2008). Additionally, experiencing negativity can psychologically affect the individual by giving them negative sensations about who they are and what they can do (Henderson et al. 1994; Kleiber et al. 2002). The negative feelings which someone can get from a situation can differ but can influence the individual in thinking that they are unable to do a particular thing(s) (Liddiard 2014; Sparkes et al. 2014). This can then affect his/her behaviour and attitudes towards different things or interpretations of who they are as a person (Kleiber et al. 2002, 2011; Smith and Sparkes 2008). Additionally, any negative experience can block out some of the individual's more positive experiences, because negative sensations can make the overall body feel negative and weak (Brock and Kleiber 1994; Smith and Sparkes 2008; Sparkes 1996). Hence, the individual can feel negative and 'unable' (Henderson et al. 1994; Kleiber et al. 1995). However, as mentioned earlier,

this is just a self-reflection of the experience and a reaction to the negative situation experienced (Kleiber et al. 2002, 2011; Sparkes et al. 2014). But, the aspect of trying to cope with a challenge is still there as the individual still has to live with (or 'cope') with the experience of overcoming a challenge and this should not be ignored (Loy et al. 2003).

The aspect of coping with issues was seen with Lisa as well, as she explained the frustrations in getting around a city:

"...getting to things is a bit of a struggle, especially trying to get across London...on public transport - you can't use the Underground, so I rely on taxis"

In this, Lisa highlighted that it is frustrating when she wants to do something but then finds it hard to do so. Lisa then continued:

"If you're a stranger in London, which we are [i.e. her and her partner], going about on a bus is a totally frightening experience, so we have to pay a fortune to use taxis to get across London...I am lucky enough to have a nice motability car, with hand controls, so that's an absolute bonus having that, so I can get around a bit better. ...I went for a year without a car and it was a bit of a nightmare getting around"

It is clear from this that experiencing the implications of her spinal injury has been hard for Lisa. For her, getting used to her acquired disability was an emotional journey. Her impairments forced Lisa to 'cope' with something that she had not created (such as the difficulties in travelling around London). As an individual, she has had to battle through her emotions to overcome the issue. Iwasaki and Schneider (2003) state that coping is a process of managing stress or difficult issues, through the use of different services (such as support groups) or different activities (such as leisure activities), in order to combat the negative implications of stress or difficult issues. In addition, Iwasaki and Schneider (2003) have explained that stress and difficult issues occur from a variety of situations which can either be classed as being connected to a life event, a traumatic situation, a negative life strain situation or any other situational difficulty (Table 4.1 (p 63)) shows examples from each category). As a whole, the experience of coping can be hard due to the individual needing to 'battle on' and experience the difficulties of challenges in order to try and overcome them (Hutchinson et al. 2003;

Iwasaki and Mannell 2000). However, the experience of stress and difficult issues can weigh down an individual's emotions and negatively affect the individual's well-being (Hutchinson et al. 2003; Iwasaki and Mannell 2000). This, therefore, reinforces that there is a difference between the individual's own self and his/her condition/impairment.

Classifications of different types of stress and difficult issues	<i>A life event situation</i>	<i>Traumatic situation</i>	<i>A negative life strain situation</i>	<i>Any other situational difficulty</i>
What is it?	A life event situation is where the individual experiences a major event within his/her life	A traumatic situation is where the individual experiences an unpleasant situation	A negative life strain is where the individual experiences a large amount of pressure from any area of life	Any other situational difficulty which the individual experiences in life
Examples	<ul style="list-style-type: none"> • Moving house • Splitting from partner • Getting married • Getting first job 	<ul style="list-style-type: none"> • Developing ill health • Experiencing a family death • Experiencing sexual abuse • Experiencing an accident 	<ul style="list-style-type: none"> • A demanding job • Managing a medical condition(s) • Caring for a family member • Disagreeing with family 	<ul style="list-style-type: none"> • Being homeless • Being bullied • Getting un-employed

(Based on ideas by Iwasaki and Schneider 2003)

Table 4.1 - Examples of situations which cause stress and difficulty

Overall, experiencing a disability can be argued as the individual's embodiment of different impairments, where the individual needs to experience and manage the effects of his/her conditions (Cook and Shinew 2014; Henderson et al. 1995; Loy et al. 2003; Smith and Sparkes 2002). However, this does not mean that the individual cannot self-manage parts or all aspects of his/her life as he/she can learn and develop different strategies, or use equipment, that helps them in managing different situations (Kleiber et al. 2008; Long 2008; Robertson and Long 2008; Smith 2013). Accordingly, Jessica illustrated that self-managing and being aware of different strategies on how to manage different situations, can become the

norm once the individual understands how to manage different situations. She illustrated this by saying:

“...when I go out with friends, I kind of do need to worry about accessibility because sometimes they completely forget there are steps somewhere, and I need to be aware of that kind of thing. ...there can be easy problems like curbs...”

This shows that whilst Jessica needs to be aware of different environments, and needs deal with different things, the task of managing the situations based upon the effect of someone’s disability can become an everyday occurrence. Smith (2013) explained that as disabled individuals learn about their conditions, individuals start to understand how to stay safe and healthy. However, as noted by Kleiber et al. (2008), the skill of managing one’s own condition still requires time and energy. Furthermore, based on how a condition has affected the individual, some individuals may find it harder to deal with negative situations than others (such as someone with a severe intellectual impairment which can affect his/her ability to cope with pressurised situations) (Collier and Truman 2008; Dattilo 2012; Garcia-Villamizar and Dattilo 2010). Consequently, trying to manage and cope with a medical condition is doable, but is not that easy as individuals can get frustrated, annoyed and restless (Liddiard 2014; Sparkes 1996; Sparkes et al. 2014). Therefore, as seen in the next subsection, the role of resilience is key in overcoming different issues.

Being resilient: thinking ‘I can’

Resilience is a concept of power, where the individual does not ‘back down’ and has the will to face different challenges and issues in order to get to where they want to be (Caldwell 2005; Eichhorn et al. 2013). The importance of resilience when living with a disability was noted by Bart and John, when they were illustrating that being determined is key for them, as individuals, and for other individuals to carry on with their lives and in preventing their condition(s) from limiting them in doing what they want to do within life. Furthermore, both Bart and John explained that problems and challenges

can be overcome through the individual not giving up and thinking positively about themselves and what can be achieved within his/her life.

John expressed that even though having a disability can be challenging:

“I just think it’s important to not give in! Just because...you’re in a wheelchair, doesn’t mean to say you have to give in...you just continue on...I just see it as a setback you can overcome, if you put your mind to it”

John explained that moving on from the consequence of a condition(s) involves determination, where people need to think about what they can do and be committed in overcoming challenges. Similarly, his explanation highlights that the power, will and determination of disabled individuals can assist them in overcoming issues, through giving them a more positive mindset of not giving up. Furthermore, reflecting on the desire to be in control, and finding something to work towards, helps the individual in staying resilient (Caldwell 2005). Moreover, Kleiber et al. (2011, p 411) added:

“As devastating as the loss of mobility is, finding alternative skills and interests and even recovering one’s old skills appear to have therapeutic effects”

Accordingly, what can be seen from Kleiber’s et al. (2011) statement is that by the individual having something already, or something to work towards, this psychologically helps them.

In relation to being resilient, John spoke of his life since acquiring his disability:

“...I suppose...I could have sat down, in the chair - in the sitting room - feeling sorry for myself and watching telly and watching everybody enjoy themselves and doing things they want to do...and [reflecting on] doing things I used to do, but think ‘oh, I can’t do that anymore’. I have never been that person when I was able bodied, and I am glad that I still have that determination to carry on”

Where, he also described that:

“The first time I came out of the lock down syndrome, I said to my wife, [wife’s name], that I wanted to do something for charity. So, I [took] on a physical challenge in my wheelchair by pushing myself round outside the Emirates stadium to raise money for a charity and it went from there. The only negative thing about being disabled is that I can’t do the everyday things that able bodied people can do, but that

doesn't stop me from having a go. ...I think the motivation I already had when I was able bodied remained within me and I put that to good use because, for the past eight years, I have taken on challenges that people have said to me not even an able bodied person would take on. For instance, I pushed myself 325 miles in my wheelchair from Plymouth to Portsmouth to London for charity. I pushed myself from Portland to London, via Portsmouth, for charity and I pushed myself from Portsmouth to London for charity. I am preparing, at this very moment, to push myself to the top of Gibraltar Rock which is next month, [he named a month and date]. But, otherwise my will to persevere and carry on as best possible is still there, I haven't lost it..."

John's vignette of adjusting to life after the car accident shows that John did not want to be stuck at home but wanted to feel like his old self again. Consequently, this resulted in him reflecting on himself and on his condition, thinking about how his condition had affected his abilities and what he could do to feel like his old independent self again. Therefore, the act of resilience and determination really did help John in getting back to his old self, as his will to stay in there and to feel like his old self again, encouraged John not to give up. However, as John said "*I just think it's important to not give in!*", this also explains that for individuals to feel they are in control, individuals have to stay determined and not to just give up because something may seem difficult. Thus when John highlighted that disabled individuals can do anything when they put their mind to it, he was suggesting that being resilient is not just confined to people who have acquired their disabilities or have experienced trauma, but for anyone experiencing a difficulty or something negative.

Bart also explained that the way in which somebody thinks is key for them to overcome his/her disability and his/her difficulties, by saying:

"...I think some of it is on an unconscious level... it's how they have been brought up, the experiences that they face and things - maybe there are specific reasons why, unconscious reasons that they can't....not can't, but they don't want to experience these things"

This suggests that overcoming a disability is based around the individual moving away from the thought of 'I can't' to 'I can', as individuals have to also reduce their fears of the negative things. Equally, overcoming a disability can be thought as overcoming limitations or an impairment(s) in order for the

individual to do what he/she would like. However, as noted earlier, individuals may be reluctant to do something because they do not want to feel negative as a result of experiencing something negative again. But, Bart explained that individuals have to face their fears and change their thinking about their abilities. Therefore, this suggests that if this is not done, this can limit the individual in doing what they want to do in life and limit themselves from being who they want to be. Equally, Smith and Sparkes (2008) proposed that feeling negative or fearing about the future influences the individual to become increasingly isolated whereby the individual closes themselves off from the world. Similarly, Bart's explanation adds to this importance of not being afraid, as the only way to get through a challenge or an issue is facing it and aiming for what is on the other side.

Bart's and John's explanations play an important role in understanding how the disabled individual can overcome his/her difficulties, explaining that resilience helps individuals to see beyond his/her challenges and encourages them to stay strong in order to get to where they want to be. However, the very fact that being resilient involves the will of the individual suggests that staying resilient can be challenging especially if the individual's confidence and/or thinking has been badly knocked (Brock and Kleiber 1994; Kleiber et al. 2002, 2011). This is because experiencing difficulty is a personal thing (Kleiber et al. 2002; Smith and Sparkes 2005), where there is a responsibility on the individual to be willing to stick with something or to try different things for them to get to the other side (Cook and Shinew 2014; Iwasaki and Mannell 2000; Loy et al. 2003; Kleiber et al. 2008, 2011). Whilst this goes back to Bart's explanation that individuals cannot be afraid, it raises other issues in that the individual's worries about experiencing something negative and that the individual might not have the necessary strength to stay resilient. Therefore, these types of psychological issues should not be ignored when talking about resilience. This is because, as discussed earlier, feelings and thoughts can influence the individual's thinking, confidence and self-esteem (Henderson et al. 1994; Kleiber et al. 1995; Sparkes 1996), meaning that how the individual feels (emotionally and mentally) can influence his/her confidence to be resilient (Smith and Sparkes 2005, 2008).

This is due to how challenges and difficulties damage a person's feelings of being capable, which can then cause a loss of self through the experience interrupting that sense of self and on being able (Kleiber et al. 1995). Therefore, as explained within the next chapter, leisure has been proposed as a very good way of encouraging individuals to think more positively. This is because leisure can help individuals to have control over what they want to do and let them to recreate senses of satisfaction and enjoyment, which can then encourage more positive thinking about what life can be like with a disability (Caldwell 2005; Dattilo 2012, 2015; Kleiber et al. 2002).

Conclusion

The aim of this chapter was to discuss the nature of the participants' disabilities and to examine their experiences of having and living with a disability. It was illustrated that whilst the participants had physical disabilities, there were many dimensions to having and living with a disability. Firstly, was the nature of an individual's condition(s) and what affect his/her condition(s) has on his/her everyday life. This is an important dimension to recognise as the effect of an individual's condition(s) can influence the individual to have certain needs and requirements, some of which influences the need for certain pieces of equipment and support packages. Another dimension which was important was to recognise the fact that the disabled individual is still an individual who has a personality and his/her own personal characteristics. A third dimension was that the disabled individual has his/her own desires and wants in life. However, a fourth dimension was the reality of the individual needing to cope with the experience different challenges and difficulties, in which a fifth dimension was the need for the individual to seek out ways around things. A sixth dimension which appeared was the need for the individual to stay resilient particularly through challenges, which in turn suggested that even though living with a disability can be challenging, this does not mean that the individual need to stop living his/her life and doing what they want to do just because they have a disability. In turn, simply saying that all the participants are 'physically disabled', with different

impairments, underestimates their worlds simply because there is a unique relationship between them, their conditions and their lives. Consequently, their conditions create unique difficulties and the participants have to deal with their disabilities in the best way that they see fit.

Disability is not a standard concept, nor is it just a condition. It is a phenomenon which affects the human body and is experienced by the individual. Therefore, because disabilities can occur at different times in people's lives and affect people in different ways, causing them to have different needs, abilities and difficulties, the very nature of the disability is complex. However, whilst a disability is a medical phenomenon, the person behind it is not.

The participants' explanations also illustrated that there can be challenges that can make life harder for them as challenges and difficulties can test their emotions and inner strength. Therefore, staying resilient and having determination has been proposed as being important in helping the individual to overcome his/her difficulties. But, sadly, this does not always work as this is dependent on the feelings and the confidence of the person, and whether they have had any previous negative experiences which can in turn affect the individual's confidence in trying something due to a reluctance and fear of experiencing something negative again.

Overall, this chapter has demonstrated that there are things that can not only affect our knowledge of disability but also show how serious disability can be as a research and discussion topic. Whilst it is easy to 'objectify' and 'standardise' people's disabilities, it is also hard and wrong to ignore the diversity of different disabilities and that people live and manage with them. Therefore, academia and society have to be able to look at disability dynamically, recognising that there are a number of medical, personal, experiential and psychological features to the social worlds of disabled individuals. Similarly, Aitchison (2009) suggested that disability-related leisure studies need to look at the real life experiences of disabled individuals more. Based on this discussion, it can be argued that there is a real ability to

do this when there is an ability to learn more about the disabled individual, his/her life and where leisure fits into his/her life (Howe 2009; Macbeth 2010; Sylvester 2014, 2015b). But, in order to do this, we have to recognise the different dimensions to disabled individuals' lives rather than just taking different sides of the debate about 'disability models'. Life is dynamic, so research needs to be dynamic too. Consequently, as seen in the next discussion chapter, the dynamics between disability and leisure is much more than just about access and equality, but about gaining a sense of self, empowerment and a therapeutic experience.

CHAPTER FIVE - THE LEISURE EXPERIENCE

Introduction

The main aim of this chapter is to examine the different aspects of the participants' leisure experiences and how their accounts feed a deeper understanding of disabled individuals' leisure choices, behaviours and experiences. As shown within Figure 5.1 (p 72), three major themes were found amongst the interviews: "*Making leisure choices*", "*The benefits of leisure*" and "*Access and inclusion within the leisure experience*". The first section (first theme) examines the participants' leisure choices and looks at how leisure was perceived as a personal aspect of the participants' own time, in which all of the participants decided to do different activities based upon what they thought met their wants and desires at particular times of the day. The second section (second theme) examines the range of benefits which the participants personally gained from participating within leisure and the reasons why they personally gained different benefits from leisure participation. Finally, the third section (third theme) examines the need of access and effective inclusion practices within the overall leisure experience. Additionally, the section will firstly look at the importance of access and inclusion from the participants' perspective, where the section will explore how an access and inclusive environment can be created.

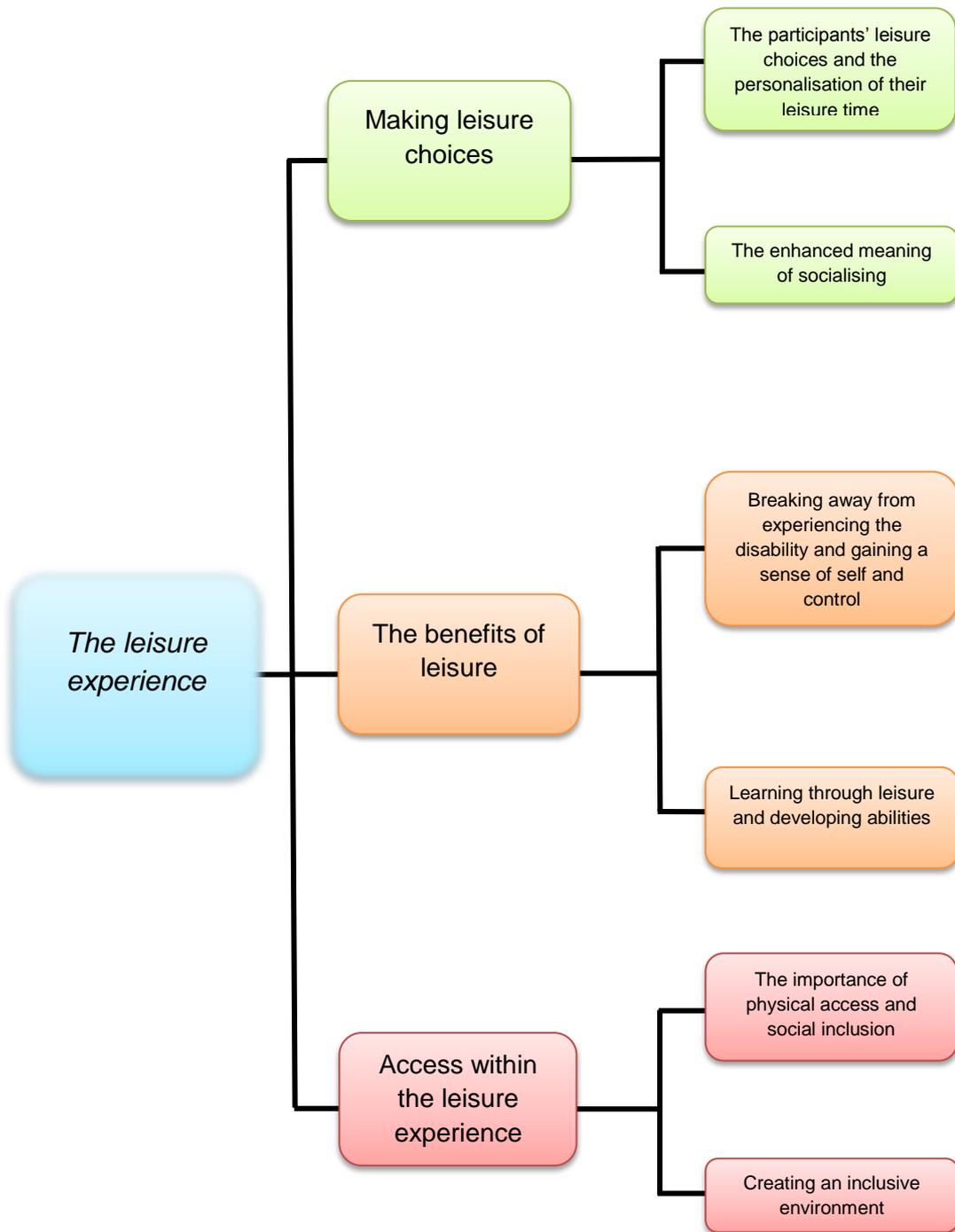


Figure 5.1 - Discussion chapter two themes and sub-themes

Making leisure choices

The foundations to the participants' overall leisure experiences were their leisure choices and behaviours. The participants' leisure choices were (and still are) influenced by their intrinsic needs and desires to do and experience different things at different times, which they perceived as being enjoyable. The participants illustrated that leisure was (and is) not just a period of 'free time', but something which they chose to do. The participants also explained that leisure enabled them to share their time with friends and family, which in turn illustrated that leisure is not just based around the enjoyment of doing an activity, but also around the pleasure of spending time with friends and family. What was seen in the interviews was that the leisure experience differed slightly when the participants experience leisure with their friends and family than when they were experiencing leisure on their own. Therefore, this section aims to discuss the participants' leisure choices. It is divided up into two subsections. The first subsection will assess the diversity of the participants' leisure choices and explore the personal meaning of leisure. The second subsection will explore socialising with friends and family as a chosen leisure activity and how socialising enhances the meaning of the leisure experience for the participants.

The participants' leisure choices and the personalisation of their leisure time

It became evident that the participants' leisure choices were all different and that they all personalised their leisure time according to their tastes as well as what they perceived as 'enjoyable'. The participants' leisure interests were not based around one particular activity (such as athletics) or one particular type of leisure (such as travel), but around a number of different activities, activities which varied from being passive to active. Lisa said:

"...I like to go to the Mountbatten Centre and I do wheelchair racing with a lovely bunch of people and then I like to throw the odd discus and shot putt around and that's good fun... I [also] like to go swimming...cinema is [also] a good one for me and X [name of her partner] - we like to go to the cinema....I [also] like taking my dog out

for a walk. I've got a mobility scooter, which gets me out, which means that I can take the dog out..."

It is clear that Lisa does a number of things which are active (such as athletics) and passive (such as going to the cinema). But, what is also clear is that she uses different spaces and activities in order to craft her own enjoyment. Along the same lines, Katie said:

"I like shopping – a lot! And...I go out to a lot of bars, restaurants and eat out with mates a lot as well. I also play a lot of sports, so I do a lot of train travel because of that... Very occasionally I go to the cinema, but not very often and, yes, I like to go to comedy nights and gigs and things like that"

Thus Katie also does a wide range of activities, utilising different activity spaces, in order to diversify her time and enjoyment of life.

John, Bart and Jessica also said that they liked to do a number of different things. John said:

"I do my training for my fundraising. I am active with the Neighbourhood Watch that we have here [i.e. where he lives]. I go out with my grandchildren and I do a lot of sports photography! I am the first disabled wheelchair photographer to take photos at Wembley for Wembley FA Cup Finals and also England matches"

This explanation shows that John also does a range of activities which require him to perform his leisure time in different ways either through being creative (sports photography), energetic (training for his fundraising), an active member of the community (neighbourhood watch) and sociable (being with grandchildren). Also, his leisure choices require him to experience leisure within different spaces. However, what is seen is that he also experiences leisure through performing them in different ways, which also diversifies the experiences of his own time.

When describing his leisure choices, Bart illustrated that:

"...I like to go to different places in different cities, see different cultural things, [where]...I [get] to see some cultural [things]"

Bart also expressed that *"I like going out with my family as well to do similar things"*. This explains that apart from going to different cities in order to

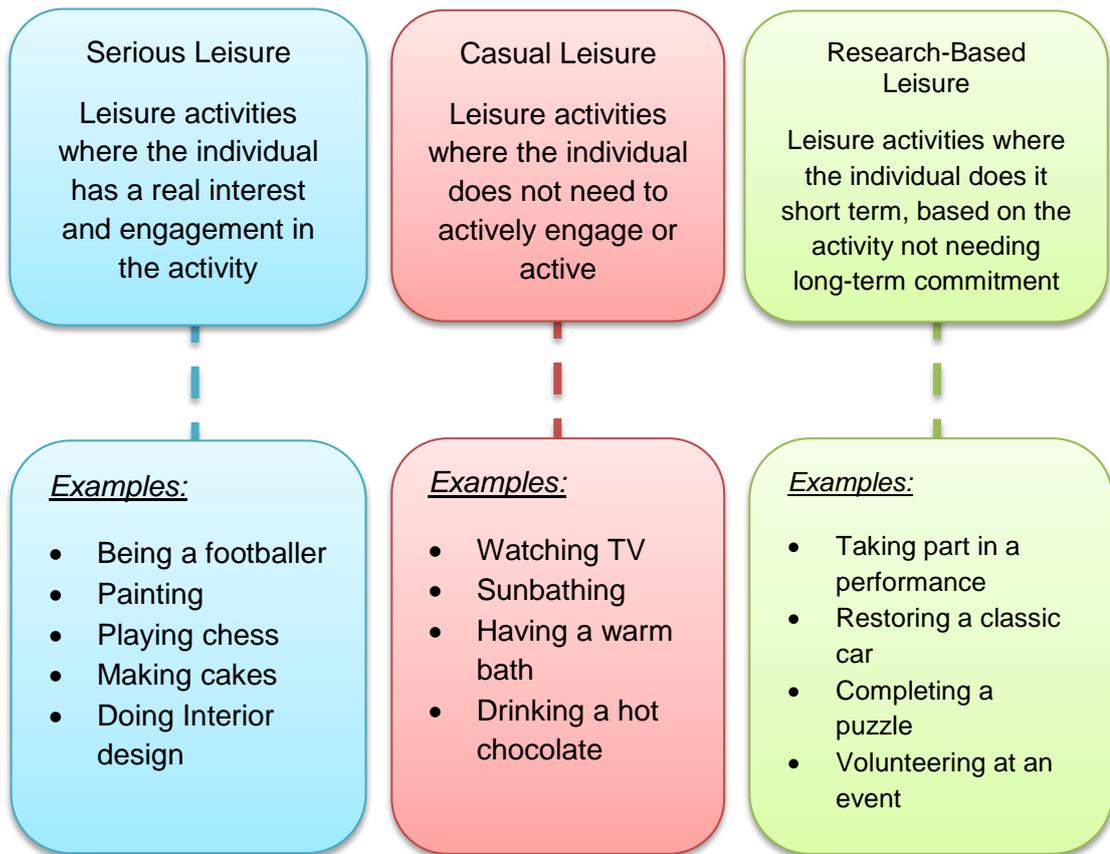
experience their culture and heritage, Bart also likes to spend quality time with his family and friends.

Jessica expressed that:

“I like socializing with friends, getting out from the four walls...you know, getting out of the Uni halls, enjoying and having a bit of fun, that kind of thing”

Apart from where she explained that she likes to go out of her university halls, Jessica communicated that socialising is enjoyable as it lets her be with her friends.

From looking at the participants' descriptions of what they like to do within their leisure time, it is clear that what they do is diverse and that they do a range of activities because they choose to have more than one interest. An interest can be seen as a phenomenon whereby an individual personally likes, enjoys and/or is stimulated by an activity/experience, which then results in his/her interest in an activity (Kleiber et al. 2011; Stebbins 1997). Therefore, in the case of the participants, they use their likes, joys and interests in being stimulated and engaged with different activities, as reasons and motivations to participate in certain activities. Equally, individuals can move geographically across different spaces and use different places, spaces and venues as settings to spend their leisure time within (Hall 2005, 2008; Hall et al. 2014). As Figure 5.2 (p 76) illustrates, Elkington and Stebbins (2014) proposed that different leisure activities can also be classified as being serious, casual or project-based leisure. This is because Elkington and Stebbins (2014) suggested that different types of leisure activities can require different levels of engagement, over different timeframes. This is due to how different leisure activities sometimes require high levels of engagement from individuals (serious leisure), low levels of engagement from individuals (casual leisure) or short-term engagement from individuals (project-based leisure) (Elkington 2011; Elkington and Stebbins 2014; Hutchinson and Kleiber 2005; Stebbins 1997, 1999).



(Ideas and adapted from Elkington and Stebbins, 2014: 4-5, 15-17)

Figure 5.2 – Classifications of leisure

The different levels of engagement can uniquely characterise the individual's leisure time. This is because as different activities require different levels of involvement, different leisure activities diversifies an individual's leisure time through creating different ways of the individual to experience leisure (Elkington 2011; Hutchinson and Kleiber 2005). Although, as Shen and Yarnal (2010) explained, even though different leisure activities require different levels of engagement, leisure is still a personal phenomenon where, in the individual's eyes, each of his/her activities is his/her leisure time. Consequently, when listening to the participants, it was clear that for them to enjoy their leisure time, they needed to be attracted to different activities and perceive them as being something from which they will gain pleasure and fun.

This idea of comfort and being attracted to an activity was regarded as being one of the key parts of choosing a leisure activity in the interviews. For example, Katie said “...if they don't have a good atmosphere, I don't go back”. Also, when asked if a good atmosphere mattered to her, Lisa said:

“Yes it does make a difference cause [if] pubs or restaurants we've been to...[are] yeah...a bit cold, a bit unfriendly and unwelcoming...you just don't go back to those, do you? You just go to the ones that have got good customer service and [where the] staff are really friendly and helpful and that all promotes a good atmosphere, so they are the ones you go back to. Definitely”

Similarly, Jessica commented that:

“If the atmosphere is good and is welcoming, I will feel more settled and I am more likely to feel good and have a good time”

It can be seen then that the feeling of an activity is vital in ensuring a positive leisure experience, as different features of an activity can affect the individual's overall experience of the activity. However, whilst Lisa, Katie and Jessica described how comfort and a positive feel for an activity is an important factor when making their leisure choices, this suggests that leisure can be personalised and that the individual's own feelings, wants and preferences are major parts of their leisure decisions.

From an individual's interpretation of a leisure activity being key in them judging whether or not to do an activity, it can be argued that leisure cannot be placed anywhere (or be anything) unless the individual sees it as leisure (McCabe 2005). Accordingly, Bart explained that leisure is based upon what mood the individual is in:

“If I'm in the mood to just relax I would find a quiet restaurant to go to or a quiet café, where, if I'm in the mood to go out for a night with friends then I would go to a more lively sort of restaurant. So...it depends on (a) what mood you are in and (b) the context of the actual place itself”

Whilst it is not new to understand that intrinsic feelings act as motivations (Middleton et al. 2009; Page 2011), it has to be acknowledged that it is Bart's moods and feelings that pushes him to do certain things, at certain times, in order to feel satisfied. Mannell (2014) highlighted that leisure is based on the individual and what they desire to do. Similarly, making use of ones' own

leisure time is a representation of someone enjoying an activity which is pleasurable and fun for them (Crouch 1999).

The element of creating meaning out of one's leisure time (or 'doing something for oneself') was seen as another primary element of the participants' decision making. Katie explained that engaging in leisure:

"It's about self-worth...So like...being able to go out and do what I want ...within reason...to whatever places that I want to go to. You know, if I need a new pair of shoes, I can go to the shoe shop. And if I need some lunch, I can go for lunch"

This shows that Katie personalises her leisure time and uses it to engage in activities which are going to make her feel happy. Cohen (2014) suggested leisure is a way of feeling like oneself, doing something which takes someone away to an enjoyable, fun, state of mind. Accordingly, Lisa highlighted that leisure is about enjoyment and doing something which she wants to do, and illustrated this from her experiences of a recent cruise:

"...it is different, isn't it, especially if it's somewhere where I wanted to go, like last year on that cruise [a Mediterranean cruise], we went to lots of different places where we had never been before. That was exciting and new, yeah. Brilliant and warm!"

Brown (2013) has suggested that within life, individuals search for something real and authentic in their lives, whereby individuals have the desire to experience something more than just living. From this research, it can be seen that the participants pursue certain activities in order to enjoy themselves and to enjoy their time. They, like other people, create their own senses of personal enjoyment in their leisure time (Brown 2013; Elkington 2011; Kleiber 2001), in order to experience a sense of self, purpose and identity (Fullagar et al. 2012; Hibbert et al. 2013; Hom Cary 2004). Consequently, the relationship between the individual, his/her needs and his/her leisure time can be seen as a lived experiential 'bubble', whereby the individual is experiencing something which satisfies his/her wants and needs (Crouch 1999; Hom Cary 2004; McCabe 2005). But, in the interviews, the

participants also identified that socialising can make leisure feel more vibrant.

The enhanced meaning of socialising within leisure

During the interviews the participants highlighted that they liked socialising with their friends and family because it allows them to share their enjoyment of leisure and, more importantly, build and maintain bonds with them. Bart, for example, described his enjoyment of spending time with his friends:

“In terms of hobbies and so on I like socializing with friends now and again to take my mind off studying and things like that, often to the cinema or something like that, with friends locally... and to go out for a meal and things like that”

Some of Bart’s leisure time was crafted around him and his friends, and he uses different leisure spaces in order to experience and maintain those relationships. However, what is significant to all of this is that the participants’ leisure experiences seem more dynamic and emotional than if the participants were to experience an activity alone.

When the participants can sense others being with them, they sense personal bonds and enjoyable exchanges between themselves and their family and friends. Hence, they feel like they mattered to people. Lisa, for example, explained:

“It’s good to have people around you that you’re friends [with] and knowing that you’ve got common interests...and support...”

Lisa showed that spending time with friends and family can rekindle a sense that the individual is not alone in the world and that bonds between people can be celebrated, through the enjoyment of an activity. Similarly, academics have noted that family and friends leisure can be a significant part of an individual’s everyday life. This is because friends and family have special relationships with the individual, relationships of care meaning that spending time with them allows the individual to enjoy his/her personal connections, bonds and relationships with his/her family and friends within a pleasurable environment (Gibson et al, 2012; Glover and Parry 2008; McCabe 2015;

Obrador 2012). Lisa also added that “...*spending time with friends, it gets you relaxed*”, which also illustrates that family and friendship bonds can make the individual feel more comfortable in his/her leisure time, as they can sense that someone is there for them. This is because, as individuals can have closer connections with family members or friends, experiencing family and friendship bonds within one’s leisure time can provide the individual with a feeling of being connected with someone (Glover and Parry 2008; McCabe 2015). Therefore, when the participants were describing their experiences, it was clear that being with family and/or friends provided a sense of company to the participants.

When exploring the concept of socialising, and in response to a question about what she would prefer (going out with friends or going out on her own), Jessica said:

“Which one would I choose...I think it would depend on the friend. If I was going out with a friend who knew me, I would know they would choose accessible places - that would be okay! But if it was someone I didn’t know very well then I would choose to go somewhere I could choose on my own. I think personally, I would rather go with somebody else and not choosing. ...Because going with somebody is always company”

It is clear that Jessica interprets socialising as an important component in the leisure experience as it enables her to feel a sense of company rather than a sense that she is on her own. The aspect of having company within the experience allows Jessica to feel like she can share her time with a friend and make her leisure experience more enjoyable. Having company within a leisure space can characterise the leisure experience as the interactions between people can help the individual to get a sense that the leisure experience is not a singular moment of them just experiencing the leisure activity on his/her own (Berdychevsky et al. 2013; Obrador 2012). Accordingly, Berdychevsky et al. (2013) explained that coming together provides feelings of togetherness and a sense of ‘social’ purpose, through the individual feeling that they are not isolated in the world and that people care about his/her wellbeing and purpose.

John illustrated that his leisure experiences become more enjoyable if he shares his enjoyment, happiness and leisure time with his friends and family. In a response to a question about what makes leisure special for him, John said that when being at a football match:

“Being there with my family, whoever takes me, that’s all special because I’m spending time with someone who is special to me! If I go to the cinema, that’s special to me because I am spending time with people I love, friends, family and...enjoying life!”

His description explains that while his leisure time can be situated within different contexts, having people with him feeds a deeper meaning to his experiences. This is because having people around him and enjoying his time with them, enhances his experiences:

“...you come away happy and, you know, you feel really good about that and mixing with other people as well, you know, I just enjoy doing that...I think um...it depends where I am, you know. If I went and gone to see a really good, funny film, or a good film, and everyone is enjoying it...you would think emotionally, you just come away pretty happy”

John’s leisure experiences therefore are much more dynamic because of his family and friends being in a leisure space with him, not just because there are others in a space with him, but also because the atmosphere becomes much more alive with other people interacting, talking and laughing. Additionally, when looking at the participants’ accounts, it can be acknowledged that leisure spaces can act as ‘backdrops’ and places of coming together, whereby deep, personal, relationships between one and another can be experienced and strengthened. Therefore, Obrador (2012) and McCabe (2015) state that leisure spaces act as nucleuses as they draw family and friends together and provide opportunities to strengthen bonds through the enjoyment of different activities.

Overall, in conclusion, not only does socialising allow individuals to share their personalities and time with others, but also socialising changes the atmosphere with people talking, laughing and interacting with each other (Obrador 2012; Page and Connell 2010). It provides the ability for people to come together and to maintain and/or strengthen bonds (Berdychevsky et al. 2013), through individuals sharing their love and enjoyment of leisure with

each other (Obrador 2012; Schänzel 2012a, 2012b). Socialising within a leisure setting therefore provides individuals with the chance to connect (and reconnect) with others (Schänzel 2012b), which can then be a fun and an enjoyable experience for the individual (Obrador 2012; Schänzel 2012a). In turn, this is why the participants enjoy it, so they can enjoy their time with others and not feel like they are alone in life. However, whilst it can be seen that the participants' overall leisure behaviours and choices are unique to them, what could also be seen in the interviews was that leisure can be a beneficial experience for the participants and other disabled individuals to consume.

The benefits of leisure

Leisure participation was perceived as beneficial by the participants in the interviews as apart from being able to pursue and experience different activities which they want to do, leisure also allowed the participants to recharge and psychologically escape from their stresses and negative experiences within everyday life. What also emerged was that leisure could help the participants with their life and independence skills as well as helping to maintain their physical fitness, where one's leisure interests could be integrated with one's physiotherapy exercises. Therefore, this section explores the psychological and practical benefits of participating in leisure, where the section will be divided up into two subsections. The first subsection will explore how participating within leisure can act as a psychological escape from the challenges of living with a disability. The second subsection will then examine how the participants thought that disabled individuals could learn more about themselves, and what they are capable of in life, through leisure participation. This subsection will also present Katie's accounts of how integrating her leisure interests with her physiotherapy regime can make the experience of doing her physiotherapy exercises more enjoyable, engaging and reliable to her everyday life.

Breaking away from experiencing the disability and gaining a sense of self and control

In the interviews, it was seen that living with a disability can be difficult at times. But, the participants illustrated that leisure can have a positive effect on the wellbeing of individual's with a disability and can be a good way of helping the individual to manage his/her disabilities and/or to overcome his/her possible negative feelings and experiences.

Katie suggested that leisure is crucial in her life as:

"...I live alone, so...I might not see anyone for a day - if I wasn't going out and about...I have a carer that comes twice a week for an hour, but other than that if I wasn't going out or doing things, I will just be sitting there, on my own and that's not healthy for anyone"

Katie's explanation details that she needs to go out of her flat, in order to avoid loneliness and isolation. Isolation can give individuals a feeling that they are alone in the world and that life is empty (Iwasaki and Schneider 2003; Kleiber et al. 2002, 2011). These feelings can also reduce an individual's well-being and risks encouraging them to start to think negatively about themselves, and even his/her relevance within the world, as they psychologically feel that they have little place within life (Kleiber et al. 2002; Smith and Sparkes 2005, 2008). Equally, not going out reduces Katie's well-being due to the feeling that there is no more to her life than what is in her flat.

What is interesting is that Katie continued saying that she can experience less negativity by, for example, visiting a coffee shop:

"So if I'm having a bad day and I don't want to go anywhere or do anything...that's when I just go into [a coffee shop], where I have a really nice coffee....I sit inside and just read my book. That's something I do that's nice for me, that's going to make me feel better and I'm actually getting out and getting some exercise and seeing people. And even if I'm only talking to the person next to me or when I ask 'Can I have a Caramel Macchiato, please' and, you know, just talking to the person on the till, then I have spoken to someone with some human interaction - you can only cope with so much dog interaction"

It is clear that just being in a coffee shop benefits Katie as she can zone out from everyday life and drift up to another state of mind where there is only herself and her enjoyment. Additionally, an individual can sense less of the dynamics of everyday life (including the challenges, stresses and frustrations of a disability) and more of themselves through leisure. This is because participating in a leisure activity, which ones enjoys, feeds into a sense of being that individual beyond the disability and doing something satisfying and enjoyable for oneself (Fullagar 2008; Fullagar et al. 2012). From Katie saying "...that's nice for me..." when she goes into a coffee shop, talks to people and reads her book, it indicates that this process of doing something for oneself allows her to feel like the person that she is beyond her disability. The experience of escaping to a relaxing place and/or just reading a book while in a coffee shop therefore helps Katie to rest and break away from the negative issues within her life. Consequently, it can be argued that the leisure experience leads to the individual sensing positivity and happiness (Caldwell 2005; Hutchinson and Kleiber 2005; Kleiber et al. 2002), whereby the experiences of battling with a difficulty, the experience of feeling pain or just feeling redrawn from the experience of a disability, is reduced (Kleiber et al. 2011).

What is seen is the activity of escaping and doing something enjoyable, allows the individual to be themselves and to forget about the implications of his/her medical conditions (Iwasaki and Mannell 2000; Kleiber et al. 2002). Similarly, when assessing John's accounts, it was clear that leisure helps him to recreate the feeling of his old self prior to his accident, through allowing him to re-experience his activities as much as possible where:

"...I feel [that] I am escaping [from] the mundane of being stuck indoors and everything. I am an outdoor person and I have always liked to go outdoors...I have always been outdoors...I have always been running. I could have been going out for miles, gone running, gone walking or gone driving..."

Clearly, John sees leisure as a way to venture back into the outdoors, as he can re-sense the outdoor experience and the feeling of being active again. But, John also finds going outside enables him to feel like he is not restrained and restricted in life, as he can experience negativity and

confinement from his condition, if he stays indoors and does nothing. Fullagar (2008) has indicated that leisure allows the individual to embody his/her 'authentic self', because the individual has the chance to experience something pleasurable for themselves. Similarly, Dattilo (2015) has stated that leisure helps to recapture the inner self and Tiyce and Wilson (2012) have illustrated that the leisure experience is a connection between the person, the activity and the break from everyday life. Therefore, it can be argued that if the individual sometimes finds living with a disability challenging and difficult, the leisure experience can help them to manage and cope with his/her medical condition(s) (Kleiber et al. 2011), by allowing the individual to experience something different to the disability and something which relights the feeling of oneself (Dattilo 2012; Kleiber et al. 2008; Robertson and Long 2008). However, what this also then illustrates is that not only can leisure participation be a form of 'escape', but also it can act as a form of 'release' whereby the individual experience themselves and not the effect of his/her condition(s), consequently encouraging them to feel positive about themselves.

What is significant is that leisure helps the disabled individual to feel positive about him/her self (Dattilo 2012, 2015; Kleiber et al. 2002). Similarly, it could be seen in the interviews that participating in leisure can help the disabled individual to relight his/her own sense of self and purpose. Lisa said:

"Yeah, leisure is important for everybody, but more so for disabled people because you are stuck in a house and stuck in a body that doesn't work. Leisure, getting out and about, really boosts your confidence, joie de vivre [i.e. the enjoyment of life], as they say..."

Lisa illustrated that leisure participation can act as a release as it enables individuals to do something different within their lives. Likewise, this illustrates that participating within leisure can help individuals to occupy their time more, instead of just doing and experiencing nothing. However, from Lisa's explanation, it can be also understood that this aspect of re-energising the self can help the disabled individual to feel that they can be an individual even though they have a disability. John also highlighted that despite the challenges, participating within leisure is important as:

“...you, and we all do, get depressed at some stage and get a bit fed up because we are disabled, we are in a wheelchair or we on are sticks or can't get around, you know...I think doing a leisure activity, and doing it with a group of people who don't treat you any different from being an able bodied person, that's the way I like it...[it is] really...important”

John's statement also shows that through leisure, the individual's own 'inner self' can be free from his/her constraints, stresses and frustrations. Although, what can also be seen from both Lisa's and John's accounts is that by the individual participating within leisure, the release allows individuals to break away from the structured element of 'coping' with everyday things such as needing to be hoisted or needing time to complete some work, to one of experiencing the pleasures of life.

More generally, Dattilo (2012) has noted that leisure can empower the individual through giving them control over an activity, which then aids the feeling of individuality and not just an experience of being disabled. Additionally, Morgan et al. (2015) evaluated that the control of the leisure activity can help the individual to get a feeling that they can do things for themselves and that they can have that ability to control life. Bennett et al. (2014) have also stated that leisure allows the individual to reconnect with themselves and to reflect upon life. This experience of doing things for oneself (whether with or without assistance) can therefore encourage a sense of empowerment in the individual (Dattilo 2012, 2015; Kleiber et al. 2011). As a result, it can be understood that John and Lisa find leisure important for disabled individuals because leisure energises a sense of self and allows individuals the opportunity experience an element of life beyond their disability. This tie into previous academic research stating that through having control, leisure also provides a sense of purpose and fulfilment (Dattilo 2012; Fullagar 2008). However, one of John's accounts also illustrated how this psychological experience has an additional impact on the person, whereby they remember that despite his/her disability, they are still an individual who has the ability to be capable of different things.

John illustrated that the 'distraction' of experiencing something else than his/her disability, allows themselves to experience his/her capabilities. In turn, rather than the individual thinking that they are limited in life because they do not have certain abilities (such as the ability to walk), John explained that a leisure activity can help the individual to experience that they are an individual and are capable of different things. John said:

"...by participating, you are not thinking about bad things that are going to happen to you...and things like that. You get distracted from that and concentrate on say, someone disabled throwing a javelin, or racing in a wheelchair and winning..."

What John's explanation shows is that leisure cannot just broaden the individual's experiences but can also enable the individual to remember that despite his/her disability, they are still his/her own person who can achieve different things in life. Kleiber et al. (2008) noted that because the disabled individual is experiencing themselves enjoying an activity and feel the motion of doing an activity, it recreates in the individuals' mind a sense of being a unique person who has abilities. Accordingly, there is a positive psychological effect to leisure, because leisure can enhance the individual's feelings and let them feel a sense of self rather than a sense of his/her disability (Cook and Shinew 2014; Hutchinson et al. 2003; Kleiber et al. 1995). Dattilo (2015) has explained that this allows the individual to sense a relationship between them and the wider aspects of life.

It is the personal connection with an activity that leads Kleiber et al. (2002, 2011) to explain that this personal connection provides strength, optimism and purpose to a disabled individual, as the personal connection with an activity provides a sense of individuality and that he/she is a human being with his/her own personality. Similarly, it can be seen from Katie's, Lisa's and John's quotations that they feel leisure enables them (and other individuals) to feel a sense of self and individuality, which then allows them (and other people with a disability) to feel a sense of being a unique person. In turn, this allows them (and others) to feel that their disabilities have not denied them from being an individual, as they can sense their own, personal, connections in the choice of leisure activity. Therefore, leisure allows a positive

unconstrained feeling to run through the individual's body, enabling them to feel like themselves as an individual despite his/her disabilities (Iwasaki and Mannell 2000; Kleiber et al. 2002). However, as personal connections with leisure activities can happen with anyone with or without a disability (Kleiber et al. 2011), this highlights that strength, optimism and a sense of purpose gained from leisure participation is not just confined to people with physical disabilities but to others with or without a disability. In addition to the personal, psychological, benefits that they gain from leisure participation, the participants mention that leisure also benefits them practically in learning about what they can do and in developing their capabilities.

Learning through leisure and developing abilities

In the interviews, it could be seen that leisure was not just a psychological release but also a chance for the participants to experience their capabilities and to explore what they can do despite their impairments. For example, Jessica explained that when she participated within leisure, the activity allowed her time to develop the skill of finding alternatives. In a context of being out with friends or family, she said:

“One thing I have found is that it [leisure] helps me look at alternatives, and by that I mean if I come to a building...which has steps in - and it's obvious there is only one entry, at first, my first thought is ‘is there an alternative entry?’, so it makes me think of alternative ways round”

It can be seen that Jessica has found that she can learn more about herself, how she can deal different aspects of life and how she can negotiate different issues, through her leisure time. This is because leisure allows Jessica time to think about different things and to think about the different ways around different problems. All of this makes Jessica feel independent. Kleiber (2001) stated that the individual can naturally develop an awareness of themselves and the world around them through his/her own leisure time. Kleiber (2001) explained that this is because as leisure is ‘their’ time, the individual is relaxed and, as a result, everything that they then do is converted easily into their understanding of themselves and of the world.

Researchers have also argued that the leisure experience can help disabled individuals to understand different things in society by letting them experience the world, what is in the world (including themselves) and to experience what doing different things (such as the need to find solutions to problems) feels like (Dattilo 2012, 2015; Dieser 2013; Henderson 2007; Kleiber 2001; Kleiber et al. 2011; Sivan and Stebbins 2011). Overall then, when looking at Jessica's account, it is clear that there can be a learning process happening when she experiences leisure, which aids her development.

In his interview, John was passionate about leisure empowering disabled individuals and explained that once the individual is distracted from their negative experiences and enjoys the leisure experience, overcoming issues converts into sensing achievement. John said:

"...I think that those who don't take part in any leisure activity are missing out greatly! I really, really do – you know, I think every disabled person should give it a go, no matter what it is, whether it is going out to play cards with people, or whether it is going out to throw a javelin, because things have been designed, especially in the sports world, for disabled people...you know, we have just had the Olympics, the disabled Olympics [London 2012 Paralympics]...that was a fantastic success and I believe that it made people feel good in themselves, watching their athletes, from their country, achieve goals that they too can achieve and it encourages them to do the same thing if they wish to do that...if you achieve something, it does help your everyday life because you look forward to the next day; what am I going to achieve the next day."

In this passage John has illustrated that leisure participation has practical benefits and can contribute towards an individual's personal development, as the sense of achievement helps him/her to learn about what they are capable of and what they can do beyond his/her disability. However, in a much broader sense, it can be seen that John was describing that individuals can also have the ability to try different things and to feel good about what they can do.

Leisure activities can reinforce an individual's personal development, as any skills and abilities which he/she has developed, can be transferred into an

everyday context (Kunstler and Daly 2010; Long 2008). However, the leisure and human development relationship is not only about experiencing new things and learning new skills, but also about the ability to be confronted with a challenge and having that ability to give something a go. Along with John's enthusiasm that leisure can help disabled individuals to understand what they are capable of, Lisa illustrated that being able to tackle a challenge can be satisfying, by stating:

"It's about meeting challenges, especially going to new places, and I'm always up for a new challenge. That's just who I am though...maybe it's because I'm gregarious..."

What can be seen here is that through having a challenge, the individual can feel happy and satisfied in doing (or at least trying) an activity. This refers to the aspect of self-determination where, when an individual experiences an activity (such as throwing a javelin over a certain distance), he/she will feel satisfied when a specific goal has been achieved which then influences them to think about what he/she can do (Dattilo 2012, 2015). This is because the achievement, or to give something a go, is an experience which provides a personal meaning to the individual, far beyond his/her disability (Kavanagh 2012; Kleiber et al. 2008), as an achievement is a personal feeling of being satisfied with oneself once he/she has completed a task (Kleiber et al. 2011). Accordingly, Dattilo (2012, p 251) suggested that self-determination is an intrinsic, psychological, process whereby:

"...self-determination results in having control over our lives in areas we value, making decisions without interference from others, [which then influences] having the freedom to live as we choose"

Dattilo (2012) therefore explained that self-determination helps to motivate individuals in overcoming challenges and gives them a sense of ability, as it gives them autonomy and a sense of control in life.

Overall, it could be seen that Lisa feels energised from having that chance to confront a challenge despite her spinal injury. But, with Lisa saying *"That's just who I am though...maybe it's because I'm gregarious..."*, this suggests that facing a challenge can become difficult and a daunting experience for the individual. Therefore, academic research suggests that organised leisure

activities (such as youth clubs and summer camps) can assist individuals to experience leisure and receive some of the benefits which can be gained from leisure participation, as they are supported environments, designed to assist individuals (Kunstler and Daly 2010).

In her interview, Katie explained that leisure cannot just be used to learn new skills or to challenge oneself, but also can be a setting where she can integrate her physiotherapy exercises with her leisure interests. Accordingly, Katie said that:

“...cause my flat is adapted for me, it has no stairs and no steps. So the only way I can do [my physio] is getting out and about, crossing roads and instead of using the drop kerb, using the actual step - making sure I'm not going to be run over! ... So that's what I'm doing. ...it helps because every time I have to get the bus, I have to get up umpteen sets of stairs to get to the bus stop. So it's helping me, cause I'm getting lots of time to walk a whole set of stairs, and...at least I'm trying and getting active and I'm starting to do it”

Katie explained that the process of going to somewhere and doing an activity can contribute towards achieving specific goals related to the requirements of the physiotherapy exercises. Whilst physiotherapy can relate to the medical model (Darcy and Buhalis 2011), it can be seen that Katie needs to do physiotherapy exercises. This is because physiotherapy is about maintaining and enhancing an individual's movement, body positions and physical activity (Green and McAdory-Coogan 2008; Percy Hedley School ca. 2016; Roush and Sharby 2011). However, what also can be seen is that Katie has got the ability to relate to her physiotherapy exercises, as she can integrated her physiotherapy regime into her everyday life and find her experience more enjoyable because her leisure interests helped her to characterise the whole physiotherapy regime experience.

Referring to her finding the experience of her physiotherapy regime more enjoyable when she integrates it with her leisure interests, Katie stated that:

“...it is very difficult to do an entire day of physical activity...right now I could spend my entire day doing physio in my flat and I will probably still have more to do!I could go on a treadmill but [that] would be really boring, I much rather go out and be walking in town or popping into shops or going into cafes and things like that... ...I could stand tall

at home and stand up watching telly for an hour. But instead of doing that I could be stood looking at clothes – shopping! I like shopping. So sometimes it's about incorporating physio and rehab stuff into your normal, everyday life, and trying to make it fun!"

Whilst Katie was the only participant who mentioned that leisure can make the experience of doing physiotherapy exercises more enjoyable, her explanation showed that this can be a crucial to understanding how leisure can be beneficial to someone with a disability. This is because Katie indicated that doing physiotherapy exercises can be a slow and uninviting process, due to the repetitiveness. Therefore, integrating a therapy regime with a leisure experience cannot just characterise the therapy experience with the enjoyment of an activity, but can also allow the individual to integrate the regime into his/her everyday life, using different situations (such as shopping) to maintain parts of his/her health and/or capabilities (such as the movement in the joints) (Kunstler and Daly 2010). Additionally, this ties into Kolehmainen et al. (2015) and Wiles et al. (2008) observations that suggest that the sole engagement with physiotherapy exercises makes the physiological experience static and unattractive for the individual. But, being able to transfer a physiotherapy regime away from the clinic into a real life setting enables individuals to integrate their therapy requirements into their everyday activities, making the therapy experience feel more dynamic (Kolehmainen et al. 2015; Wiles et al. 2008).

Overall, from looking at Katie's account, doing physiotherapy exercises becomes the norm if integrated into her everyday life. Yet, it becomes less of a medical experience and more of an experience which is not only relatable to Katie, but is something that is controlled by Katie. Additionally, Jennings and Guerin (2014) have explained that integrating therapeutic regimes with a leisure activity, allows the individual to enjoy and control more of the therapeutic activity because a leisure activity will make the experience more personal for the individual, through letting the individual to characterise the experience with his/her leisure interests. Equally, whilst some disabled individuals may enjoy doing physiotherapy, as it gets them out of a static position from sitting in a wheelchair all of the time (Aitchison 2000), what can

be seen is that the leisure experience breaks the structural element of therapy, making it more reliable and helping the individual to feel less of a 'client' and more of an 'operator' of his/her own therapy regime (Fullagar 2008; Iwasaki and Mannell 2000; Kleiber et al. 2011).

Access and inclusion within the leisure experience

Throughout this chapter, it has been discussed that leisure is a personal experience of enjoyment where the individual has a chance to escape from the challenges of living with a disability and to develop as an individual. However, the participants also raised the importance of access and inclusion when taking part in leisure activity. The participants expressed that if they have a negative experience of access, or feel excluded in anyway, then this can damage their leisure experiences. Accordingly, both Dattilo (2012) and Stumbo et al. (2011) have both argued that access and inclusion are essential in the leisure experience. Eichhorn and Buhalis (2011) also explained that accessibility and inclusion involves making adjustments and creating positive attitudes. Therefore, this section aims to discuss the relevance of access and inclusion in the participants' experiences. It will start by examining the importance of having physical access and positive attitudes towards disabled individuals, and it will end by discussing how an inclusive environment can be created.

The importance of physical access and social inclusion

Within the interviews, it was clear that access and inclusion are important for disabled people when taking part in leisure activities. Lisa highlighted the importance of having accessible provision when, in reference to discussing the importance of forward planning of a trip, in order to avoid access issues, Lisa said that when she goes out on the train with her partner:

"...it still takes planning, ringing up the railway, making sure that they have the staff available to help you on and off the train with the ramp - so you always have to book in advance in that respect with the

disabled access people and whichever railway that we are using...stuff like that. So, it's never just a case of 'let's go somewhere', we always have to plan ahead and think, what we are doing, how we are getting there...and what we need to take with us!"

Lisa highlighted that forward planning helps her to make sure that different provisions are in place, in order to ensure that her trip goes smoothly. Equally, planning in this context is about doing research on different accessible services and ensuring that provisions are going to be in place, such as assistance at airports (European Network for Accessible Tourism 2016). Even though Lisa benefited from forward planning, what can also be seen is that, in order to make sure that Lisa can smoothly get on and off the train, Lisa has to use different types of accessible provisions. This is because different accessible provisions at different stages of the whole leisure experience (such as information on accessible services, accessible hotel bedrooms and gate-to-gate assistance at airports) are crucial in enabling individuals to experience their activities effectively with minimal pain or frustration (Boes 2014; Darcy et al. 2017; Eichhorn and Buhalis 2011; Eichhorn et al. 2008). As a result, access was (and still is) a requirement in order to help Lisa to consume her leisure experiences. However, access was (and still is) not just important to Lisa but to all of the participants.

Whilst it can be argued that meeting individuals' access requirements is not an easy job, creating effective access around individual needs is essential (Dattilo 2012; Patterson et al. 2012; Veitch and Shaw 2011). For example, Bart said that when he wants a hotel room, he finds it difficult to find an accessible hotel room which meets his access requirements, as:

"...if I want to stay in hotels, because I've gone on an outing somewhere that is not local, I regularly find that it's very difficult to do things, because there aren't the facilities there, and obviously that is affecting the experience, might be the experience altogether - because you can't go... ..not all public hotels...have a ceiling track hoist, which for people with my sort of condition and similar ones, [we] would really require. Portable ones are okay but they take up a lot of room, and hotel size rooms, there [is] not that [much] room..."

What can be seen here is that hotels do not effectively meet Bart's needs simply because most hotel rooms are not designed to accommodate

important pieces of equipment (such as a hoist), together with the space that he requires. In relation to this, Darcy (2010) stated that the accommodation sector has much to improve on as there is limited awareness and appreciation of what individuals really need, therefore resulting in accommodation providers offering low quality accessible services. Accordingly, when Bart has not got the appropriate facilities and equipment that he requires, he needs to cope with the limitations of the space. This reduces his enjoyment of his overall leisure experience. Small and Darcy (2011) have noted that provisions which do not satisfy the individual's access needs risk turning his/her experiences negative because the individual then experiences discomfort. However, this problem was not just confined to Bart, as one of Lisa's stories also illustrates that ineffective accessible facilities can disrupt her overall enjoyment of her leisure time.

From her story of going to the cinema, what could be seen was that whilst Lisa's local cinema does provide accessible facilities, these were not designed well, meaning that although Lisa could access her local cinema, she still experienced pain and discomfort. Lisa said:

"...I've got a particular beef about cinemas. ...they always have wheelchair seating pretty much, [but] in my experience of the local area, the wheelchair seating is way up the front of the cinema so you're sitting with your neck [up]..."

What can be seen here is that Lisa's local cinema has been designed with limited thought about how comfortable individuals are going to be within their accessible facilities. Equally, Lisa's story highlights that even though accessible provisions can be created, such provisions need to be designed with the individual's safety and comfort in mind. Similarly, whilst access is about removing barriers, it also should make sure that the individual can experience leisure free from pain and trouble (Dattilo 2012; Eichhorn and Buhalis 2011). However, in the interviews, what was also highlighted was that peoples' attitudes towards, and assumptions about, disabled individuals is also an issue when delivering an inclusive leisure experience.

It was clear in the interviews that inclusive leisure is not just an issue of having the physical facilities and services, but also about having a positive attitude toward individuals with a disability whereby individuals' needs are appreciated. Katie told a story of when she received a bad service experience within a shop:

"...I hate it when I go to a place and there's an attitude about one's disability. Recently I was shopping and I needed some jogging bottoms and I wanted to try them on, and I was in [Shop A] and I went to the till and I said 'Excuse me, which floor is your accessible changing room now because I need to use an accessible one with grab rails and stuff', and they said 'Oh, it's downstairs'. And I said 'really?' because, I have been there before. And they were like 'Yes it is downstairs. You just close the big outer door. It's got a different lock on there and the whole changing room is yours then'. And I was like 'ok... right...'. I went downstairs and the shop assistant was like 'you can't close the big outer door, other people have to come in and get changed – a lot.' I said to her 'I have a disability, my guide dog is here. My guide dog is not going to fit into the little cubicles'. She was like 'Oh, I have to get a manager.' And she really was fed up about it and grumpy, and that I was like the worst customer in the world. And I said 'I've just been from upstairs... they told me that I could use the whole room and that it was not a problem. Because I need to use the grab rails and things like that.' And she said 'Oh, go on then. I'll just stop other people using it.' And at one point she said 'actually can't you just stand there and let other people walk in while you're getting changed?', and I was like 'No...um, no! I don't think that [Shop A] is ready for that image...' ...it was a really degrading, horrible experience, which I can laugh about now but I was really pissed off at the time"

What is revealed is that Katie's distress was caused by the shop workers being more concerned that they would need to use up some of the shop floor, in order to open up the accessible changing room, rather than on letting Katie use the accessible changing room. Consequently, what is clear is that by the shop being reluctant and asking her whether she would just get changed where other people could see her, this made Katie feel angry and upset. Katie's vignette therefore demonstrates that discrimination can be a challenging and an overpowering situation for the individual, where the individual is being suppressed and his/her feelings are being ignored. Therefore, Katie's situation signals that attitudes, judgements and passive assumptions that disabled individuals will just do anything, can take away the rights and humanity of disabled individuals. Likewise, when people suppress

this right, simply for what is more 'convenient' to them, this provides little appreciation of the individuals' feelings and well-being (Dattilo 2012).

Bart suggested that what is:

"...very difficult for people to understand is what disabilities they need to think about...I think that in terms of accessibility that is something that could be improved. I have also had problems with equipment and stuff when flying... it made things a bit problematic. It was doable, but it wasn't easy for a disabled person, and I think it did make me feel a bit awkward and uncomfortable. ...it doesn't necessarily have to be you being hurt by someone because they don't understand how to lift you in the correct way or something, but if you feel awkward and uncomfortable I don't think that's right"

It is clear that Bart thinks that when people do not appreciate the importance of accessibility and/or have a limited understanding of it, then this can make the individual feel more uneasy. Bart has highlighted that society will benefit from broadening out the understanding of accessibility. In turn, accessible design can be more effective through a better accessible strategic approach. This is where there is more effective awareness on why facilities and wider society need to be accessible and inclusive, but also awareness of the diversity of individuals' different needs and the way leisure supply can be adapted to suit different individuals' needs (Darcy and Pegg 2011; Dattilo 2012; Devine 2008). Similarly, from understanding some of the participants' explanations about what make things accessible and inclusive to them, this highlights how an inclusive environment can be created.

Creating an inclusive environment

When creating an inclusive environment, it is important to remember the individual and centre the inclusive strategy on them and see them as an individual rather than just as someone with a medical difference (Devine 2008). Additionally, both Katie and Lisa illustrated that when leisure providers saw them as individuals, talked to them as individuals and adapted their services accordingly, both of their experiences were much more positive. From going to one of her local restaurants, Katie said that she feels

extremely happy when the restaurant really tries to understand her needs and delivers a service that 'enables' her to experience the restaurant with minimal issues:

"...my local [chicken restaurant] is amazing. Praise where it's due. I'm such a regular that I just go in and they hand me a large print menu, which is fantastic, they take me to the table and say 'we'll give you five minutes and then we'll come and take your order'. They come and take my order, they go and put it through the till, they come back, they take the mango mac or whatever, they bring me my drink, they bring me my cutlery, they bring me the sauces that I want and everything"

What can be seen is that by the staff doing what they can to help Katie and make her feel like an individual, Katie feels really happy as her needs have been catered for, yet she can still proudly carry on enjoying the activity as an individual.

In addition, Lisa highlighted that when she works with her personal trainer, she loves the idea that the trainer understands what she can and cannot do, and then adapts her exercises according:

"...I enjoy going to cross fit but I don't actually do the cross fit workout, I [just] do a weight training workout and there is a lovely lady there, who looks after me and adjusts everything to suit my ability... she's always there to make sure that I don't fall off the equipment and also always got like safety side training"

Equally, what is revealed is that by providers adapting different ways of working around the individual's needs, the inclusion experience moves beyond just having accessible facilities such as having ramps and lifts. Research by Schleien et al. (2014), for example, has highlighted that services which are orientated around the individual and his/her requirements enable the individual to be supported in the best possible way, which then maximises his/her ability to experience leisure with minimal problems. Mayer and Anderson (2014) also suggested that making modifications and creating inclusive services and activities (such as creating disabled sporting competitions), brings the service or activity to the individual's level. In addition, this level of inclusion ensures that there are further opportunities for disabled people to progress with their leisure interests (Mayer and Anderson 2014).

When talking about the importance of adapting to a person's needs, Lisa also explained that orientating around the individual's needs helps the individual to not only feel involved, but makes sure that they are not overwhelmed by an activity. Accordingly, Lisa expressed that if an individual's needs are not met, then the individual may find the activity hard to manage psychologically. From an example of working as a personal trainer herself, Lisa said:

"...yesterday there was a young lady and she had anxiety issues and she didn't respond very well to one of our able bodied instructors, but she ended up coming to seeing me again. She had a more positive...experience, because I think I was able to talk to [her] ... I like to talk to people on the same level and not feel one's better than the other, cause they seem to be completely able-bodied and sometimes [their] body language, or the way you say things, can come out all wrong but if you're talking to each other on the same level...you can kind of interact a bit better..."

By Lisa adapting her approach to her client, Lisa's client feels more settled. However, for Lisa's benefit, this also enabled her to understand the individual more, as the female client was more willing to talk and interact with Lisa because she felt less overwhelmed and intimidated. Equally, Long (2008) has explained that just assuming the individual's needs and implementing a strategy based upon personal assumptions about the individual's capabilities, is ineffective as there is little understanding of what the individual really requires. Long (2008) stated that when facilities and activities are geared towards the individual's needs, individuals are more likely to benefit from them not just because they are 'accessible', but also because it is easier for them to then overcome other issues and barriers.

In relation to the importance of understanding the disabled individual's needs, Bart explained that what is needed is more education as society:

"...need to take a range of disabilities into consideration, rather than just one because with lifts and things, it's alright for someone like me who is just physically disabled, but when you have someone with hearing or sight problems maybe -...I don't want to talk about things I don't know, as I don't know how they are catered for as much, because I don't face those issues – but, for example, things like that could be forgotten about..."

Bart also said:

“...I think it’s just about taking small steps and making people put themselves in the perspective of other people, and then they can work from there, and I think maybe promoting disabled people to high positions within work and things I think is good, because if you have people in hotels and cinemas or anything, and they are disabled themselves...they can help you...I think that is important as well - leisure facilities and things, if you had someone working there, whose thinking about the structures, who is disabled themselves – I think that can be the odd benefit as well, which is why, at my college, for example, there are some accessibility issues - which have frustrated me. Although it is a good college and I have had a good time there, ... I have had meetings myself with the assistant principals and things, rather than going to one of my support staff and saying ‘can you pass this message on’, because that is not as effective I think. If you have a disabled person saying, this is how things could be improved, I think that they will listen to that a lot more...but, which I said before, it not all about the structure and things, it’s also to do with peoples’ ways of thinking and, yeah, if I’m to say how leisure facilities could be improved and things, I think that...the key is education to how you could break down barriers for everyone, and how to give them the full experience”

What can be taken from Bart’s statement is that inclusive environments can only be created through slow, critical and creative thinking. Whether or not disabled individuals are employed to assist with this process, it is nevertheless obvious that disabled individuals have to be at the centre of the planning process. As decisions can be taken by able-bodied individuals (Mobily 2015b), any decision making without any understanding of disabled individuals and/or even their input, creates a top-down power relationship between the service provider and the disabled individual (Darcy and Pegg 2011; Sylvester 2015b). However, even the very process of providing inclusion can be undermined by others.

From explaining that the development of inclusion practices and leisure opportunities for individuals with a disability can be undermined by others within society, John said the creation of opportunities for individuals with a disability to experience leisure:

“...depend[s] on the attitude of social care people and also the government...it depends what kind of attitude that they have...if they care about the rest of society. Because we are all human beings at the end of the day and it is nobody’s fault that we are disabled...whether we are born disabled or we become disabled during our life, through be it an illness, accident or whatever, then it’s

all down to the attitude of each individual group”

John suggested that inclusive leisure practices are partly controlled by ‘others’, meaning they have power over what is created. What this means is that access and inclusion can be ineffectively developed if providers, governments and policy makers, see access, inclusion and leisure services (such as youth clubs or summer schemes) as a low priority on their ‘agenda’ (Miller and Kirk 2002). The power relationship between the supplier and the disabled individual seen above is equally true in this context. If wider society takes the decision that they just want to follow their own agendas over thinking about what is right, fair and is going to support individuals, it risks suppressing and ignoring their needs (Sylvester 2015b). Similarly, whilst laws and policies should encourage, promote and protect disabled individuals, Veitch and Shaw (2011) have explained that these can be undermined and be weaker than they are made out to be. Therefore, Bart’s proposal about the need for more education on disability is reinforced here. It can be argued that people with disabilities need to be consulted in order to understand more about them and their disabilities, their lives and experiences, as well as the dynamics of their leisure choices, behaviours and experiences, and the leisure opportunities available to them (Aitchison 2009; Dattilo 2012; Mobily 2015a, 2015b; Sylvester 2015b).

Conclusion

The main purpose of this chapter was to look at the participants’ leisure experiences. What was seen was that the participants’ leisure experiences are not just about having the right to access and inclusion, but also about enjoying their own of free time and just enjoying themselves. It was seen that their leisure experiences are multifaceted and that, instead of just experiencing an activity, the participants choose what they want to do and they sense a meaning and purpose from it, which can then have a positive impact on their lives. Also, their leisure time evolve from experiencing different things, at different times, based on what they want and need to feel at a specific time.

There are many things which can be learned from this chapter. Firstly, I have identified that the participants' experiences are driven by what 'they' want to do, based upon their needs, wants and desires at any particular time. Therefore, what this suggests is that researchers and individuals within society should not look at disability and leisure as just being about access or a couple of activities which can be experienced easily by individuals with a disability. There is a need to be able to understand that disabled individuals' leisure choices, behaviours and experiences, as well as the other leisure opportunities that they can experience, can evolve into different things and can be experienced in different ways. Consequently, by thinking that disability and leisure is more than just one thing, researchers and society are then able to move forward, understand and educate more effectively about the dynamics of leisure which can be experienced by individuals with disabilities. Additionally, by thinking that disability and leisure is more than just one thing, researchers and society can move forward, understand and educate more effectively the importance of adapting services and the how and why leisure activities for people with disabilities evolves into different things such as the Paralympics and inclusive summer camps.

The second element which has been significant within this chapter is the insight into the benefits of leisure for individuals with disabilities. It is apparent that we can use, teach and research leisure more effectively, in order to help different disabled individuals with their everyday lives. Of course, it would be wrong to see disabled individuals as being 'incapable', as this would just undermine and discriminate against them. However, with the possibility of experiencing negativity through having a medical condition, it would be also wrong to undermine the value of leisure to a disabled individual. Equally, it can be seen that the effects of leisure can make a real impact to disabled people's lives. Therefore, it is recommended that there needs to be more research on the positive aspects of leisure experienced by an individual with a disability, and the more general experiences of leisure activities which is consumed by an individual with a disability (especially from a UK perspective).

Finally, whilst the importance of access and inclusion has been documented before, the chapter has reinforced the awareness of access and inclusion, and the understanding that there are not only physical barriers but there are also attitudinal barriers which affect the individual's experience. Furthermore, in order to improve individuals' experiences, there has to be not only some critical thought about what individuals will require and what will make them comfortable, but also a narrative that providers cannot just design different things based upon their assumptions of disabled individuals and what they 'may' require. They have to be active and willing to learn about disability and what are disabled individuals' needs.

CHAPTER SIX – CONCLUSION

Introduction

The aim of this research was to critically assess the social worlds and leisure experiences of individuals with physical disabilities. This chapter aims to conclude the research project and identify its contribution to knowledge.

The contributory themes: insights to the participants’ social worlds and leisure experiences

The aim and objectives of this study have been met through a collection of semi-structured interviews. Overall, this research project’s aim was:

To critically explore the social worlds of individuals with a physical disability and their leisure experiences

Where the objectives were:

- 1. To understand disability from an individual person’s perspective*
- 2. To examine the ‘individual’ behind the disability, their ‘social’ world and leisure experiences*
- 3. To explain the connections between leisure and the individual, in order to discuss physically disabled people’s leisure choices and how leisure can allow physically disabled people to experience their ‘free time’ and enjoyment of life*
- 4. To critically discuss whether physically disabled people gain any benefits from participating within leisure*

Chapter 4 (“*Living and experiencing a disability*”) contributes to objectives 1 and the non-leisure based element of objective 2, through highlighting the different dimensions of living and experiencing a disability from the participants’ own perspectives. Chapter 5 (“*The leisure experience*”) meets the demands of objectives 3 and 4, as well as the leisure based element of objective 2, through describing the dynamics of the participants’ leisure experiences, the personal meanings of their experiences and the benefits in

which they gain from leisure, as well as how these 'benefits' can affect their (and other disabled individuals) lives. As a whole, from interviewing five participants who have physical disabilities, it could be seen that all of the participants are their own person where they have their own medical condition(s) which uniquely affect their everyday lives. Similarly, their own desires, wants and personalities, also influence the shape of their worlds and leisure experiences. However, what was also seen was that external factors to their selves (such as the attractiveness of a leisure activity, the opportunities to relax or to be empowered through leisure participation and the accessible and inclusive nature of different spaces), also positively or negatively affect their experiences of leisure and everyday life. Therefore, from listening to the participants, it is clear that their social worlds and leisure experiences are not static as their lives are different to each other's and they each have their own individual experiences of living and experiencing life and leisure with a disability.

Overall, two major themes were identified in this research ("*Living and experiencing a disability*" and "*The leisure experience*"), in which five further sub-themes were found ("*Being disabled*", "*The individual behind the disability*", "*Making leisure choices*", "*The benefits of leisure*" and "*Access within the leisure experience*"). The different themes and sub-themes drew detailed pictures of the participants' social worlds and leisure experiences as well as their opinions on living life and experiencing leisure as a disabled person. The participants' accounts explained the challenges of coping with a disability and how different medical conditions affected people in different ways. Yet, they also stressed how the individual is still a person and that resilience can be the key in overcoming challenges. The participants' explanations about their experiences showed how their leisure time is directed by their personal wants and desires which means that their leisure time can occur in any space and/or form that they choose. The participants' vignettes also highlighted that leisure can be beneficial both psychologically and practically. However, leisure needed (and still needs) to be accessible and inclusive to them where access and inclusion has to be carefully planned and that the disabled individual(s) has to be at the heart of the process.

Contribution to knowledge

As the main two themes of this study were “*Living and experiencing a disability*” and “*The leisure experience*”, it can be identified that this research project reinforces, expands and challenges current understanding of disability and the leisure experiences which are already, or can be, consumed by individuals with a disability. This claim can be made as whilst previous research has looked into the subjective experiences of disabled individuals (such as Devine 2003, 2004; Henderson et al. 1994; Smith and Sparkes 2002, 2005, 2008), current knowledge and understanding of disabled individuals’ lives and leisure experiences have been reported as lacking in depth and exploration (Aitchison 2009; Goodley 2011b, 2013; Howe 2009; Macbeth 2010). Accordingly, the following subsections detail how the research reinforces, expands and challenges the current understanding of disability and leisure which can be for individuals with disabilities.

Reinforcing and expanding the current knowledge of disability

When looking at the participants’ explanations of their medical conditions and everyday life, it was clear that the findings reinforced the previous literature which highlights that each medical condition is different (Darcy and Buhalis 2011), and that living with a disability can provide different emotional and physical challenges for the individual (Brock and Kleiber 1994; Henderson et al. 1994, 1995; Hutchinson et al. 2003; Smith and Sparkes 2005, 2008; Small and Darcy 2011). However, the findings also reinforce previous research which states that despite the individual having a disability, they are still a person with his/her own personality, wants and desires within life (Kleiber et al. 2008; Smith and Sparkes 2002; Sparkes and Smith 2003). Accordingly, when reflecting back on the findings, it is clear that this research reinforces the idea that disability needs to be seen in a multi-dimensional way (Goodley 2011b, 2013). Although, from literature only stating that disability needs to be understood through a multi-dimensional lens, this

research expands the reasons upon why this is. This is through describing the social worlds of the participants and giving details into not just the nature and effect of the participants' conditions, but also to their experiences of living with a disability such as the experience of adjusting to the implications of an injury or the experiences of discrimination. In turn, from a knowledge perspective, the findings expand the understanding of disability stating that there is not just the disability which affects the individual's everyday life but also the experiential factors (such as needing to cope with a condition or the process of being resilient), which affects the individual's everyday life. Therefore, when understanding different disability issues, it is important to identify not just the aspect of access and inclusion but also what the individual may experience and how that affects his/her life.

Reinforcing and expanding the current understanding of disability and leisure

The findings of the research also reinforce and expand understanding of disability and leisure. It reinforces the importance of access and inclusion (Eichhorn and Buhalis, 2011), that leisure can be personal to the individual and driven by his/her needs (Hom Cary, 2004; McCabe, 2005), that leisure can be a psychological escape and a release from the disability (Bennett et al. 2014; Cook and Shiness 2014), and that leisure can empower a disabled individual (Dattilo 2012, 2015). The research findings also reinforces that leisure can be used to help disabled individuals to have more control over their therapy regimes, where their therapy regimes can be less of a medical experience and more of an experience which they can control and enjoy (Jennings and Guerin 2014; Kleiber et al. 2008; Kunstler and Daly 2010; Robertson and Long 2008). Additionally, whilst research on disability and leisure has been conducted internationally, it is clear that different international academic communities look at leisure for individuals with a disability in different ways. Therefore, from a UK perspective, the findings of the research detail that leisure which can be experienced by individuals with disabilities is multifaceted and that in order to understand disability and

leisure effectively, as well as disabled individuals' leisure experiences, there is a real need to understand their leisure experiences through their eyes. This is because disabled individuals have different access requirements, leisure needs and can benefit from leisure in different ways. As a result, when standardising the phenomena of the different leisure opportunities which can be experienced by individuals with disabilities and disabled individuals' current leisure experiences, there is more of a risk of misunderstanding how leisure can be inclusive, how it can be an integrated into part of an individual's life and can be a beneficial experience which can aid his/her confidence, sense of self and how they experience life.

Challenging the current understanding of disability and leisure

The research also challenges the current understanding and attitudes to how disability should be seen and researched within society and academia. Firstly, the debates around the different models of disability and the argument that academia and society should not need to understand the role of a condition in a person's life. This research has argued that there is a real challenge in understanding disability and disabled individuals if people do not consider the understanding of a person's conditions as being important. This is because it was clear within the interviews that the participants' conditions influence their lives, needs and requirements, whereby situations that they experience in connection to their conditions (such as the challenges of adjusting to a disability), can affect their confidence and sense of self.

With the debate of whether or not academia and society has to understand an individual's conditions when understanding disability, academic research have suggested that disability can be understood without understanding the condition and how a condition affects a disabled individual's everyday life (Aitchison 2003; Fullagar and Darcy 2004). Additionally, academic research also suggested that understanding of an individual's medical condition may risk influencing others in society to see the individual as being unable rather than as a person who has his/her own feelings and capabilities (Fullagar and

Darcy 2004; Pegg and Darcy 2007). However, from understanding that the participants can be empowered and benefit from leisure, the findings contradict the philosophy that a person's condition is not relevant in understanding his/her world. This is because when the participants were explaining that they felt empowered, capable or a sense of self through participating within leisure, it illustrates that impairments can influence the individual functional capabilities and how they think and feel as a person. Similarly, whilst it is right to not define a person by his/her medical condition, rather than by who they are as a person (Fullagar and Darcy 2004; Pegg and Darcy 2007; Sylvester 2015b), it is also wrong to ignore the implications of a condition as by understanding the implications, there is a real ability to understand the importance of being empowered and of accessibility and inclusion. Thus it can be argued that by understanding the participants, and how their conditions affect their lives, it was possible to see that being empowered and being themselves through leisure was meaningful to them, and that by their access and inclusion needs being met, their experience of leisure became much more positive. Furthermore, this supports previous literature which argues that in order to understand disability there is a need to understand the individual's conditions and the effects of his/her conditions, as his/her condition can influence his/her access requirements, everyday feelings and also his/her wellbeing (Devine 2008; Dixon 2008; Goodley 2013; Hughes 2004, 2007; Hughes and Paterson 1997; Thomas 2004a, 2004b; Stumbo et al. 2015).

Secondly, the research also challenges possible negative attitudes of disability and the lack of engagement in research on leisure for individuals with disabilities. This is because it was seen within this research that disability and disabled individual's life can be dynamic, whereby having and living with a disability is not only about the individual 'having' a disability, but also about 'living' with a disability. This means that research on disability and leisure (and even disability research more generally) is not just about the effect of the impairment or on access and inclusion, but is also about the individual, how the individual feels, his/her quality of life and what can enable the disabled individual to be themselves. As this research has shown, the

disabled individual can experience a range of things from challenges to the enjoyment of a leisure activity. This highlights that by academia having a limited view of the individual, his/her leisure experiences and his/her world, there is a greater risk of suppressing disabled individuals through ignoring what they experience everyday and not appreciating their world or leisure time.

Overall, this research reinforces, expands and challenges the current understanding of disability and of disability and leisure. However, what it also shows is the dynamic social world of the disabled individual, whereby his/her world is not always based upon the implications of his/her disability and that his/her leisure experiences can be deemed as just being about accessibility and inclusion.

Conceptual framework

From conceptualising the findings, as seen within the discussion chapters, it can be viewed that the social world and leisure experience can be conceptually divided into two, in which there is the idea of being disabled and the notion of the individual's leisure experience. From this, these concepts can then be broken down into smaller concepts. There is an ability to see that being disabled is about the individual having a condition(s), in which the condition(s) affects the individual functionally and, in some cases, psychologically depending upon the individual. Equally, on the leisure side, it can be seen that the phenomena of the individual's leisure experience can be personal, meaningful and needs to be accessible. Therefore, from looking at the conceptual framework (Figure 6.1 (p 112)), it can be argued that when looking at the disabled individual's social world and leisure experience, there is an ability to appreciate the disabled individual's social worlds and leisure experiences. From a knowledge perspective, this is really important as by understanding the details of the disabled individual's social worlds and leisure experiences, it is evident that when looking at disability or the leisure choices, behaviours, experiences and opportunities which can be

consumed by individuals with disabilities, they cannot be looked at from an objective perspective only. The conceptual framework demonstrates that by understanding more about disability and the leisure choices, behaviours, experiences and opportunities which can be consumed by individuals with a disabilities from a subjective, individual, perspective, there is an ability to be more sophisticated in understanding disabled individuals, their lives and how disabled individuals can be empowered by and use leisure to reinforce their confidence, abilities and sense of self.

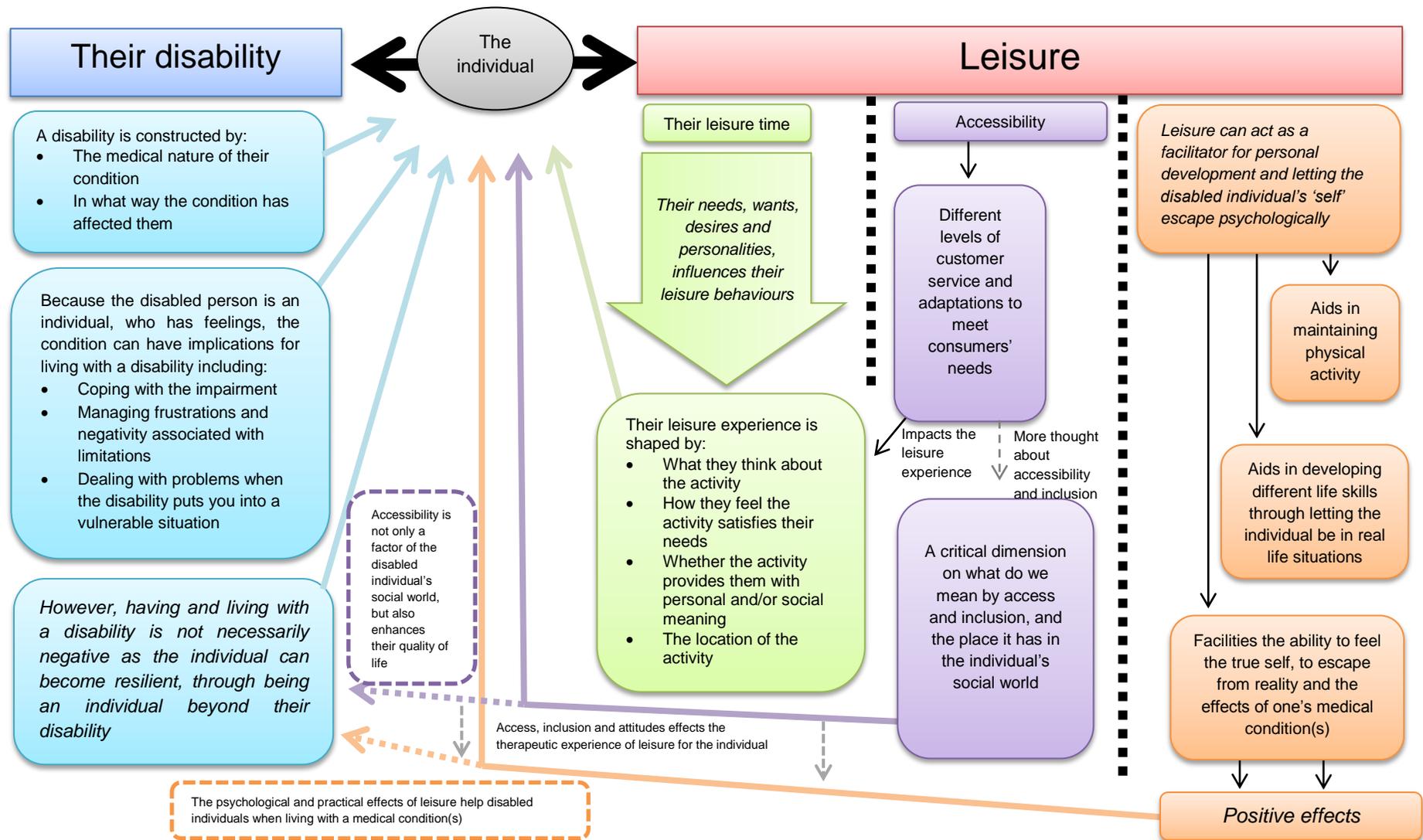


Figure 6.1 – The individual, his/her leisure experience and his/her social world: a conceptual framework

(Created by the author)

Recommendations for future research

It is clear that there is room (and a need) for future research. However, from conducting this research project, there are a number of recommendations for future research.

Firstly, it is recommended that research needs to not just examine the concept of disability and to understand the physiological effects of different conditions but also there is a need to do more research in order to understand the social worlds of disabled individuals better. It was seen in the study that a medical condition can affect the individual's everyday life not only practically but also psychologically. In turn, it was seen that this can affect the individual's wellbeing, confidence and how they think about themselves. It is recommended that future research not only needs to understand the implications of different conditions, in order to help to create effective ways of helping disabled individuals, but also that future research has to look at exploring disabled individuals' narratives of their everyday lives more. It is predicted that by doing this there is a greater ability to understand the feelings of disabled individuals and therefore enhancing the understanding of disabled individual's lives.

Secondly, it is clear that the phenomenon of leisure, which can be experienced by individuals with disabilities, is more than the concepts of accessibility and inclusion, and future research has to bear this in mind. Whilst accessibility and inclusion are important, it is recommended that future research either expands on the findings of this study, or when is looking into the experiences of a particular leisure activity, should research disability and leisure from the individual's perspective and see leisure through his/her eyes. This recommendation is because through understanding leisure from the individual's perspective, there will be a real ability to understand leisure from his/her perspective and to understand the subjective details of his/her experiences, instead of making objective comments about disability and leisure with very little context of the individual. Equally, there is an opportunity for future research to look more at disabled individual's personal

connections with leisure and how those personal connections can enable them to feel empowered, to help them with challenges and the everyday life of living with a disability, as well as how leisure can be a way for them to maintain his/her physical and mental health. These recommendations are being made because within the interviews there was a real sense that leisure is important to disabled individuals because of how personal enjoyment can empower them and improve their well-being. Therefore, more subjective research on the leisure choices, behaviours, experiences and opportunities which can be consumed by individuals with disabilities, may enhance not only the overall knowledge of leisure and their choices, behaviours and experiences, through understanding individual's behaviours, but also it is likely to help to understand more about how leisure can be a part of disabled individuals' actions in becoming resilient, overcoming challenges and not to feel negative about themselves.

Finally, it is recommended that future research needs to look at access and inclusion from an individual's perspective. This is because in the interviews it could be identified that access and inclusion practices are 'enablers' for the disabled individual, rather than specifically things that are requirements by law. Furthermore, in the "*Creating an inclusive environment*" subsection in Chapter 5 (p 97-101), it was seen that access and inclusion practices can be undermined by others. Accordingly, in order to effectively create inclusive environments, research is recommended to put disabled individuals at the very heart of access and inclusion research and understand the basis of access and inclusion from the individual's perspective, rather than a piece of research which is driven by predictions of what individuals might need or lacks rigor.

Reflecting on me and my research

When I reflect upon my time doing this MRes thesis, I have identified that there have been many lessons which have taught me different things about life and about how I can improve as a person. At the start, I remember

thinking '*I am a bit nervous...*' but by looking at the topic and being amongst well known academics, I thought that I will be well on my way and publishing in no time. However, trying to write and think in fine detail, in a clear, academic, way, as well as the hours of reading qualitative research methods books, was challenging, stressful and gave me doubts about whether doing research was right for me. Trying to cope with the feedback, the transcription of my interviews and making a story out of my data, also made me sometimes feel that I was not qualified and that I was just a kid in an adult only environment. However, now I understand and appreciate why I experienced and needed to go through these processes. This is because in order to truly improve understanding, research cannot just assume the world but needs to understand the fabrics of how the world is constructed. In relation to this I have learnt that it is acceptable to have weaknesses but it is important to do things with quality. On top of this, I feel that I have learnt a lot about disability and of the leisure choices, behaviours, experiences and opportunities which can be consumed by individuals with disabilities, where before I maybe had a bit of a trait for assuming different things because I am disabled myself. I now feel that I have learnt a lot more academically, where I feel that much more can be understood about disability and leisure.

Overall, I feel that the research has aided my personal development, where I should not lose my enthusiasm for different things but approach them in a calmer and more thought-out way. Accordingly, the research has helped me to think about what career paths interest me and has made me interested in helping people with their health and well-being, helping disabled individuals, and continuing with sports coaching, where I currently sometimes assist fellow disabled individuals in the field of athletics. This research has also made me interested in developing more knowledge on disability and on the leisure choices, behaviours, experiences and opportunities which can be consumed by individuals with disabilities, as well as to share my research project with others. Therefore, this research has given me some real food for thought about the future.

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Appendixes

APPENDIX A

INTERVIEW SCHEDULE

1. Their disability			
2. The effect of their disability in everyday life			
Do they want to answer?			
			
		Yes	No
		Ask about how they feel their disability affects their everyday life – not sensitive aspects, but a generic view.	Move on to question 4.
3. What leisure time activities are carried outside of activities home?			
4. How would they value these experiences?			
5. What improves these experiences (e.g. friends, family, the design of the facility)?			
6. When you visit a city or a town, where do you like to go?			
7. What makes these leisure experiences special or enjoyable?			
8. How does the atmosphere enhances this enjoyable experience?			
9. What about the characteristics of the space around you?			
10. How important do you feel it is to have a leisure escape?			
11. How you feel like you are escaping from everyday life?			
12. How you do you feel that being within a different place helps with the feeling of escaping?			
13. How would you think that going to a different leisure spaces helps you in everyday life?			
14. A lot of research states the importance of leisure for people with disabilities... how would you agree with this?			
15. Would you say it is really important that wider society understands the social and personal benefits of participating in leisure for disabled people?			
Thank you for letting me interview you			

APPENDIX B

CONSENT FORM

Consent form

Bournemouth University - School of Tourism

Researcher and Contact Details: Graham Condie (email: condieg@bournemouth.ac.uk or tel: 07851307733)

Project title: Escaping to an urban leisure environment: examining how physically disabled people value escaping to different urban leisure spaces

I have read and understood the project information sheet, and anything which I have not understood, has been explained to me by the researcher

I am aware that I will be anonymous throughout the project

I am aware of why I am being interviewed and I am willing to talk about why escaping to different leisure facilities in a city/town is important to me

I am willing for my interview to be recorded by a digital voice recorder

I am willing for the researcher's support worker, who is only there to support the researcher who is disabled himself, to be present at the interview.

I am aware that I can withdraw up until the data analysis

I am aware that the researcher will try and present his overall research project in conferences and/or publications, and that people will not be able to identify me in any academic output

I am aware that the information that I give to the researcher will be stored in a safe location, backed up, and that the data will be kept for a maximum of 2 years.

I am aware that my data will only be seen by the researcher's supervisors and support workers, up until the point of submission or publication

Researcher's name

Researcher's signature

Date:

Participant's name

Participant's signature

Date:

APPENDIX C

PARTICIPANT INFORMATION SHEET

Participant information sheet

Dear Potential Participants,

My name is *Graham Condie*. I am undertaking a Master by Research degree at Bournemouth University. I am providing this information sheet to you, to see if you will be willing to be an interview participant in my study of whether physically disabled people value their leisure experiences of cities and towns. This participant information sheet is to inform you about the role of an interview participant.

What is this project about?

The aim of this project is to examine whether physically disabled people value escaping to different leisure facilities in cities or towns, such as shops, cinemas or cafes. This is to evaluate the importance of leisure participation for someone who is physically disabled, and whether it can benefit them.



Why does this research matter?

Researchers and the leisure industry are very keen to learn about how to meet physically disabled peoples' needs. However, there is limited understanding of disabled leisure participants and whether physically disabled people could benefit from having a leisure escape. Therefore, this research will contribute to the understanding of physically disabled people's experiences of leisure and whether they benefit from leisure participation.

Why are physically disabled people needed for interviews?

By interviewing physically disabled people it will be possible to assess if they value, and benefit from, leisure escapes within cities and towns. In order to interview physically disabled people, the researcher is going to go straight to people that he thinks may agree to be a potential participant. The researcher will also advertise the need for other potential participants on Facebook and through disability organisations. Once participants have been recruited, the researcher will arrange possible interview dates and gain consent from participants



What will I be asked in my interview?

At first, the researcher will want to know a bit about you. He will then start asking you about where you like to go, the reasons why, and what you may feel when you go to these places. The researcher might then suggest some other places which you may have been to, and whether you like them or not and the possible reasons why.

I am a bit worried about being interviewed

The researcher will not make you feel uncomfortable or insecure. He will just explore your urban leisure experiences and how you value a leisure escape. All of the interview questions will be approved by senior members of staff at Bournemouth University.

Will there be anyone else at the interview?

Yes, there will be a support worker attending the interview. The support worker is just there to help him due to his own disability and speech impediment. However, you have the right to say you do not want the support worker present.



Will I be recorded?

Yes, this will be by a digital voice recorder. The recording will be destroyed after the project. If you do not wish to be recorded, you will not be able to take part as the voice recordings will help the researcher to record the interviews and to do the data analysis effectively. However, this will not be held against you by the researcher.

Will my interview be confidential and how long will it be kept?

All interview recordings, findings and transcripts will be managed in accordance with the Data Protection Act and Bournemouth University's research ethics policy. All your answers will be stored in a digital PDF file which will then be saved into two secure locations, only accessible by the researcher. The researcher will also have a hard copy, and this will also be filed away in a safe location. All interview recordings, findings and transcripts will be kept for no longer than 2 years.

Will the research be published?

As any research is important to society, the researcher will try to get this research published, in order to help people to understand physically disabled people's leisure experiences. The researcher will make sure that you cannot be identified in any findings published.

Am I allowed to withdraw if I want to?

Yes, up until the data analysis, where the researcher cannot withdraw any of your data from the research project.

Is there anyone I can contact regarding the research project other than the researcher himself, if I have any enquiries, problems or issues?

If you have any questions about the research please contact Dr Emma Kavanagh (my supervisor). Her contact details are:

Email - ekavanagh@bournemouth.ac.uk

Telephone number - 01202 965221

If you have any problems with the research or the researcher and wish to raise a complaint please contact Dr Ian Jones (Associate Dean for Sport at Bournemouth University). His contact details are:

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If you do contact them for any reason, the researcher will not be offended and use this against you.

Thank you for being potential participants,

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APPENDIX D

EXEMPLAR REFLECTIVE DIARY

Reflections on Male (1) which was last Friday

I felt that interview was different, interesting, thought provoking, but also probably quite a good insight into a disabled person. What I got from the interview was the interview participant had a broad sense of despite his disability and what he could do as an able bodied person. He wanted to keep that sense of achievements, that sense of 'he can do stuff' and also a sense of 'he is someone'. What I found really interesting is even passive things like photography, shopping and so on was actually, for him, an important thing to do and what made me really inspired by all this he said that ten years ago he was unable to speak, walk, talk and he was lying in bed and he said it's quite easy to lie in bed and, like, feel sorry for you, but really he did not want to do that. I'm not saying that leisure is a form of healing, but it's also forgetting that his leisure activities could help him live that life that he did and I thought that was really important. I get the feeling that the idea of urban leisure, rural leisure, was to him not really relevant, it was more about going out and doing stuff outside of the home. I think for someone who has studied leisure and Dann's (1981) typology and Leiper's tourist system so on and so forth, but actually what we are missing actually is the question of what is leisure? From the Male (1) interview was very subjective, very individual, where I think when you talk about therapeutic recreation or using leisure as a therapy tool, then actually it's more about having an idea of doing something free time related, not work related, which makes it nice to do, so yeah.

Male (2)

Interesting interview. There was a strong sense of disability, equality issues within the interview, which sort of moved the debate from leisure, it's fun and what you like to do, to it's like more about ramps or lifts or the frame or gaining a sense to be equal and it is more about actually what the leisure participant, what they want to do, what they can access. Can they access what they want? In my view, I felt that was an important discussion point which took me to a massive subsection or chapter of the discussion and the viewpoint I would say is actually is what don't we know about disability, what don't we know about disabled people, what don't we know about disabled peoples' lives and the participant went on about how we....when he does a leisure activity like restaurants, cinemas, he feels nice, he feels free, he feels like he is enjoying something. However you could also say there is a debate that he makes about if I can't access somewhere he can't enjoy, he can't feel

happy, he can't get that emotional subjective experience which leisure can provide. Another point that I love is that actually he has Muscular Dystrophy and that disability does prevent him doing stuff because it's a condition of the weakening of the muscles which is beyond his control. Generally what he suggested is he needs to bear that factor into his decision making and, like he says, he never stays at home and so on and so forth, which I think is a fantastic attitude but he also said about when he go to a hotel they don't have space, they don't have the track hoists, don't have room to move about, it is not appropriately designed and that can be an emotional barrier i.e. he is not able to gain as much enjoyment as he would like, which I think is awful, really. So, that raises another question: how do we make things accessible or how easily can we? He makes a good point about how nothing can be accessible, and I think that is a valid point. Is anything perfectly accessible? And almost that is just bad, but it highlights the previous interviews about disability. What is a disability? Is it subjective? Can it be subjective and more importantly, can we meet everyone's needs? But that is moving to an equality issue of we need to be equal but how do we do it? That is a question and a half! But the interview of Male (2) where we open up a new way of thinking and what I keep on thinking before the interview is that all of them relate back to therapeutic recreation, and not the point of normalizing people or making people normal, but that idea of actually, you are entitling people to these experiences you are making them feel that they were normal. Politics in research is always controversial but I think that even though some people say therapeutic recreation normalizes people, you kind of think the philosophy of it is more important. I think that could be a real discussion point within the discussion, so yeah.

Female (3)

I went to an interview workshop before Christmas and they said about getting data and that you need to get new data from people. The interview felt a bit repetitive and a bit hard but that might be the participant's personality of feeling a tiny bit reluctant to share everything - but that might be me! Even though I asked more questions and I tried to ask her about more I felt I got important data out of it. It might not be loads, it might not be in depth but I got data. I think any researcher other than me needs to recognize that any data is data even though it doesn't relate to your project the participant's thought and feelings but also it might be me being a bad interviewer! I felt the participant shared interesting thoughts. A lot came out about socializing

with people. The word safe cropped up a lot and also the concept about doing more of what able bodied people do its important a lot as well. I think I get the feeling that with Female (3) it's not so much about what she does, it's more about who she is with, and a really good debate I found with her is she wants to feel secure, safe and enjoyable and that's her main motivation. I think that is an important discussion point, an important concept. She did say that she liked to do her own things but she liked to feel secure. What she meant by that is if she liked the place, its looks to feel nice, if its dark she wouldn't, if its cold she wouldn't, but she also talked about accessibility. This came up in all my interviews and you would have thought... but actually the project is not on accessibility so how on earth does it matter? But what I get from everyone, more than just with Female (3), is that accessibility is not just a physical barrier, not just a political issue, not just an authority issue but it can be a social and personal issue. Now none of the participants have really cried 'oh I can't access this, I'm upset' but they have connected their experience and their emotional personal perspective experience to the concept of accessibility and that is a real thinking point. For example Female (1) said if she can't access something she gets annoyed and she cannot have an escape. But escape is an emotion, it is a feeling so, if you can't access something it's a feeling as well you can't access and that is not a great thing where you go in to somewhere and go 'oh I don't like this' but it's a related emotion, something which you cannot help. You can help going into a place and not liking it. You can help going into a concert and hating the concert but you can't help going to a cinema, finding that you can't get in to the cinema, and then deciding to go back home. And she made another point, as all of the participants have said, that leisure can have an impact on their well-being, happiness and also how they feel about themselves. Female (3) said it helped her with her decision making process but that connected to escaping and if you can't escape then you cannot escape. When we found out that escaping can improve well-being and improve confidence, can improve a whole lot of things and bearing in mind you have got different types of leisure, so sport, creative arts and tourism hence that's a minefield; then if you can't access it how can you develop it? This has made me think about my life. I don't go out a lot for a coffee but it made me wonder: do you need a reason to do something? Do we need a reason to do a certain activity? That is another point. Do we need a reason to do stuff? Have we been conned into we need a reason for something? I think all of this can be a debate not just about one thing, tourism, leisure, sport, but health care, education, schools, colleges, universities. Actually, out there in the big wide world what we do helps us, it's constructive and also even some people will say 'I thought he was having an interview with Female (3) but there's not much data but there is also an argument that there is data even if we don't know it. Interesting thinking ahead!

Reflections on first interview, which I did today

Due to my disability I thought I would record this as a diary entry, simply because, from being disabled myself, I found the interview very, very, interesting yet quite emotional as well. I think the reason why that is, it's because when I started out to research I basically thought 'oh yes, yes, I will just find people's feelings and thoughts and ask them about urban leisure escapes and sort of that will be it' but I really found out that what the participants today have said, some of it isn't right and some of it is not nice. However, some of it is true and meaningful if humane and you feel across the new media you hear about something and you hear about funding cuts, problems with social care, problems with understanding care, the treatment of care, and you also sort of think that things that its in some ways like you do think of the three week piles of things to sort out but really from what I gathered today is the issue is not what does it mean, a definition of policy, of good PR or even trying to meet people's needs. The issue is more about actually, does it matter if you are disabled? Does it matter if you need help walking upstairs? Does it matter if you need assistance? What I gather from the participants is she does want to do what everybody else does feel, what everybody else should feel, has that humane experience, and this is really important for the project because what is the basis of humanity? Because really society is based on, not what people want but on what people need. The feelings they need, the confidence, the support, and I might be going off track, but I really found this interview quite emotional, yet important because from being disabled myself I understand about confidence and about being able to go out and do what you do and so on but in many ways, we are our own and at the end of the interview the argument about the models of disability and if you look at crip theory, queer theory, and so on and so forth, what you see is that actually society wants a reason for why we have got these things and how to manage these things, and so on and so forth, where in reality, yes, every disability needs to be managed by society, we need a guide to tell us what to do and how to sort of cope with disabled people but yes, you could say that actually are we just being too, I hate to say it, but blind when we look at disability? Do we look at what we need to do, rather than the person? From the interview today I got the message and on a concept and I don't like to say it has affected me but it has but that is why I am here to help, to provide information and even when I sat in the refectory just now queues of people rushing about doing business, talking about the next week at university probably but really what about people who I

interview? Where do they come in? Do they come in? Some argue, we may all need to move forward to the business economic case but really are we ready for that? Do we know what is the business case? There is a topical question. Do we know about the business case, the economic case, the policy case? I know we build what we know from these cases and if so, are they valid? It just makes you wonder, are they valid? When the participant talks about her disability, which I won't talk about here, does it make what we know about disability valid? I would argue, not really because any type of bullying or emotional force or anything is not ready. It is like trying to build a car but having the wrong wheels on it, or the wrong people in the car, you can't leave until you have the right wheels and the right people in the car. Hence do we actually know? Another argument is, I might be biased, and probably am, but really am I just saying this because I don't wear a suit? Or, and I said this, other than academics... or is it because I have a different view point and different force field, as John Tribe would put it, a different force field on the way I think? That would say maybe I am biased, maybe I'm overthinking it to immerse in the concept but even still it doesn't take away what Female (1) said because what she said is meaningful and is valid. Why? Because they are her thoughts, not mine. The next interview is Friday. Let's see what it says. This data collection process may be very emotional for me.

Interview 2

Yeah, I just felt like, and I am probably worrying, but I felt the interview went really well. I got some information which actually linked up to the idea of therapeutic recreation, which yet again shows my argument of 'why on earth are we not talking about therapeutic recreation'. But I think I was worried that the interview was more general about her, rather than about her inner feelings, but saying that, people behave and people interact and people communicate in totally different ways. I think that, from the two interviews I have done so far, the data is sort of turning everything I have done in my secondary data and sort of saying 'this actually doesn't matter' but it does. That's like the concept of me being in a space doesn't matter, but the concept of me doing something different does matter. The thing that makes me worried, but making me happy and over the moon, but also so happy should this be happening, but saying that, this is the point of qualitative research. The very fact that both Female (1) and Female (2) talked about their disability and talked about their, let's say, confidence and so on, sort of does make you wonder whether we even know about disability and the very fact that the participant today said you can't really explain a disability, you

need to experience a disability, just makes you wonder about (a) can we explain a disability and (b) if we do explain a disability, do we need to break it down even more into tiny little things, such as where the person is, how being somewhere can affect their ability to cope in everyday life . I think overall it was a really good interview but I think maybe I'm worrying a bit too much about getting depth and about getting the specific timing of the interviews right.

I don't know yet but from what I understand from the interviews so far is academia sort of goes on about this place, space, shape, feeling, affected so on and so forth. And I think what it's trying to do is classify what happens rather than explaining what happens. The thing is Female (2) talked about how, without a partner, she wouldn't have gone out as much as when she had a partner with her and I think maybe that is another idea: is the concept of leisure or the concept of recreation, the concept of tourism, is it more for disabled people a concept of just getting out and doing stuff and using leisure, tourism or basically the whole of the leisure spectrum as a sort of tool for doing things. But I would say is it a tool for, let's say, forgetting the disability, is it a tool of how I put it, like having an escape, not from everyday life but the limitations of the disability?

Well, not so much isolation but you could say that Female (2) said about the tiny issues such as confidence, self-esteem, well-being and so on and so forth. You can almost say that leisure can be a tool in order to overcome those feelings of 'I can't get out, no one wants to be with me' and apart from learning skills and learning how to push yourself and so on, you do also argue that maybe doing those things maybe helps with reducing the negative impact of feeling alone, feeling isolated, and the interviews are really throwing some light. What is interesting is if we sort of plan out how a day out or how a leisure activity outside works, like you start at home, you go out and get to where you want to go to, so maybe taking the theory from Leiper and the tourist system, almost what you can argue is: there is a barrier in the middle of the process, whether it's needing to use a train or needing to walk upstairs or even just being out on your own and feeling like you got that right and you can almost say when you break down that barrier and do the leisure activity and everything is in place you can sort of argue that when they do the leisure activity that almost all the minor issues of self-worth, self-confidence, self-esteem, having the right to be there, sort of they are flushed away when they do the activity. I think what I'm finding is, and this is not good for the title of the research project! but it's not so much where the activity is, or whether it's urban, rural, sport, an event, staying in a hotel, anything that we classify as different things. You could argue that actually it's more about the ability to do those things rather than the ability of, oh yeah, rural leisure and maybe the emphasis which can be turned up in my consciousness 'I can't do

them' and maybe the emphasis should be on actually it doesn't matter where they are, what matters is what they do and how they feel about themselves and their disability. The next interview, next Friday (unless I get any more people by then) should be interesting.