SILENT VOICES OF TOURISM:
A NARRATIVE EXPLORATION OF CERVICAL SPINAL CORD INJURY AND LEISURE TRAVEL

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Thesis submitted to the Cardiff School of Management in partial fulfillment of the requirements for the degree of Doctor of Philosophy

2010

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DECLARATION

I declare that this work has not been previously accepted in substance for any degree and is not being concurrently submitted for any other degree. I further declare that this thesis is the result of my own independent work and investigation, except where otherwise stated (a bibliography is appended). Finally, I hereby give consent for my thesis, if accepted, to be available for photography and inter-library loan, and for the title and abstract to be made available to outside organisations.

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Finally, this thesis is dedicated to all people with cervical spinal cord injury - and also to the memory of two remarkable women who were inspirational in my life. The first, my closest friend, Azita Khajehhosseini, interrupted her doctoral studies in 1988 to return briefly to her native Iran to peacefully support the Resistance Movement against Khomeini’s oppressive regime. She was captured, tortured and put to death for her beliefs. The second, my beloved, late grandmother, Annie May Stevens, despite having to start work at just thirteen, nevertheless struggled to ensure that all five of her children received Higher Education. Her concern and endless generosity also extended to all those in need locally and in unknown, far off lands. The souls of both women will, for me, forever be two of the brightest stars in the sky.

Wales, May 2010
A. Luther
Utilising an inter-disciplinary approach, this qualitative inquiry seeks to create a space for an absent group and experience by addressing severe physical disability, social exclusion and leisure travel. Drawing on a blended methodology - critical discourse analysis, feminist standpoint and narrative inquiry - it explores, via in-depth interviews, discussions and non-participant observation, the lived experiences of twelve individuals with cervical spinal cord injury (C-SCI) in the USA in relation to travel constraints and what impact (non)participation might have on their overall well-being, quality of life and social inclusion. The challenges of working with such medically and socially-vulnerable research participants are detailed together with those of the study’s inclusive and reflexive research approach and presentation, in narrative form, of their unheard stories. Using an approach involving social constructionism and a largely social model of disability, the individual, social and societal analysis of the data illustrates increased levels of obstacles for those who are ventilator-dependent, those who acquired the condition around birth or as young children, and for females in general. Details of the plethora of complex, inter-related environmental, intrinsic and interactive barriers and constraints to participation reveal that most are connected to, or are exacerbated by, socio-political practices and structures. The most significant and long-term psycho-social benefits of leisure travel are associated with those with the highest level of C-SCI, chiefly with the desire, post-holiday, to abandon daily pleas for assisted suicide and to begin to live life again, often within mainstream society. Furthermore, the analysis reveals the power of the dominant medical discourse of disability on the participants’ largely negative self-concept, knowledge and non-actions in relation to leisure travel. A number of potential practical solutions are suggested. Key policy-driven solutions centre on the provision of a brief, one-off, local holiday towards the end of hospital rehabilitation - to provide a goal and the practical skills necessary for re-integration - as well as on the availability, during hospital rehabilitation, of a different or alternative narrative resource of disability and travel.
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LIST OF ABBREVIATIONS

ADA  Americans with Disabilities Act
BASICS  British Association of Spinal Cord Injury Specialists Survey
BBC  British Broadcasting Corporation
BSA  British Sociological Association
EESC  European Economic and Social Committee
ETB  English Tourist Board
ETC  English Tourism Council
CDA  Critical Discourse Approach
C-SCI  Cervical Spinal Cord Injury
CSO  Central Statistical Office
DDA  Disability Discrimination Act
DWP  Department of Work & Pensions
FHA  Family Holiday Association
NHS  National Health Service
NSEM  NS Educational Manual
ICCP  International Campaign for Cures of Spinal Cord Injury Paralysis
SCI  Spinal Cord Injury
SIA  Spinal Injuries Association
UK  United Kingdom
UN  United Nations
UPIAS  Union of the Physically Impaired Against Segregation
USA  United States of America
UWIC  University of Wales Institute, Cardiff
WHO  World Health Organisation
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CHAPTER ONE
INTRODUCTION

1.1 Overview of chapter

This opening chapter begins by highlighting the issue of involuntary non-participation in leisure travel. It then explores the benefits of participation and discusses the impacts of ‘social holidays’. Next, the focus of the thesis is introduced, namely: the issues and implications of (non)holiday-taking for individuals with cervical spinal cord injury (C-SCI) who are paralysed from the neck down, the most impaired of whom require a ventilator to breathe and twenty-four hour assistance with all personal tasks. Whilst their bodies may be ‘broken’, their minds, however, are not. The chapter then presents a very brief analysis of previous research in order to develop new research questions and an aim and objectives for the thesis. Finally, the chapter closes with an outline of the study’s research agenda and an overview of the structure of the thesis.

1.2 Non-participation in holidays

Holiday-taking has long been perceived to be an important part of contemporary social life in most Western cultures, with global travel estimated to reach one billion in 2010 (Rodriguez-Garcia, 2001). Yet, over sixty years since the UN’s Declaration of Human Rights (1948) was credited with being the first international legal document situating the taking of holidays within a person’s rights of citizenship, holidays are still not universally enjoyed or accessible to all (Minnaert et al., 2009). They remain the domain of the same ‘privileged’ section of society (Long et al., 2007). In fact, as much as 40% of the population in the UK does not participate in holidays (Shaw & Williams, 2002), yet involuntary non-participation is far more complex than the main body of literature on constraints to participation seems to suggest by its focus on low-income (Brent, 1999; Jolin, 2004; Shaw et al., 2005). Society’s ‘poor’ are not a homogeneous
group though as 'Poverty means going short materially, socially and emotionally. Poverty means staying at home, often being bored, not seeing friends, not going to the cinema, not going for a drink and not being able to take... a trip or a holiday' (Oppenheim, 1990: 3). Thus, apart from, or in combination with, low-income, participation can also be affected by other factors that marginalise individuals, such as: race (Klemm, 2005); gender (Shaw & Williams, 2002); age (Sedgely, 2007); serious illness (Hunter-Jones, 2003); sexual orientation (Hughes, 2005); and disability (Eichhorn et al., 2008).

Since 'Everyone has the right... to leisure time that enables them to develop every aspect of their personality and their social integration' (EESC's Barcelona Declaration, 2006), the implications of missing out on a common lifestyle - or a 'need' for escape (Shelton & Tucker, 2005) or simply a 'right' to exist in a socially-meaningful way (MacDonald, 2006) - can be considered a form of deprivation or social exclusion (Collins, 2006). In fact, research has shown how feelings of deprivation and social exclusion deepened when children from disadvantaged backgrounds were unable to go on school trips or holidays with classmates (Lewis, 2001; Ridge, 2002). These feelings were exacerbated in Summer when they remained in their deprived areas as their peers departed on annual holidays (Gill & Wellington, 2003), and even further feelings of social exclusion were evoked when they and their families were later unable to join in conversations about holidays (Long et al., 2007). Furthermore, neither they nor other similarly disadvantaged groups were able to enjoy the perceived benefits generally associated with holidays (Shaw & Coles, 2003; Gilbert & Abdullah, 2004; Card et al., 2006).

1.2.1 Benefits of holidays

Since tourism is perceived to be the world's largest industry and one of the most important sectors of the economy in many countries (Rodriguez-Garcia, 2001), most academic inquiry has treated the phenomenon of tourism more as an economic activity, that benefits the hosts, rather
than understanding it as a social process contributing to the well-being of an individual or society. Nevertheless, participation in tourism is regarded to be a generally positive activity for visitors also, with multiple benefits including 'health' and happiness. Yet, while Gilbert & Abdullah (2004) and Nawijn et al. (2010) found that holiday-makers enjoyed enhanced well-being and happiness - often prolonged by anticipation of the holiday but not, according to Nawijn et al. (2010), by increased happiness post-holiday unless the holiday was extremely relaxed - there remains a dearth of work on the impact holiday-taking may have on the broader notion of an individual's health (Haukeland, 1990; Hughes, 1991; Ragheb, 1993; Hunter-Jones, 2003, 2004), particularly in relation to disabled people. According to the WHO (1990), this notion of health extends beyond the traditional perception of the physical body to include mental health so that it is a more 'multifaceted phenomenon, encompassing physical health, emotional well-being and social cohesion' (Stokols, 2000: 136).

Recently, however, there has been a small yet growing number of studies on holidays, well-being and social cohesion focused on low-income and socially-disadvantaged families and children. Moreover, building on earlier work by the ETB (1976) and by the FHA and ETC (2000) which suggested people's overall health and well-being improved following a holiday, a study examining serious illness found that holidays also had a very positive impact on cancer patients - 'particularly of a sociopsychological nature, ...[and on their] social effectiveness,...self-image, independence, future career prospects, and personal behavior' (Hunter-Jones, 2003: 170). Additionally, the study found that holidays offered a necessary means of escapism and a vehicle for transcending illness, however short-lived.

For those financially or otherwise disadvantaged groups who do not have 'access' to holidays to accrue such benefits, advocates of visitor-related 'social tourism', which seeks to counter social exclusion, propose that the State provides a holiday (Minnaert et al., 2009) as 'holiday travel is [to be] treated like any other human right whose social loss should be compensated by the
welfare state' (Haukeland, 1990: 178). Part of the provision in Belgium, for example, ensures that tourist attractions offer reduced fees so that the entrance fee for persons on low-income at, for instance, Antwerp Zoo would be 5 instead of 17 euros, and the same reduced price for an accompanying assistant (Minnaert, 2009).

1.2.2 Social tourism

Although Canada and many continental European countries have a long-established tradition and wide public acceptance of social tourism, even the concept is barely recognised in the USA or UK, and what little provision does exist is largely dependent on charities (McCabe, 2009; Minnaert et al., 2009). Part of the problem is that relatively little research evidence currently exists on the benefits of social tourism to sufficiently ‘scientifically’ justify it for medical practitioners or policy makers. However, the situation is not helped by public-sector tourism agencies or private tourism-sector providers who, due to further financial pressures caused by increasing costs of public services, tend to prefer to follow a tourism strategy that seeks to accommodate fewer, yet more higher-spending, tourists. Part of the blame must also lie with the research community which has consistently focused on the ‘positives and presences’ of tourism and largely ignored the negatives of, and absences from, tourism (Botterill & Klemm, 2005) which, in turn, has not inspired greater investigation of social tourism.

Although the strongest strata have a moral obligation to support the weakest without any net gain to society (Haukeland, 1990), provision for social holidays is likely to remain inadequate, informal and largely dependent on charities in ‘individualist societies’ like the UK and USA, unless expenditure of public money can be seen to benefit the whole of society and not just the weakest strata (Minnaert et al., 2009). Minnaert et al. (2007: 10) thus demonstrated in their study that ‘social tourism could be a cost-effective part of social policy’ as the £500 the FHA spent on a social holiday for a whole family compared relatively well with the estimated cost of
£750 to the Department of Health in 2003 for providing parenting classes for just one person with children at risk of anti-social behaviour. Since uptake for these classes was low, the authors suggested that social holidays would not only be more cost-effective, but would also have the greater potential to positively affect the life-quality of both the individual and the wider community.

1.2.3 Social holidays

Research examining non-participation in tourism and social exclusion has predominantly focused on the effects of a one-off, and mostly charity-funded, social holiday on low income families and disadvantaged children, and the potential impact the holiday had on both the individual and the wider community. Nevertheless, some similarities could be drawn between these groups and disabled people given the economic disadvantage of many disabled individuals, and the findings of Shaw and Coles' (2004) study of disabled tourists which indicated that the meanings of holidays for disabled people, such as escape from routine and a sense of freedom, were similar to those of disadvantaged families outlined in the studies of Smith and Hughes (1999), Quinn et al. (2008), McCabe (2009) and Minnaert et al. (2009).

McCabe's (2009) study examined both low income families and families living with severely-disabled children and thus shed further light and detail on the multiple, complex and interrelated reasons for and benefits of a social holiday. Participants ranked in order their perceived needs for a financially-assisted holiday. First, was to spend time together as a family and rebuild relationships; second, to experience some 'normality', or a distraction, away from their problematic lives and difficult physical and social environments; and, third, to get over a 'bad experience' or find relief from the stress of temporary or untreatable health conditions. A holiday also gave them something to look forward to as well as fond memories. Post-trip, this,
together with ‘having fun’ and being able to enjoy themselves, was ranked as the greatest benefit.

Additional benefits were found to be a multifaceted sense of ‘freedom’ from everyday depressing circumstances and routines - and even from going to bed early and getting up early (McCabe, 2009) - all of which benefited family bonding (Hazel, 2005; Corlyon et al., 2006; Long et al., 2007; McCabe, 2009). Furthermore, holidays provided opportunities for new experiences and ‘had the effect of “recharging batteries”, taking their minds away from daily problems and being better able to cope, and enjoy life’ as well as to put bad experiences behind them and to deal better with health issues on return (McCabe, 2009: 13). In fact, for some individuals, both physical and mental health conditions improved on return, enabling them to cope better in general (Voysey, 2000; Corlyon et al., 2006; Long et al., 2007; Minnaert et al., 2007, 2009).

Several adults stopped taking medication for depression (Minnaert et al., 2007, 2009), reinforcing claims that participation in holidays has the potential to reduce pressure on health and social care services (Hughes, 1991; Hazel, 2005; Corlyon & La Placa, 2006) thereby benefitting both the individual and the wider community (Hughes, 1991; Smith & Hughes, 1999; Long et al., 2007; Minnaert et al., 2007, 2009; Quinn et al. 2008). Benefits were equally evidenced as children’s cultural, educational and social horizons were broadened, and their enhanced self-worth, positivity and happiness resulted in improved communication, respect, behaviour and relations with teachers and classmates (Corlyon et al., 2006; Long et al., 2007; Quinn et al., 2008).

While benefits to well-being were generally associated with actual holiday-participation (Lewis, 2001; Brimacombe, 2003; Wigfall, 2004), Gilbert & Abdullah (2004) also highlighted the importance of holiday anticipation and expectation on an individual’s prolonged sense of well-
being. Such was the case following a social holiday. The change in the children’s outlook on life and the future meant that anticipation of the next holiday extended the immediate positive effect on their overall well-being for some time afterwards (Quinn et al., 2008). Conversely, McCabe (2009) found that when the majority of the responses came from families with severely-disabled children, the ability to look forward to the future was ranked the lowest perceived holiday benefit, followed by the ability to cope better with their situation. However, this could reflect more the relentlessly difficult nature of the role and circumstances of many full-time ‘carers’ to severely-disabled individuals, rather than the actual feelings of the disabled children post-holiday, although it is not disclosed what the severe disabilities were and how or whether the children were able to express their feelings.

As for the time-frame of benefits, Minnaert et al. (2007) noted how after just one social holiday a number of adults were motivated to make changes in their lives for up to six months post-trip and displayed a more proactive attitude to life at least for the medium term; some enrolled on courses, changed jobs or budgeted better, often to save for another holiday. Nevertheless, Smith (1996) questioned both the long-term positive impacts of a holiday as well as the merits of a one-off holiday compared with regular holiday-taking. McCabe’s (2009: 17) study suggests, however, that, given regular holidays can enhance subjective well-being and happiness, a holiday break away from multiple difficult circumstances could, in fact, ‘open up new ways to live, which may have a lasting impact’.

Although social holidays cannot solve everything, the reported wide-ranging benefits to both the participants and the wider community suggest the adoption of social tourism to be a legitimate policy response to counter the negative effects of social exclusion (Smith, 1998; Jolin, 2004; Long et al., 2007; Quinn et al., 2008; McCabe, 2009; Minnaert et al., 2007, 2009). Moreover, the impacts relate to numerous current UK Government policies, such as ‘health and well-being’ and education (McCabe, 2009). As such, investigation of other socially-excluded groups is
equally necessary (Hazel, 2005; Corlyon & La Placa, 2006; Long et al., 2007; Minnaert et al., 2007, 2009) since many of those who do not participate could be most in need of a holiday, and perhaps even stand to gain most from holiday-participation (Hughes, 1991; Long et al., 2007). They may even reap very different benefits from those associated with low-income families and disadvantaged children (Minnaert et al., 2009). Furthermore, as Shaw (2007: 97) points out, given that disability legislation has done relatively little to assist those disabled people who are constrained by both income and disability, greater holiday-participation by them is likely to come not from increased legislation on anti-discrimination but from a comprehensive policy of social tourism

Yet the impact of holiday-taking on the well-being, quality of life and social inclusion of disabled people still remains a seriously under-researched area (Morris, 2001) because, 'in the academic sense, disability issues and tourism have remained separate areas of study' (Darcy, 2002: 61). Furthermore, while researchers in disability studies and sociology recognise the impact of the multifaceted barriers and experiences of disabled people in, for example, mainstream education, employment or housing (Barns et al., 2005), there appears to be within tourism research a 'reluctance to explore the experiences of the disabled traveller' (Shaw & Coles, 2004: 399). Consequently, little is known about the actual experience and impacts of (non)holiday-taking on disabled people. Thus, research with an aim to facilitate their social integration through leisure travel should not merely offer a list of the barriers which inhibit participation. It needs to include details of the causes and consequences of the barriers together with participants' lived experience of disability, impairment and (non)participation in order to fully understand how they have been excluded so that practical suggestions to counter non-participation may be offered.
1.2.4 Disability & holiday-participation

Although some progress has been made since the passing of disability discrimination legislation, such as the UK's Disability Discrimination Act (DDA, 1995) and the Americans with Disabilities Act (ADA, 1990), there is still a significant difference in life-satisfaction between people with and without physical disabilities (Avis et al., 2005). Since holiday-taking is generally equated with an enhanced quality of life, participation in holidays may offer disabled individuals greater overall satisfaction in life (Avis et al., 2005). However, holiday-taking is often still rare amongst disabled people as multiple barriers and constraints continue to exclude many from participation (Shaw & Coles, 2004).

Despite their limitations, however, the introduction of the ADA and DDA acted as a catalyst for a period afterwards to draw the attention of tourism scholars to disabled tourists - even if only a relatively small literature emerged with just two main foci of inquiry. The first largely centred on reviews of policy measures and predominantly physical accessibility and staff attitudinal barriers to participation (eg, Gall, 1993; Upchurch & Seo, 1996; Bendini, 2000; Gleeson, 2001; Israeli, 2002; Mekercher et al., 2003; Stumbo & Pegg, 2005). With increasing awareness of the power of the 'disability pound' estimated at £80 billion (DWP, 2005), the second advocated the removal of physical barriers essentially as a means to increase market share for the tourism industry, rather than promoting the social dimensions of access to tourism (Shaw, 2007) or exploring the impact of non-participation on their lives. Nevertheless, there has been some 'vocalisation' that the removal of barriers is also a fundamental human rights issue and thus a moral imperative (eg, Darcy, 1998; Turco et al., 1998; Darcy & Daruwalla, 1999; Darcy & Harris, 2002). That said, all such literature has focused on already-participating disabled tourists, virtually all of whom had 'only' minor to moderate physical disabilities.

Consequently, and due in part to the challenges in undertaking research with individuals with more specialised needs, the most significant gap in the literature relates to severely-disabled
tourists and, within this category, to those who have never taken a holiday or even experienced a one-off social holiday. Such is the situation of many individuals with C-SCI, the focus of this inquiry. Paralysed in all four limbs, they are amongst the most severely mobility-disabled citizens. Their exclusion as a distinct group is two-fold as they are largely excluded from mainstream society, including tourism (Darcy, 2002), and they also remain one of the most neglected disabled groups in tourism inquiry to date. Moreover, in highlighting the possibilities, the positives and presences of tourism rather than the risks, the negatives and absences (Botterill & Klemm, 2005), the tourism community has presented only the facts and statistics about the positives and presences which subsequently become the ‘truth’ about tourism. However, the true character of tourism remains unknown as questions about those who are involuntarily excluded from participation remain unexamined and absent from the analyses of the facts and statistics of the phenomenon of tourism. Arguably, since it is these facts and statistics which generally stimulate debate and/or action to facilitate the inclusion of would-be-tourists, the tourism academy could be seen as colluding with discriminatory practices - especially in the current political climate dedicated to ‘widening participation’ in all areas of social life - by not engaging with those who have never participated.

Consequently, although the central research question posed in this study relates to the constraints to holiday-taking for individuals with C-SCI and the potential solutions to counter them, a contribution of the thesis is also to challenge extant approaches to the study of tourism. This is pursued by the way in which ‘discourse’ - what is said, written or represented in another form (Burr, 2003) - constructs society’s, including the tourism research community’s, understanding of phenomena known in the world. Thus, the largely negative discourse of disability influences research agendas within the tourism academy which, in turn, inform the attitudes and (non)actions of various stakeholders who directly or indirectly affect disabled people’s participation in tourism.
1.2.5 Discourse of disability

While there will always be different discourses, or narratives, offering alternative foci or ‘realities’ on the nature of the same phenomenon, the medical-scientific explanation of disability has, in Western societies, long been the dominant, ‘rational’ and non-reflexive one (Barnes et al., 2005). Virtually all public narratives of disability are still underpinned by the ‘medical model of disability’ which influences the health service and determines how we, as a society, think and write about disability (Barrow, 2004). Within a tourism framework, this translates into the notion that disabled people’s reduced levels of physical functioning prevent them from participating in tourism, and particularly those with severe disabilities whose physical dysfunction is even greater.

Such ‘knowledge’ influences able-bodied people’s views on disability and participation, the tourism community’s included. Moreover, since ‘explanations individuals offer of their lives are inevitably shaped by the prevailing norms of discourse within which they operate’ (Rosenwald & Ochberg, 1992: 5), this discourse also controls and limits disabled people’s understanding and knowledge of themselves, their situation and potential (Smith & Sparkes, 2005, 2008b). Consequently, this informs their actions, including holiday-taking, unless it is subject to resistance through different discourses, or ‘counter-narratives’, based on the ‘social model of disability’ that views disability as a social construction. Yet counter narratives are generally trapped within the academic literature on disability and not readily-accessible to disabled people, their relatives or the general public (Barrow, 2004). Thus, as Smith and Sparkes (2008b: 232) point out, ‘certain narratives are foregrounded and celebrated while others are marginalized and silenced’ - together with disabled people’s own voices (Barton, 1996).
Although the use of narrative does not generally claim to offer any greater insight into an area than another method, it can, however, be especially effective in uncovering hidden information particularly in relation to socially-excluded groups such as those with C-SCI. Setting their experiences of holiday (non)participation in the context of their life history, everyday life and impairment can illuminate the barriers encountered and allows both the general and the academic reader to gain a more complete and detailed picture (Ellingson, 2009) of the prejudice and discrimination they face as well as their personal journeys, assumptions and responses to (non)participation. Furthermore, as Rosenwald and Ochberg (1992: 7) note, 'culture actually speaks itself through each individual story. Thus the content, vocabulary and voice of each individual within the different narratives will, together, be able to offer a 'collective narrative', revealing how the social world in which it is constructed affects disabled people’s holiday-participation.

1.3 Background to research interest

The decision to investigate an issue related to tourism and severe disability evolved from the voluntary work I undertook as an eighteen-year-old student with disabled individuals. My awareness of disadvantaged groups first developed, however, as a school pupil when I witnessed a racist attack and experienced sexual discrimination.

The racist attack was against my older brother. As an Anglo-Indian in an all-white community and school, his ‘different look’ resulted in his being frequently verbally abused and then physically attacked by a group of school boys. The violent kicks to his head broke his teeth; the psychological damage was even greater. Later at university, I was again to witness racist verbal abuse directed by city folk towards student friends from ethnic minorities. However, it was the experience of sexual discrimination as an A’ level pupil which left an even greater impression on me and a desire to connect with disadvantaged groups.
As girls entered the old boys’ grammar school in our town in South Wales for the first time, the headmaster introduced a weekly towel rota to be undertaken by only the female A’ level pupils. This rota had been successfully undertaken by a long line of girls before ‘the baton’ was eventually passed on to our year. Each week, as the boys studied in the common-room during their free periods, two girls would be assigned to change the towels for the whole school during theirs, usually in the rain, and as no bags were provided, the piles of clean and dirty towels had to be carried in our arms against our clothes.

With growing frustration and, indeed, naivety, I suggested to my classmates that if the much larger number of A’ level boys shared the rota, no one would need do it so frequently. Whilst the girls did not dare disturb the status quo, the boys responded, alongside flat refusals, with comments such as ‘the girls have always done it’ and ‘that’s women’s work’. Yet the towel rota ceased the following week after my meeting with the school’s pastoral deputy head. Although her reaction was by far the angriest, insisting ‘only when men have babies will you girls ever see equality’, she nevertheless took the matter to the headmaster. By the end of the week, it was announced that an elderly gentleman had been employed to change the school towels from then on.

Later, as I reflected on the whole event, it was the response of one of the boys which had the greatest impact on me, my outlook on life, and ultimately influenced my choice of research. Unlike the other boys, he admitted that he recognised the inequality of the situation with the towel rota. However, because my solution meant effort on his part and loss of unfair privilege, he was not interested in joining forces to implement change. Consequently, it was his ‘conditional empathy’, or ‘bad faith’, in maintaining his privilege when fully aware that it was morally wrong, that first gave me the impetus to appreciate other people’s situations and struggles for equality. To understand others’ struggles against discrimination, I therefore chose to undertake voluntary work with disabled people who experienced inequality in my
'privileged' world designed for and run by able-bodied people. Importantly, by not focusing on issues of race or gender for which I personally stood to gain, I hoped to genuinely engage with the concept of social responsibility.

1.3.1 C-SCI & voluntary work

First they came for the communists and I did not speak out - because I was not a communist.

Then they came for the Jews and I did not speak out - because I was not a Jew.

Then they came for the trade unionists and I did not speak out - because I was not a trade unionist.

Next they came for the Catholics and I did not speak out because I was not a Catholic.

Then they came for me and there was no one left to speak out for me.

(Pastor Niemoeller, victim of the Holocaust)

Although Niemoeller’s words on taking action in the name of the oppressed are powerful and thought-provoking, it is regrettable that they still appear to infer social responsibility in the name of self-interest. That is, the many different groups which make up society are interdependent and thus must be supportive of one another for their own survival. This pseudo-functionalist stance tends to collapse, however, when no one is dependent upon groups such as the very elderly or severely-disabled people. Surely, the moral imperative should thus be to support all disadvantaged groups to ensure that no group remains isolated in its struggle for
equality of opportunity and basic human rights. Such a philosophy was reflected in my choice of voluntary work undertaken at the end of my first year of university.

My first voluntary experience, however, was teaching adults with and without learning disabilities to read. Later, as a foreign language student in Germany, I taught English to recently-arrived Vietnamese 'boat children'. Today, when called upon, I continue to teach English in my free time to pregnant women from ethnic communities and also assist lawyers who volunteer to work with refugees who face persecution, or death, if returned to their countries. Yet the voluntary work which has endured the longest began when I spent my Summer holiday at the end of my first year at university at a specialist nursing home in the USA for individuals with C-SCI.

The first visit to the home was spent mainly talking with clients who never, or only very rarely, received visitors. On other visits I accompanied staff and a small number of former clients to local restaurants and also visited them in their private homes. Later, I audited and produced a report for UWIC on the provision for disabled students within the academic curriculum of the Welsh Centre for Tourism and Hospitality, and was involved in UWIC's first 'outreach' Access to Education course for mature students and students from the ethnic minorities. The nursing home's director therefore asked me, during my next visit, to discuss an outreach educational programme for her clients with her managers and representatives from a local college. On yet another visit I worked with both staff and clients to prepare presentations and speeches for a forum to promote client-community integration.

My contact with this home has endured to this day. In part, this is because the clients are the most socially-isolated individuals I have ever encountered as well as the most despairing of their lives ever improving. Thus, with an emancipatory philosophy and aim to reconnect disconnected people through holiday-participation (Larsen et al., 2006), an exploration of the
lived experiences of (non)holiday-taking of individuals with C-SCI became the clear choice of subject for this doctoral study.

1.4 Previous research

Existing research has revealed that disabled tourists have the same travel motivations as the general population (Yau et al., 2004). These are predominantly socio-psychological in nature such as: meeting new people and experiencing new things and places; a need for escape of routine and pressure; and a desire for a feeling of freedom and general well-being (Shaw & Coles, 2003). However, disabled people experience considerably more constraints to holiday-taking than most other tourists (Stumbo & Pegg, 2005) and thus have a less satisfying tourism experience and consequently participate less (Turco et al., 1998). Severely-disabled people tend to face even greater barriers and constraints than those with minor to moderate disabilities (WHO, 2002; Packer et al., 2007). Consequently, compared with other disabled people, they travel even less and with reduced enjoyment (Burnett & Bender, 2001; Darcy, 2002; Packer et al., 2007) and are thus denied the feelings of social inclusion, well-being and other life-enhancing benefits associated with holidays (Gilbert & Abdullah; 2004; Card et al., 2006).

Yet, potentially, severely-disabled people have the most to gain from holiday-taking as, according to Hughes (1991), the perceived psycho-social benefits are more deeply-felt by those who experience the most constraints to participation. Furthermore, since they tend to be the least satisfied with life of all disabled people (Avis et al., 2005), it is ironic and a ‘reflection on our social policy that those who are most in need of the benefits that a holiday can bring are least able to take one’ (ETB, 1976: 5).
1.4.1 C-SCI & holiday-taking

The increase of unstructured free-time with decreased levels of functioning following a spinal cord injury (SCI - ie, the broad term used for all levels of injury including C-SCI) can lead not only to negative thoughts and emotions (Kewman & Tate, 1998), but also to complete social isolation (Levi et al., 1996). The importance of 'hope' (Smith & Sparkes, 2005, 2008b) and of actively engaging in life post-injury is therefore crucial to 'recovery' (Caldwell et al., 1995; Krause, 1998). Thus, just as leisure research has long demonstrated the importance of leisure activities, such as sport, in contributing to an individual’s overall well-being and self-concept (Hendrey et al., 1993; Roberts, 1997), studies examining SCI found leisure activities, particularly disabled sport, had a direct and indirect positive influence on individuals' adjustment and well-being following injury (Henderson et al., 1995; Lee et al., 1996; Dattilo, 1998; Kleiber et al., 2002; Loy et al., 2003). Loy et al. (2003) therefore called for research on the impact of engagement in leisure on the adjustment to SCI following discharge from hospital rehabilitation. They added that if leisure can provide:

> active coping mechanisms such as companionship and mood enhancement through one's social support networks, it may be beneficial for professionals to assist individuals with SCI in building and developing social support networks through leisure participation.

(Loy et al., 2003: 251)

However, due to the emphasis on sport and the associated physicality, these largely quantitative studies have been, once again, largely concerned with people with mild to moderate SCI rather than with C-SCI. Thus alternative recreation is necessary for those with greater functional limitations (Mannell & Kleiber, 1997). Loy et al. (2003:237) therefore called for qualitative inquiry to 'examine more fully the spectrum of variations in leisure activity and experience' that influence subjective well-being and perceived health, and which may have practical and theoretical implications for work with disabled people. Nevertheless, to date, there still appears to be an absence of work examining the impact of non-sporting leisure activities, such as
holiday-taking, on the general well-being, self-concept, quality of life and social inclusion of those with C-SCI, the forgotten spinal cord injured individuals of both tourism and leisure inquiry.

1.5 Research questions

As indicated earlier, those few tourism studies which have included people with more severe disabilities (eg, Burnett & Bender, 2001; Darcy, 2002), have, however, examined only the barriers encountered by those who have already participated, however little or unsatisfactorily, in tourism. Yet the ‘absent’, or the non-participant, as well as the ‘present’, or the participant, need to be equally examined in order to fully comprehend issues of participation. This study will explore, therefore, both the lived experiences of consumers with C-SCI who have and those who have never taken a holiday. For brevity, these individuals will be referred to as ‘travellers’ and ‘non-travellers’ throughout the thesis. The study thus seeks to address key questions about their ability to take holidays, the quality of their holiday experience, the positive and negative aspects of participation - including the barriers, risks, denials, delusions and potential solutions necessary for holidays to take place - and the overall impact of their (non)participation. These questions are presented below.

1. What are the issues associated with the condition of C-SCI, and how might they affect holiday-taking?

2. With regard to holiday-participation, what factors (a) facilitate, (b) inhibit or (c) exclude individuals with C-SCI?

3. What is perceived to be the impact of: (a) non holiday-taking for individuals with C-SCI; (b) holiday-participation for individuals with C-SCI?
4. Who are the stakeholders, and what are their roles in affecting holiday-taking for individuals with C-SCI within mainstream tourism?

5. What are the possible solutions to the barriers and constraints to holiday-taking experienced by individuals with C-SCI?

1.6 Aim & Objectives

The aim of this study is to ‘give voice’, through narrative, to individuals with C-SCI to extend the repertoire of narratives of disability in order to provide new insights and critical reflection on former assumptions and (non)actions with regard to C-SCI and holiday-taking. To fulfil this aim, five objectives are formulated, namely:

1. To explore the concept and theory of disability, and to document the condition and impact of C-SCI;

2. To conduct a critical review of literature to:
   - investigate non-participation in holiday-taking and potential interventions to facilitate participation;
   - identify constraints to holiday-participation for disabled consumers and, in particular, mobility-disabled individuals;

3. To document the research process of working with and the attempt to ‘give voice’ to previously unheard, silent voices of tourism;

4. To listen to and present in narrative form the lived experiences of (non)holiday-taking of twelve individuals with C-SCI (six non-travellers & six travellers);
5. To present emerging themes and issues of the experience of (non)holiday-taking for individuals with C-SCI in relation to the reviewed literature; and to offer practical suggestions that might minimise holiday constraints in order to afford individuals with C-SCI the opportunity to take a holiday within mainstream tourism or, for those who have already participated, to offer an enhanced tourism experience.

1.7 Overview of thesis

The thesis is organised to reflect the ways in which the research questions were developed, posited and answered by this qualitative inquiry. It comprises eight chapters. This one, chapter one, introduces the issue of involuntary non-participation in holidays of disadvantaged groups and the benefits of government or charity-funded ‘social holidays’ to the well-being of the individual and society. It later highlights how much greater the barriers to participation often are for disabled people, and how the dominant discourse of disability impacts on them and the rest of society. Background information on the decision to focus the inquiry on individuals with C-SCI is then provided and the effect of leisure activities on their well-being discussed. The chapter concludes by outlining the study’s research questions, aim and objectives.

Chapters two and three locate the research in its theoretical context with a review of literature that first examines debates surrounding disability theory, then moves on to explore the medical condition and the impact of C-SCI. Finally, it examines constraints to tourism participation for mobility-disabled people.

Chapter four sets out the methodological framework of the study. It provides a detailed and reflective account of the methods that were used to work with marginalised and vulnerable research participants, and concludes by highlighting the importance of narrative in understanding disability along with its inherent challenges.
Chapters five and six focus on the data that were collected from previously untold and unheard accounts of twelve individuals with C-SCI of their experience of (non)holiday-taking. The data are presented in narrative form, beginning with the stories of six non-travellers and concluding with those of six travellers.

Chapter seven presents the emergent themes and issues of the data collected and presented in the two previous chapters, and discusses them in relation to the literature on disability and on tourism. In addition, it offers practical suggestions to counter the constraints and barriers to holiday-participation for individuals with C-SCI and other severely-disabled people.

Finally, chapter eight concludes the study by presenting a review of the research objectives and key research findings. It outlines the significant contributions of the research and the research limitations, and closes by suggesting opportunities for further research.
CHAPTER TWO

DISABILITY THEORY & THE CONDITION & IMPACT OF C-SCI

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CHAPTER TWO

DISABILITY THEORY & THE CONDITION & IMPACT OF C-SCI

2.1 Overview of chapter

The travel interests of severely-disabled individuals will, in part, only be better served when the tourism community acquires a more comprehensive knowledge of the complexity of barriers to tourism participation faced by disabled people. Understanding the relationship between tourism and disability is critical to this knowledge. Thus, this chapter first explores the theory of disability together with the on-going tensions of the various ‘models of disability’. It then examines the medical condition of C-SCI and the impact the condition may have on an individual’s life and leisure in readiness to explore the issues of holiday-participation for individuals with C-SCI addressed later in the study.

2.2 Disability theory

Just as disabled people have been portrayed throughout recorded Western history in different ways - though, predominantly, with negativity, ‘mawkish sentimentality, indifference, rejection and hostility’ (Thomas, 1982: 4) - various approaches to conceptualising disability have evolved over time and influence how society views disabled people. As ‘The power of language is overwhelming’ (Corbett, 1996: 2), definitions of disability are crucial as they are able not only to make legitimate disablist assumptions and discriminatory practices (Barton, 1996), but also to influence policy development and service development (Barnes et al., 2005). Furthermore, given that our awareness of social issues is influenced by the concepts and terminology employed in any given society (Oliver, 1996), both the terms ‘disability’ and ‘physical impairment’ need to be defined before attempting to outline the most recognised and influential theories, or models, of disability. Prior to that, however, the terms ‘disabled people’ and ‘people with disabilities’ must also be considered as there is a subtle, yet important, difference (Darcy, 2002).
2.2.1 Definitions

According to Oliver (1990), the term 'disabled people' is a political statement to signify the reality of disabled people's oppression by society. In other words, disabled individuals are 'created' by society's disabling structures. Thus, for political purposes, Oliver (1990) and other activists insist that the word 'disabled' is emphasised and placed first. Conversely, as many disabled people do not consider disability to be paramount to their self-concept (Fine & Asch, 1988), the term 'people with disabilities' is preferred as it places 'people' at the beginning of the term to highlight that they are first and foremost people who just happen to be disabled - or retired, blue-eyed, Hindu or anything else. This does not, however, diminish the oppression they face on a daily basis, but 'provides personal dignity to their interactions with the community' (Darcy, 2002: 62). Although there is merit in the use of both terms, the term 'disabled people' will be predominantly used in this thesis as its fundamental purpose is to identify and challenge society's disabling structures that inhibit leisure travel and social inclusion. Nevertheless, both terms will be employed when appropriate, and usage will also reflect the terms used in direct citations of published work.

2.2.2 Impairment or disability

Returning to the many contradictory definitions of disability, which only serve to illuminate how deep-seated society's discomfort with disability is (Zola, 1993), the following definitions are offered since they were developed, and are still in current use, by disabled activists. Moreover, these activists contend that their definitions are critical as 'social theory, coming to terms with social life, means defining, describing, or naming our experience, our historical reality for ourselves rather than living with a definition imposed upon us' (Wallach Balogh, 1991: 38). Thus, the Union of the Physically Impaired Against Segregation's (UPIAS) definitions of the following read:

*Impairment:* Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.
Chapter 2: Disability theory & the condition & impact of C-SCI

Disability: The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

(UPIAS, 1976: 3-4)

Given this important distinction between impairment and disability, UPIAS (1976: 14) went on to assert what was to underpin the social theory of disability:

In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.

This attempt to rename and reclaim their ‘lived experience’ was first brought about by disabled people in the UK in the 1970s, and rejects the traditional theoretical approaches to disability which concentrate on the impairment as the chief cause of the difficulties experienced by disabled individuals in society (Oliver, 1990). However, these theories continue to impact on the general population’s perception of disability today, professionals included (Smith and Sparkes, 2005, 2008b), as the disabled individual is often still negatively defined by impairment alone (Ellis, 2001; Aichinson, 2003). Such a notion emerged from the early charity model, or ‘personal tragedy theory’. It focused on the root cause of each impairment in order to distinguish between disabled people, and concluded that only those persons rendered impaired through no fault of their own deserved sympathy and financial support (Barnes et al., 2005).

Thus evolved the idea that disabled people were tragic ‘charity cases’ to be pitied. Although the charity model may not be suited to informing legislation, and has since been superseded by other models, remnants of it are still very much locked into people’s psyche as many citizens still continue to debate who is, and who is not, worthy of public support in society today (Swain et al., 2003).

2.3 Medical model of disability

Next emerged the highly-influential theory of disability commonly termed the medical model – or named the ‘individual model’ by Finkelstein (1980), Oliver (1983) and other activists. This
encompasses the ‘medicalisation’ of disability underpinned by the personal tragedy of disability (Mullen, 2003). Here disability is located fully in the individual’s loss in function, so rather than seeing the individual as separate from his/her impairment, the person is wholly and negatively defined by it (Ells, 2001; Aitchinson, 2003). Thus, if a person has difficulties participating in mainstream tourism, the problem is situated within the impairment, not the industry, as ‘disability’ springs totally from impaired functioning levels, not societal structures. Consequently, since the nineteenth century, this has placed the fate of disabled people in Western societies entirely in the hands of healthcare professionals (Barnes et al., 2005). Moreover, they have focussed solely on impairment with ‘cure’ (Oliver, 1999) since this model assumes that an individual with an impairment cannot be healthy even though there is a clear difference between being temporarily sick, or in bad health, and having a permanent impairment. Even today, healthcare professionals, along with therapists, social workers and those in the caring professions still largely operate within this model (Darcy, 2002) which, in turn, extends to other professionals, tourism providers and researchers included, when exploring disability issues.

From this medical perspective, therefore, participation in any mainstream activity is possible only through individual change/‘cure’ and rehabilitation in order to be able to ‘fit’ into a society - or tourism industry - which has been constructed by and for the needs of the most dominant group, able-bodied citizens (Barnes et al., 2005). Consequently, those who are different and cannot ‘adapt’ to fit into the mainstream, experience disadvantage, marginalisation and, in some cases, complete social exclusion. Furthermore, since disability is defined by an individual’s functional ability, people with more ‘deficits’, or a greater number of impairments or degree of dysfunction, experience even greater disadvantage and social exclusion (Darcy, 2002). As British and other politics did not take disability issues seriously until social protests of the 1980s:
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The development of social policy through the twentieth century has done little to overturn the marginalization of disabled people. State guaranteed citizenship has far less meaning for a group whose members experience high levels of exclusion from the labour market and low standards of living, where disability is 'naturalized' as a social division and unequal treatment justified on grounds of biological deficiency....

(Barnes et al., 2005: 151)

2.4 Social model of disability

In contrast and direct challenge to the medical model, an alternative and more politically-motivated social model of disability was developed and, for the first time, redefined the experience of disability as being completely external to the individual (Hughes & Patterson, 1997; Barnes, 2003). It turned the early person-centred theory on its head and declared disability to be wholly socially-constructed (Imrie, 1996; Tregaskis, 2002). It showed that society's social and political structures disable, oppress and exclude those who do not easily fit into the mainstream (Barnes et al., 2005). Furthermore, central to the social model is the notion that disabled people are disabled by prejudice implicit in socialisation, language and cultural representation (Freund, 2001).

2.4.1 The role of culture

Culture 'consists of the values the members of a given group hold, the norms they follow' (Giddens, 1989: 31) and, in today's culture, leisure and lifestyle are increasingly seen as the principle mark of status and identity (Giddens, 1993):

*It is in the sphere of consumption - conspicuous leisure on the basis of adequate disposable income - that many will seek to express their sense of freedom, their personal power, their status and aspirations.*

(Tomlinson, 1990: 6)

Thus, as much as 17% of the UK's household expenditure at the close of the twentieth century went on leisure activities and, significantly, on holidays (CSO, 1994). However, although disabled people have the same desires and motivations as others to take holidays (Yau et al., 2004), restricted financial means ensues that they are often unable to make use of any of their
unrestricted ‘free time’ (Martin & White, 1988; Barnes et al., 2005) to go on holiday. Shakespeare (1994) thus called for greater analysis within the social model of the role of ‘culture’ in disabled people’s oppression.

Furthermore, more than over a decade after the ADA (1990) and the DDA (1995) were introduced, physical inaccessibility still prevents wheelchair-users from entering many tourism and hospitality establishments (Barnes et al., 2005). Institutional discrimination persists in these industries because the law gives disabled citizens limited protection from unfair treatment in the provision of goods and services as service providers are exempt from implementing change if they are able to show that compliance would damage their business (Barnes et al., 2005). Society as a whole is therefore failing to adjust to disabled people’s social needs and aspirations (Hahn, 1986; Darcy, 2002) because, in denying them these conspicuous leisure practices, it both discriminates against them and also ‘assaults upon [their] self-identity and esteem’ (Barton, 1996:8). As such, this is ‘an area which amply illustrates the force of analysing disability as a form of social oppression’ (Barnes et al., 2005: 185) which very few studies, to date, have addressed.

2.4.2 The media

Part of the reason why disabled people’s leisure needs have rarely received attention is that disability researchers’ political focus has not deviated from matters such as employment or housing. Added to this, Lonsdale (1990) asserts that society in general, to which tourism scholars naturally belong, holds consistently low expectations of disabled people which arguably translates into the common misconception that disabled people either cannot or do not have the desire to take holidays. The media plays its part in perpetuating this misconception because, while images and stories of able-bodied people’s leisure abound in society, those relating to disabled people are generally absent or negatively portrayed (Davis, 1997; Barnes et
This negatively affects disabled people's self-concept (Barnes et al., 2005) as Cross' experience (1994: 164) reveals:

_We live in a world which depends for its smooth functioning on marginalising all those for whom its living, working and leisure space was not designed. But we are not just marginalised, we are oppressed and the oppression and abuse have one central identical effect – to make the victims blame themselves and feel that they are bad._

This, in turn, negatively affects many disabled people's actions and social integration (Smith & Sparkes, 2005, 2008b). Thus, the social model is intent on creating strategies to remove or significantly reduce the restrictive cultural, social and political barriers which negatively affect an individual's self-concept and inclusion in mainstream society and activities. To do so, it promotes a specifically socio-political approach to understanding disablement, highlighting a whole range of subtle and overt disabling processes and structures which deny disabled people basic human rights and rights of citizenship, such as the right to take holidays. According to Oliver (1996), the solution to such disablism rests solely with societal change to counter institutional discrimination and individual prejudice with regard to attitudinal barriers, inaccessible buildings and transport, segregated education, inadequate welfare provision and a lack of work and leisure opportunities. In essence though, as Vasey (1992: 44) notes:

_The social model is not about showing that every dysfunction in our bodies can be compensated for by a gadget, or good design, so that everybody can work an 8-hour day and play badminton in the evenings. It's a way of demonstrating that everyone - even someone who has no movement... – has a right to a certain standard of living and to be treated with respect._

2.5 Tensions within the social model

Given the diverse personal and political background of the disability theorists, different emphases have naturally emerged within the social model (Barnes, et al., 2005). The more radical social theorists (eg, Oliver, Abberley, Finkelstein) argue that disablement is a by-product of a capitalist society's values, and that the root of disabled people's oppression is founded on the material and cultural changes witnessed in the nineteenth century with the emergence of
Western capitalism (Barnes et al., 2005). With its emphasis on speed and a rigid, uniform and mass-produced form of production – and thus an idealised physical form to keep pace - capitalism replaced the slower, more flexible and inclusive agrarian and cottage-industry based society; disabled people were therefore excluded from the work place and, subsequently, due to poverty of income, from the social and cultural world also (Abberley, 1993).

With this development of capitalist mass production, disabled people’s fate was to become dependent and ‘to exist’, out of sight, on insufficient ‘handouts’ outside mainstream society and social consciousness; they thus became the forgotten, the powerless, the rejected and the silenced (Young, 1990). ‘Hegemony’ ensued as disabled people then adopted the oppressive views of the dominant group that oppressed them (Young, 1990). Thus, just as they experienced rejection, they subconsciously rejected themselves and others whose biological difference did not conform to the idealised, physical ‘norm’, resulting in low self-esteem (French, 1994) as indicated earlier, and ‘internalised oppression’ (Rieser, 1990). Yet, although disabled feminists (eg, Morris 1991; Crow, 1992; French, 1993; Parker, 1993; Wendell, 1996; Thomas, 1999, 2004) acknowledge the role of capitalist mass production and the importance of addressing societal structures, they are opposed to an entirely materialist approach as the oppression of disabled people predates Western industrialisation.

2.5.1 The multiplicity of disability

Since the very basis of oppression lies in the interpersonal relations between people with and without impairments, disabled feminists seek to highlight the individual or personal experience of disability (Wendell, 1996). They contend that, whilst disabled people have some similar, shared experiences of disability, differences in individual circumstances and experiences should also be recognised in the social model. For instance, compared with disabled men and able-bodied women, disabled women experience ‘double disadvantage’ as women are often already
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economically, socially and psychologically disadvantaged in society (Fine & Asch, 1985; Lonsdale, 1992).

Furthermore, although all wheelchair-users have to endure being simultaneously ignored and stared at in public (Murphy et al., 1988; 239), in a culture where physical attractiveness is especially highly-prized for women, disabled women are more likely to suffer from poor body image and self-identity intensified by these public ‘stares, by condescension, by pity and by hostility’ (Morris, 1991: 25). Compared with disabled men, they are also less likely to have sexual partners, attract able-bodied spouses or become parents (Campling, 1979; Lonsdale, 1990; Morris, 1991; Begum, 1992). Thus, with an emphasis on ‘how we feel and think about ourselves’, Thomas’ (1999: 46) ‘social relational theory’ of disability adds the social undermining of disabled people’s emotional well-being to the social oppression involving restrictions of activity.

Critique of the social model, however, lies not only in the absence of analysis of gender but also of other basic social divisions affecting disabled people’s economic and social lives, such as race (Hill, 1994); age (Morris, 1992) and sexual orientation (Hearn, 1991). Thus, alongside the collective political accounts, disability theory should also include the ordinariness of living with disability (French, 1993) as ‘personal experience can powerfully illuminate aspects of these “social barriers”, and so point to areas of social change’ (Thomas, 1997: 624).

2.5.2 The corporeal experience of disability

Since ‘disability is, at some level, undeniably to do with pain or discomfort of bodies’ (Williams, 1996: 206), another perceived inadequacy of the social model is that the real, biocultural nature of disability is not acknowledged (Thomas, 2004). Thus, with reference to C-SCI, Humphrey (1994: 6) observes that ‘the social model appears to have been constructed for
healthy quadriplegics [as it] avoids mention of pain, medication or ill-health'. Likewise, the ‘Horrendous pain’ felt by a man with high-level C-SCI and by others with SCI in Smith and Sparkes’ (2008b: 229) study is discredited by healthcare professionals who do not recognise phantom limb pain. The belief these men have in their understanding of their own experience, and of themselves, is therefore undermined and, according to Wendell (1996), they may even feel stigmatised, marginalised or socially oppressed by such a lack of recognition of their physical experience by others.

Again, in relation to the individual with C-SCI, Smith and Sparkes (2008b) acknowledge that his incapacity to breathe without a ventilator, the pain and fatigue he feels, and the fact that he has no control over his bladder or bowels are, as Thomas describes (2004), effects of impairment which, unlike disability, is not socially-constructed and thus not a form of social oppression. Speaking from personal experience, Morris (1991:10) draws attention to the:

\[\text{tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability - and do indeed disable us - to suggest that this is all there is to it is to deny the personal experience of physical or intellectual restrictions, of illness, of fear of dying.}\]

Similarly, French (1993:16) adds:

\[\text{I believe that some of the most profound problems experienced by people with certain impairments are difficult, if not impossible to solve by social manipulation. Viewing a mobility problem as caused by the presence of steps rather than by the inability to walk is easy to comprehend... However, various profound social problems that I encounter as a visually impaired person which impinge upon my life far more than indecipherable notices or the lack of bleeper crossings, are more difficult to regard as entirely socially produced or amenable to social action.}\]

The gulf between the medical and the social models of disability have thus led to calls to redefine disability so that the biology and sociology of impairment might coexist (Hughes & Paterson, 1997). International classification of disability was revised by the WHO in 2002 to a more bio-psycho-social one. By accepting that social factors are not wholly responsible for
disability, some disability scholars begin to mention the unmentionable in disability politics, that is, that impairment or associated complications, pain or fatigue are, in some cases, also highly relevant to the experience of disability.

Social theorists like Oliver (1996:38) reject such inclusions, insisting that ‘the social model is not an attempt to deal with the personal restrictions of impairment but the social barriers of disability’. Moreover, to highlight impairment would run the risk of reducing disability once again to simply ‘physical limitations’ of the old medical model rather than focusing on the real causes of discrimination and prejudice created by structural factors (Shakespeare, 1992). Whilst these theorists acknowledge the impact of impairment, they still believe that highlighting the embodied nature of impairment will adversely affect the development of a ‘disabled identity’ necessary to challenge structural barriers (Watson, 2002). Thus tensions within the model continue. Many insist (eg, Morris, 1991; French, 1993; Crow, 1996; Thomas 2004) that the individual, personal experience and embodied nature of impairment is integral to their lived experience as a disabled person, and should be included in the social model, whilst others like Oliver (1996), who privilege a materialist approach, totally resist their inclusion.

Oliver (1996), Barnes (2003 and other social theorists nevertheless concede that, although neither impairment nor ‘the personal’ belong in the ‘social model of disability’, they do belong in a separate ‘social model of impairment’ which should stand alongside the former to create a ‘comprehensive theory of disability’. Currently, however, there is no comprehensive theory of disability that recognises the full bio-psycho-socio-political nature of disability which is able to embrace what Oliver (1996) calls the ‘totality’ or hegemony of disability with its three contrasting, yet interacting, levels of disablement: the personal, the social and the societal.

Finally, although the social model’s emancipatory goals are admirable, the fact remains that part of disabled people’s lived experience is undeniably linked to their level of corporeal impairment.
which is not socially-engineered. Furthermore, by downplaying physical impairment to focus on political-structural barriers and a positive identity for disabled people, there is the danger of representing disabled people as one homogenous group with the same needs (Smith & Sparkes, 2005). Calls for the inclusion of the corporeal, together with personal experience of gender, ethnicity and sexual orientation, will therefore continue as impaired bodies have been silenced far too long, not only by society and its rehabilitation ethic to return disabled people to ‘normal’ (Gallagher, 1998), but also by the disability movement itself in its drive to demonstrate assimilation into normal life or disability only as oppression by society (Stiker, 2002).

2.5.3 The social model & the research agenda

Despite these controversial omissions, the current social model still offers a fresh, non-medicalised way of conceptualising disability and, importantly, the greatest emancipatory approach (Darcy, 2002; Barton, 2003). Thus, with its central goals of ‘redefining disability in terms of a disabling environment, repositioning disabled people as citizens with rights, and reconfiguring the responsibility for creating, sustaining and overcoming disablism (Dewsbury et al., 2004), its demise is premature. Furthermore, as it stands, the social model has the power to transform consciousness and offer non-disabled professionals, such as those within the tourism community, a means by which to reflect on their own practices (Oliver, 1996).

With such a strong ‘disabled identity’, the social model is also the most effective in connecting a research agenda with political action by focussing on social barriers to overcome disablism and reclaim human rights (Oliver, 1996; Barnes, 2003; Snape et al., 2003) as it: ‘identifies society as ‘the problem’, and it looks to fundamental social and political changes to provide the ‘solutions’ (Barnes et al., 2005: 2-3). Yet, to date, research examining the issues of disabled people has been predominantly from non-disabled people’s perspectives and from the medical model’s conceptualisation of disability (Oliver, 1999; Barnes, 2003). Similarly, in tourism
research, 'few, if any, of the social constructs of disability have permeated the tourism literature' (Shaw & Coles, 2004: 214). Shelton & Tucker (2005: 211) thus urge tourism academics to fully acquaint themselves with the subtleties of the developing body of disability theory because:

The academic study of tourism so far largely has failed to address the implications for the social theories of disability, concentrating rather on practical issues of dismantling barriers to physical access...[which], although of value, has served to perpetuate person-centred models, and thus is itself potentially disabling.

Ultimately, however, if the right to take a holiday is to become a reality for all disabled would-be tourists, the complex nature of disablement, including the restrictions and consequences of various functioning levels which are not socially-constructed, need also to be considered. Both the personal experience and the bio-nature of disability will therefore be addressed in this study which inevitably involves acknowledging an element of the medical model. That said, as the emancipatory goal of the thesis is to suggest potential solutions to afford individuals with C-SCI an 'opportunity to participate' in mainstream tourism (Shelton & Tucker, 2005), the social model approach to disability will be the predominant focus. Finally, since the individual and collective conditions of disabled people are largely not fixed, the work will also acknowledge that the experience of disability may also have:

an 'emergent' and temporal character. This spans the individual's experience of disability, in the context of their overall biography, social relationships and life history, the wider circumstances of disabling barriers and attitudes in society, and the impact of state policies and welfare support systems.

(Barnes et al., 2005: 31)

2.6 The condition of C-SCI

2.6.1 Background

Few members of the public, or even the general medical profession, have much knowledge or understanding of C-SCI (Creek et al., 1989; BASICS, 2005). Yet the condition known as
tetraplegia, formally called quadruplegia, which involves paralysis in all four limbs, and for which there is currently no cure, is one of the most devastating both physically and psychologically (NSEM, 2006). From 2,500 BC when the Egyptian physician Imhotep’s conclusion was that C-SCI was ‘an ailment not to be treated’ (Smith, 1862: Case 31, cited in Lifshutz & Colohan, 2004), the prognosis for spinal cord injuries remained totally negative until the mid twentieth century. Such negativity was equally apparent in Homer’s ninth century Greek epic the ‘Odyssey’ whose character, Elepenor, broke his neck falling from a roof and was relegated to Hell as ‘his soul went to Hades’ (Lifshutz & Colohan, 2004). It was not until spinal cord injured World War heroes returned in 1944 that Sir Ludwig Guttmann created the world’s first specialist spinal unit in the UK dedicated:

... to rescue those men and women from the human scrap-heap, and to return them, in spite of their profound disability, to the community as useful and respected citizens.

(Guttmann, 1964:116)

Before then, however, many people who sustained a SCI died within a year, or sometimes weeks, of SCI. Yet, today, due to advances in specialist medical care, many people with even C-SCI can today approach the lifespan of non-disabled individuals.

2.6.2 SCI statistics

The declining mean age at injury has led to a long-term increase in the prevalence of people with SCI in the population, now estimated up to 2.5 million worldwide with 400,000 in the USA and over 250,000 in the UK (ICCP, 2004). The latest available statistics on the incidence of SCI in the UK indicates that in 2001, 745 new patients with an average age between 20 and 29 were admitted to Spinal Injury Centres (BASICS, 2001). This may be an underestimation of the true numbers of people living with SCI, however, as SCI is not a notifiable condition. Of the 745 patients, 590 (441 males and 149 females) were admitted with paralysis caused by trauma due to, most often, falls, then road accidents and sporting accidents. Although, for many
reasons, the general public tends to see fewer people with C-SCI than SCI (paraplegia) in public, traumatic C-SCI is actually slightly more common than SCI (BASICS, 2005). Both, however, involve paralysis as a result of damage to their spinal cord, details of which will follow and which, unless otherwise stated, are sourced from Seymour (2002) and NSEM (2006), the comprehensive, medical education manual for staff at NS where fieldwork for this study was conducted.

2.6.3 The Spinal Cord

The spinal cord is approximately 18 inches/ 45.7cm long and runs from the base of the brain, down the middle of the back, to around waist level. It is the largest nerve in the body with millions of nerve fibres transmitting messages between the brain and different parts of the body in order to activate movement and sensation. The spinal cord’s vital importance to the functioning of the body means that it is surrounded and protected within a column of separate pieces of circular bones called vertebrae which, together, constitute the spinal column, commonly known as the spine or the back bone comprising 33 vertebrae (7 cervical, 12 thoracic, 5 lumbar, 5 sacral and 4 coccygeal).

Individuals may break their back or neck, but as long as the fragile, gelatinous spinal cord encased within the vertebrae is not damaged, they will be able to walk again once their bones have been stabilized. In most cases, damage (eg, from car accidents, gunshot wounds) occurs when fractured vertebrae pinch the spinal cord causing it to bruise, swell and partially, or completely, tear. Infection and disease (eg, spina bifida, polio) can cause similar damage, again resulting in some form of permanent paralysis since the spinal cord and the brain are the only parts of the body which are unable to repair themselves when damaged. Damage may be complete or incomplete, however, and results in varying degrees of functionality.
2.6.4 Names & levels of C-SCI

The exact point of damage along the spinal cord, known as the lesion, determines the actual severity of paralysis. The higher up the lesion occurs towards the brain, the greater the degree of dysfunction as the spinal nerves below the point of injury, which send messages to the brain, will be partially or completely blocked. The most severe cases are those affecting the cervical (neck) region and are labelled C1-C7 depending on the position of the vertebra with which the lesion is associated. ‘High-level C-SCI’ is from C4 to C1, with C1 the very highest injury possible. The most common injury in this region is at C5, however, followed by C6 and then C4.

2.6.5 Functioning levels

Table 1 below offers a general guideline indicating the different functioning abilities of individuals with varying levels of C-SCI.

Table 1: C-SCI & Functioning Ability

<table>
<thead>
<tr>
<th>Level of Injury</th>
<th>Functionality</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1, C2, C3, C4 (High-level C-SCI)</td>
<td>Many trauma patients above C4 die before being hospitalised as they are unable to breathe unassisted. Those who survive require a ventilator to breathe and assistance to properly cough to clear the chest and avoid infection. Assistance is needed with all movement and personal tasks: washing, dressing, feeding and bladder and bowel management. Electric/power wheelchair is used and controlled by a mouth or chin piece which can also manoeuvre and change the angle of the wheelchair seat to relieve skin pressure points.</td>
</tr>
</tbody>
</table>
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<table>
<thead>
<tr>
<th>C5</th>
<th>Shoulder and biceps control but no wrist or hand control. Assistance is therefore needed for bladder and bowel management and adaptive equipment required for self-feeding.</th>
</tr>
</thead>
<tbody>
<tr>
<td>C6</td>
<td>Generally wrist control but no hand function so adaptive equipment required to carry out all personal tasks.</td>
</tr>
<tr>
<td>C7</td>
<td>Can straighten arms but may still have dexterity problems with hand and fingers. Generally independent in transfer to bed, the WC and accessible car which they can drive. With low-level C-SCI more agile manual wheelchair can be used, which is far narrower, costs and weighs much less, and can be disassembled into smaller pieces to assist travel.</td>
</tr>
</tbody>
</table>

Source: NSEM, 2006

#### 2.6.6 Medical complications

One of the world's most well-known individuals with C-SCI was the late actor, Christopher Reeve. The former 'Superman' star was paralysed from the neck down in 1995 after he sustained a very high-level C-SCI (C2) from a horse-riding accident. As with so many formally highly-active and adventurous young people, the painful irony was all too evident with Reeve. The man with the once super-human physical condition was unable to move below the neck or to breathe without the aid of a ventilator.
Just nine years after his injury, Reeve died at the age of 52 having succumbed to an infection from a skin sore which had spread to the rest of his body. This caused a heart attack after which he fell into a coma and died the same day. His untimely death illustrates the devastating consequences that such a common complication of C-SCI may have on anyone with the condition if some one like Reeve, with all his fame, fortune and round-the-clock care by resident medical staff in his home, could also fall victim to the common skin sore.

Thus, once an individual with C-SCI has been stabilised, careful attention to the prevention of potentially life-threatening medical complications must play a major role in the daily management of the condition. The skin sore, known also as a bed or pressure sore, is the most common complication associated with C-SCI. It can lead to amputation or death as in the case of Christopher Reeve. Other common, and potentially life-threatening, complications are: **Autonomic Dysreflexia** (ie, an overreaction of the nervous system due to an irritation such as a full bladder, pressure sores or temperature changes); **respiratory problems; urinary problems; temperature regulation; and circulatory problems**. Hospital rehabilitation programmes thus tend to focus on the medical condition rather than the person (Loy et al., 2003), much to the cost of patients’ psycho-social well-being and re-integration into mainstream society. Yet, with the advancement of medical science, the central issue is no longer whether people with SCI can be kept alive, but more about their quality of life. Thus, *‘the process of rehabilitation and integration of the person with spinal injury into society ...are areas requiring further attention’* (Creek et al., 1989: 4; Barnes et al., 2005).

### 2.7 The impact of C-SCI

In general, when acceptance of impairment is not reached, anger is often felt and turned on oneself resulting in depression (Zola, 1982). This is particularly true for those with SCI as theirs are *‘injuries embedded in time. The body becomes a perpetual memory to the split second*
of time in which the spinal cord was severed' (Seymour (2002: 138). Alongside anger, a whole range of emotions like grief and guilt are frequently felt by individuals with SCI, and sometimes by their family members as well; amongst the most commonly-acknowledged are: fear, sadness, loneliness, anxiety, low self-esteem and hopelessness at having lost control of every aspect of their lives (SIA, 2005).

Thus, like other survivors of traumatic events, those with SCI are often referred to in terms of mental disorders, post-traumatic stress disorder, hostility, suicide rates, substance and alcohol abuse, boredom, and depression (Charlifue & Gerhart, 1991; Coyle et al., 1994; Radnitz & Tirch, 1995; Kewman & Tate, 1998). Furthermore, as social contact is greatly reduced with disability (Barnes et al., 2005), yet ‘the self is fundamentally social in nature’ (Charmaz, 1983: 170), researchers have developed themes of isolation, dependence and loss of self through the lack of work and restricted leisure activity and social integration following injury.

In fact, many with SCI feel that life is practically over having bought into the widespread notion in Western cultures ‘that says that if you can’t walk, then your life isn’t worth living’ (Morris, 1992:3). Such body fascism is reflected around the world in the inaccessible built environment which generally excludes non-walkers – and even in hospital rehabilitation where the focus has tended to be on walking or near walking with crutches (Oliver, 1996). Thus Oliver (1996) argues that links between rehabilitation practices that encourage walking, and wider aspects of social control can be drawn, and that through therapeutic practices, non-walkers are negatively controlled both individually and as a group, which ultimately becomes an abuse of human rights that governments must address.

2.8 Rehabilitation & functionality hierarchy
Even when a person's impairment cannot be cured, normative assumptions are not discarded and still dominate rehabilitation professionals' perceptions of the rest of the patient's life (Oliver, 1996; Barnes et al., 2005). Moreover, since the condition, not the person, is treated (Lonsdale, 1992; Loy et al., 2003), failure to achieve the rehabilitation unit's adjustment goals tends to be interpreted as the individual's failure (Triechman, 1980; Oliver, 1981). The medical model of disability and the power of one group over another are thus very much reflected in rehabilitation as:

> the identification and pursuit of goals chosen by the powerful and these goals are shaped by an ideology of normality which... goes unrecognised, often by the professionals and their victims alike. ...[This] gives rise to a set of social relations and a range of therapeutic practices that are disabling for all concerned.

(Oliver, 1996: 104)

In addition, as rehabilitation programmes are traditionally geared towards men's needs, they especially impede disabled women's re-integration into society (Lonsdale, 1992). The male bias with regard to the priority given, for instance, to male sexuality and sports has been noted by male and female disabled authors alike (eg Morris, 1989; Lonsdale, 1992; Oliver, 1996). Thus, during his rehabilitation at the UK's leading specialist SCI hospital, Oliver (1996: 7-11) commented:

> the culture at the Stoke Mandeville was definitely macho, and I was encouraged to take as much physical activity as I wanted. ...While I think the value of sport for disabled people is over-stated in therapeutic and rehabilitative terms, there is no doubt that is was valuable to me personally; it enabled me to maintain a positive self-identity... and embedded me in a network of social relationships, many of which remain today.

For those physically-able to engage in sport, 'a sense of connectedness to others' with similar impairments can therefore be achieved (Groff & Kleiber, 2001: 330). Consequently, a number of studies (eg, Coyle et al., 1994; Krause, 1998) have indicated the significance of leisure activities, though predominantly disabled sport, on subjective well-being during the initial stages of SCI rehabilitation. Yet, clearly, those patients with C-SCI who have no movement below the neck, and are thus physically unable to play sport, are disadvantaged in this...
environment. This exposes, therefore, a psychologically-damaging hierarchy of level of functionality within hospital rehabilitation where the most physically-impaired become, along with the females, the most invisible and socially-excluded. During such a rehabilitation experience of nine months, Smith and Sparkes (2008b) found that the identity of an individual with high-level C-SCI became damaged and, as it had not been repaired or restored since leaving rehabilitation, this later led to profound despair and social isolation. His deterioration both during, and since, rehabilitation is apparent in the following comment when he describes how he was: 'a mess... in the rehabilitation unit ...[but] I'm still like that. Some days are even worse now. ...Maybe I've got worse.' (Smith & Sparkes, 2008b: 225).

2.8.1 Sexuality

Since disabled people are generally perceived not to have sexual feelings or needs (Barnes et al., 2005), disabled writers have frequently commented, 'Sexuality is often the source of our deepest oppression' (Finger, 1991). Yet, when Zola (1982) stayed at Het Dorp's self-contained disabled community and village in the Netherlands, he noted that, although all its inhabitants had come to the village post-rehabilitation, they were still influenced by it as overt functionality hierarchy still existed amongst them. Furthermore, the men were far more likely to be able to attract their first choice of partners: able-bodied women. Their choice not only reflects rehabilitation's hierarchy of functionality, but also society's negativity and distancing from non-walking people, particularly non-walking women. Moreover, disabled women are further disadvantaged because they are generally able to attract neither able-bodied or nor disabled men (Zola, 1982; Begum, 1992).

The social advantage of disabled men is further reflected in rehabilitation practice as it is they who often have the only opportunity of experiencing intimacy as a newly-disabled person during rehabilitation (Oliver, 1996). Arguably, this later instils in them greater social
confidence and expectations. Speaking from such experience during rehabilitation, Oliver (1996:7) explained:

there were the women; nurses, physios, OTs, all of whom were required to perform professional acts of intimacy. It is not surprising that the boundaries between these professional and personal acts of intimacy were often blurred in the evenings and at weekends, given that the majority of the patients were young men and the majority of the staff were young women.

In contrast, the women’s lack of opportunity for intimacy in rehabilitation appears to set a precedence for what they are likely to experience on return to mainstream society. Given that women generally tend to be viewed in Western cultures as sexual ‘play-things’, much of their self-worth is connected to their being perceived as sexually attractive (Lonsdale, 1992). However, in not being able to conform to the ‘body perfect’ of the idealised sexual images of women with which society is bombarded (Barnes et al., 2005), Lonsdale (1992: 63) asserts that she and other disabled women are viewed as asexual and, with that: ‘Society has more or less successfully barred us from participation in the only sphere in which it has been deemed we might experience self’.

2.8.2 Relationships

In one of the most comprehensive social studies of SCI to date, albeit based exclusively on the experiences of 550 men, Creek et al. (1989) found that the men were largely satisfied with their social contacts post-SCI which reflects what Oliver (1996) and others reported, in general, in relation to males. Single men were, however, concerned that their disability would restrict their chances of finding new partners post-rehabilitation, although a minority admitted that it was easier making contact with women since becoming disabled as: ‘it’s easier for a man in a wheelchair to start a relationship with a female; people in general, especially women, talk to you more, they don’t feel threatened’ (Creek et al., 1989:168-9). However, as the injury levels of these men are not disclosed, it is not known whether or not the men with C-SCI had similar experiences or, indeed, what women encountered post-rehabilitation.
2.9 Psycho-social adjustment

Developing skills to adjust to and manage their new lives and concerns as wheelchair-users is paramount for the on-going period of rehabilitation, particularly for those with low social and psychological adjustment post-injury (Coyle et al., 1994) since:

persons who have a high level of social support, who are satisfied with their social contacts and who feel they have high levels of perceived control report high levels of well-being.

(Schulz & Decker, 1985:1162)

However, psycho-social adjustment is complex and far from one-dimensional as it:

refers to the complex relationship between the functional limitations of the person with a spinal cord injury, and social restrictions faced and the meanings that both these functional limitations and social restrictions have for the individual.

(Creek et al., 1989:415)

Due to limited resources and the time-consuming practical management of SCI in order to avoid medical complications, rehabilitation programmes are often unable to provide the psycho-social assistance (Creek, et al., 1989; Loy et al., 2003) necessary to facilitate adjustment within a wider social context (Triechman, 1980; Oliver, 1981). Most of the non-medical research on SCI, however, centres on studies on the psychological impact of impairment. The earlier ones focused particularly on how the recently-disabled individual passes through a number of stages similar to that of bereavement: grief/mourning, shock, denial, anger and depression (Kerr & Thompson, 1972; Weller & Miller, 1977). This approach was criticised for taking no account of the personal reality of many disabled people, however, and the fact that some might never grieve or pass through this series of adjustment stages (Triechman, 1980; Oliver, 1981), or might even ‘experience distress or disorganization long after recovery might be expected’ (Silver and Wortman, 1980:309). Although, again, levels of SCI were not specified, Creek et al. (1989) found that the length of time, particularly after nine years, was a crucial factor in getting back to leading a reasonable life in the community.
Later psychological research on disruption of self and identity post-injury (Asbring, 2001) has largely focused on those who adjust successfully - often attributed to full-time employment (Galvin, 2002) - rather than on ways to assist those who fail to adjust (Triechman, 1980). The latter, Triechman (1980) suggests, would involve measuring the effectiveness of rehabilitation, although suspects failure to adjust would also be influenced by the general societal environment and the individual's own social and physical situation. Manns and Chad (2001) later determined that the ability to adjust to a new quality of life following traumatic SCI was, indeed, affected by physical function and, specifically, by the level of achievable independence in relation to spontaneity, physical access, employment and finances, social function, relationships and emotional and physical well-being. Thus, the authors found that those with C-SCI were more greatly affected by issues to do with physical function, independence and physical well-being.

2.9.1 Physical well-being

The lack of physical well-being often due to skin sores or bladder problems resulted in the majority of men with SCI in Creek et al.'s (1989) study being readmitted for periods to hospital. However, further health problems occurred as non-specialist hospitals were unable to provide the necessary specialist medical and physical care, particularly for bladder and bowel programmes, to prevent secondary complications from occurring. The researchers thus suggested that the general medical profession's knowledge and practice needed to improve alongside more systematic and comprehensive monitoring with regular check-ups following individuals' discharge from hospital spinal units so that the risk of readmission could be minimised. Yet, as Triechman (1980) suggested, and Younis (1998) confirmed, the issue of re-occurring medical complications actually lay more with the quality of rehabilitation programmes. Only when patients fully understand their condition, and are properly trained to
take charge of it by taking an active role in the daily management of it, can medical complications ever lessen to prevent an endless cycle of readmission to hospital (Younis, 1998).

2.10 Self & identity post-injury

Just as physical health can fluctuate, psychological research on the reshaping of self and identity post traumatic SCI has conceptualised the reconstruction as a process which ‘swings back and forth like a pendulum between the nondisabled and disabled aspects of self’ (Yoshida, 1993: 217). It suggests that the experiences of loss, sustainment, integration, continuity and the development of self post-SCI can influence identity outcomes.

The first of these identity outcomes Yoshida (1993: 224) describes as the ‘former self’ which is particularly problematic for those with SCI as the majority of those who sustain traumatic SCI are generally aged between 18 and 30 (Trieschmann, 1988; BASICS, 2005), and so there is ‘a lack of defined aspects of self upon which to rebuild a valued self’. Furthermore, society’s general ambivalence towards long-term disability appears to reflect the theory of chronic illness as ‘biographical disruption’ which, according to Williams (2000), tends to occur in mid or later life and to be accepted stoically. The problem with this notion of ambivalence is that, as most traumatic cases of C-SCI occur in young people (BASICS, 2005), the impact of such an abrupt and severe disruption to their physical self compared with the former self and life style is rarely met with ambivalence by them (Radnitz & Tirch, 1995).

Next, the ‘supernormal identity’ emerges when people engage in extraordinary activities requiring greater time and energy or refuse assistance from others (Yoshida, 1993). As the dominant view of SCI is that it is a personal tragedy, those who appear to cope and engage in former and new activities are ascribed with heroic characteristics (Kleiber & Hutchinson, 1999;
Smith & Sparkes, 2005, 2008b) rather than viewed as ordinary people managing extra-ordinary circumstances (Creek et al., 1989).

The ‘disabled identity as total self’ is regarded as a negative identity when individuals expect assistance without asking and/or believe others should know what someone with SCI can or cannot do, and so they often become angry when this is not forthcoming; in contrast, the ‘disabled identity as an aspect of total self’ appears when individuals see the impairment as just one aspect of themselves rather than viewing it as encompassing the whole self (Yoshida, 1993). Finally, the ‘middle self’ perfectly illustrates the notion that identity reconstruction post-SCI is shaped like a pendulum because it:

acknowledges and acts upon the nondisabled and disabled aspects of self while incorporating a wider social concern for other persons with disabilities and other segments of society. ...It means that both aspects of self may be taken into consideration, or not...in proportions that are important and specific to the individual and appropriate to the situation at hand.

(Yoshida, 1993: 230-1)

2.11 Lived experience of disability

Interest in the actual ‘lived experience of disability’ only emerged in the 1980s. Drawing on feminist narratives in the 1970s of traumatic experiences and illness, which opened the debate on the long-term effects of disability (Davis, 2002), researchers began to use narratives to attempt to understand the social and emotional aspects of these lived experiences (Anderson & Bury, 1988; Becker, 1997), and to make sense of people’s disruptive lives (Riessman, 1993; Becker et al., 2000; Garro & Mattingly, 2000; Bruner, 2002; Skultans, 2004; Smith & Sparkes, 2005, 2008a, b). Through narrative, a shift therefore began to take place from early interest in problems of disability to viewing disabled people as agents dealing with and finding meaning in ‘situations’ (Bury, 1991).
Telling illness or disability stories have a unique and important position in that they represent ‘*the attempt...to give voice to an experience that medicine cannot describe*’ (Frank, 1997: 18) in a culture where medical stories are considered to provide ‘the truth’ and against which all other stories are judged (Frank, 1995). One of the most powerful medicalised storylines is that life with an impairment is a tragedy, and not worth living, if a cure cannot be found (Thomas, 1999) - the current obsession with stem cell research, a point in question. Without a cure, all hope of leading a fulfilled life as a disabled person is dashed, and despair is likely to follow once hope is lost (Smith & Sparkes, 2005, 2008b).

### 2.11.1 Narratively-constructed notions of hope & well-being post SCI

Since depression and suicidal thoughts are relatively common post-SCI (Keyman & Tate, 1998), understanding the meaning of the hope that individuals with SCI have for the future is crucial to the possibility of rebuilding their lives. It is also problematic because of its subjective and elusive quality, yet, as hope is narratively-constructed (Little & Sayers; 2004), it is used with particular effect by narrative researchers to determine hope in illness and disability narratives (Crossley, 2000; Del Vecchio Good & Good, 2000; Lupton, 2003; Smith & Sparkes, 2005).

Smith and Sparkes’ (2005) study of the narratives of fourteen rugby players post-SCI illustrates that their different forms of hope have been shaped by Frank’s (1995) three categories of narratives, *restitution, quest and chaos*, into which the men’s reconstructed identity narratives are fit. How individuals experience hope following traumatic SCI is bound up with the ‘meanings’ they attach to make sense of what is happening to them which are not ‘*solely the product of individual consciousness, but arrived at as a result of interactions with other people, close relatives and friends and the public at large*’ (Oliver, 1981:52) who, in turn, are influenced by the dominant narrative of disability. Thus, Smith and Sparkes (2008b: 218) observe that, framed by a cultural repertoire, ‘*stories are both personal and social at the same*
time’ and continue to influence those who hear them (Coffey & Atkinson, 1996; Murray, 1999). The authors question, therefore, whether the first two types of narratives, restitution and quest, are naturally told by disabled people or whether they are told primarily to maintain treatment from and relationships with others since these are the stories favoured by their able-bodied personal and professional contacts.

Thus eleven of the fourteen men’s stories offered concrete hope which was framed by Frank’s (1995) restitution narrative which Smith and Sparkes (2005: 1096) translated to: ‘Yesterday I was able-bodied, today I’m disabled, but tomorrow I’ll be able-bodied again’. Some of the men preferred not to be in the company of disabled people as they perceived their disability as only temporary until an immanent medical cure enabled them to walk again. Many therefore devoted their time to lifting weights to prepare their bodies for this cure - behaviour influenced by one of society’s most common and influential stories, or ‘metanarratives’, (Smith & Sparkes, 2005, 2008b). As Oliver (1996) previously noted, the authors also stressed that these are not simply the men’s own wishful creations but culturally and historically situated stories framed by the medical model of disability and brought to them during and post-rehabilitation via reading material, the media, able-bodied friends, family, doctors, nurses, physiotherapists and other health professionals.

While such ‘cure’ stories can be important following traumatic SCI (Del Vecchio Good et al., 1994; Ezzy, 2000), they can also be ‘precarious because [if] the person invests heavily in one particular anticipated future that is predicated on restoring the body-self via medical advances’ which may not deliver, ‘the potential... to develop different senses of self and explore other identities as disabled [people] is constrained and limited’ (Smith & Sparkes, 2005: 1102). Moreover, if faith is lost in a medical cure, ‘it is likely narrative wreckage will ensure’ (Smith & Sparkes, 2005: 1102) as ‘there is no other story to fall back on (Frank, 1995: 94) having limited themselves to the heroic recovery narrative (Kleiber & Hutchinson, 1999). This was the case
for one of Smith and Sparkes’ (2005, 2008b) former rugby players who was the only participant with high-level C-SCI (C2).

Having first bought into the restitution narrative believing he would walk again, this man later lost all hope for the future when this did not happen (Smith & Sparkes, 2005, 2008b). He consequently experienced a premature conviction that his life story was over and, in despair, he told a chaos narrative which says that life like this cannot get any better. Thus, as life was deemed to be over - tragic and meaningless - thoughts of suicide surfaced (Smith & Sparkes, 2005, 2008b). Although Smith and Sparkes (2005; 2008b) draw no conclusions about a possible connection between the despair of the chaos narrative and severity of impairment, it is pertinent, however, that while the other men with SCI used gym equipment to physically prepare themselves for the future, this man’s lower functioning level appeared to be inextricably bound up with his despair when he says: ‘No cure. ...I can’t even move my fingers. What can I do? ...I may as well be dead. ...Life is not worth living like this.’ (Smith & Sparkes, 2008b: 224-7). He further comments:

I have no future.... ...I’m useless. My condition won’t improve. No point anymore. I’m no one now. It’s a matter of sitting here alone until I die. ...I just survive. No ambitions. ...Sometimes I don’t think I can go on. ...There is no hope in my life. ...Everyday is like the last. ...Everyday is another day of emptiness. ...Without anything to look forward to I just exist. ...It’s lonely existing like this. I don’t see or speak to people. ...And, talking to you now, I forgot I could speak. ...No one wants to speak with me. ...My life is hopeless. (Smith & Sparkes, 2005: 1101-2)

To move away from such despair and social isolation and try to build a new life is, as Smith and Sparkes (2005) observed, only possible when ‘those who care are willing to become witness to the [chaos] story’ (Frank, 1995: 110). When less fear and greater tolerance is displayed by able-bodied people towards this frightening story, the person is allowed to be a ‘wounded storyteller’ (Frank, 1995), and to ‘reclaim the voices that SCI has taken away from him [or her]’ (Smith & Sparkes, 2005: 1104). Nevertheless, Frank (1995; 101) stresses how difficult
chaos stories are to narrate - and hear - as they are ‘told on the edges of speech. Ultimately, chaos is told in silences that speech cannot penetrate or illuminate’.

Yet the personal responses of individuals to their SCI can never be understood merely as a reaction to trauma; they ‘have to be located in a framework which takes account of their life histories, their material circumstances and the meaning their disability has for them; in sum, social adjustment’ (Oliver, 1996: 139). This must take into account all the structural barriers they face when attempting to reintegrate into mainstream society (Thomas, 1999, 2004) or tourism. In the former rugby player’s chaos narrative, it is evident that ‘deprivation of opportunity’ (Nelson, 2001) caused damage to his psycho-social and emotional well-being (Smith & Sparkes, 2008b:224-6) as his comment below reveals:

It’s...living in darkness like this... ...I have no one. No friends. No one to socialise with or speak with. I stay clear of people now. ...if I worked, I would have people to speak to. Feel human again, maybe. ...I’d have money. Make friends. Something to fill my days. ...[But] I can’t get into most buildings. I can’t see people employing me when I need lots of space and good access. ...too many obstacles. No transport. ... The pavements are not made for what has happened to me. ... What can I do anywhere? I was in the town centre not so long ago. That is a rarity. I struggle. I feel even worse after going there. I feel useless because I can’t get into places. ...So I mostly stay inside.

Finally, in complete contrast to the culturally-dominant chaos and restitution narratives, two of Smith and Sparkes’ (2005) men told quest stories which are framed by the affirmative model of disability (Swain & French, 2000) and work as a ‘counter-narrative’ (Nelson, 2001) to promote acceptance of disability and an ability to re-fashion one’s life. Quest stories incorporate transcendent hope and the belief something positive has come out of their experience of SCI such as: possessing a more rounded, open-minded character; becoming better people; or opening themselves up to the possibilities of following new life paths by releasing themselves from the burden of resting all their hope on a cure (Smith & Sparkes, 2005, 2008b). In a similar vein, and in contrast to most research findings on the implications of traumatic SCI, a number of predominantly quantitative studies provided glimpses of unexpected positive by-products of
SCI (McMillen & Cook, 2003), concluding that those who reported benefits from traumatic injuries tended to fare better long-term than those who did not (Affleck et al., 1987; Park, 1998; Frazier et al., 2001).

2.11.2 Positive by-products of SCI

Remarkably, most of the individuals with SCI surveyed in Schulz & Decker's (1985) study reported ‘positive meaning’ in their injuries. These included changes in life priorities, increased self-efficacy, spirituality, compassion, faith in people and improved family relationships (Lehman et al., 1993; Affleck & Tennen, 1996; Mcmillen, 1999). There was no evidence that SCI increased marital disharmony and family break-up or that the divorce rate was higher than the national average; in fact, most post-injury marriages were happier than pre-injury ones (Crewe et al., 1979). Few details or explanations of these findings were provided, however, although in the case of the individual with C-SCI in Smith and Sparkes' (2005, 2008b) study, the reverse was true as he and his wife were no longer together and he was completely alone apart from his care-assistant.

In contrast again with most social research following trauma, substance abuse and alcohol consumption deceased (Lehman et al., 1993; Heineman et al., 1994; Affleck & Tennen, 1996; Mcmillen, 1999) and, despite or because of, the extra challenges disabled women generally face in society, new insights and capacities were formed giving some disabled women greater self-esteem (Lonsdale, 1992). In fact, women with SCI developed increased self-worth having overcome numerous obstacles in their new situation, and even felt liberated no longer having to conform to gender stereotypes (Bonwich, 1985). Although least acknowledged, material gain and an increase in community closeness were also reported (McMillen & Cook, 2003).

Those with higher level injuries, however, tended not to be associated with increased self-efficacy, but with increased material gain - although the reverse is usually the case (Darcy,
2002) - and 'hostility sensitivity' due to their material gain, as well as with lower psychological well-being and depression (McMillen & Cook, 2003). It perhaps follows therefore that, as the only despairing chaos narrative in Smith and Sparkes' (2005) study also belonged to an individual with high-level C-SCI, those with high-level C-SCI are less likely to fare well.

To what degree the findings of these participants' self-assessed positive by-products of SCI offer real concrete gains or are 'illusions' to help people cope with adversity is unclear (Taylor, 1988). Moreover, those close to the participants did not necessarily recognise these benefits, and as participants were paid per interview, they may also have been more inclined to give answers they felt the interviewers wanted to hear (McMillen & Cook, 2003). Further research therefore needs to examine not simply the overall percentage of people with SCI who consider themselves better off than before their injuries but, as McMillen & Cook (2003) suggest, how and why individuals might feel better, or more positive, about their situation. Crucially, however, research needs also to explore what practical steps can be taken so that more disabled people might experience subjective well-being in the future.

However, Frank (1995) cautions that by emphasising positive by-products of SCI, one is in danger of promoting the romantisation of disability together with the notion that all individuals have the same ability as the quest storyteller to rise above disability. In fact, the quest narrative ignores the problematic side to living with a high-level impairment which may be so severe, life-threatening and all-consuming that it leaves little opportunity for reinventing oneself (Barnes et al., 2005). All this is complicated by the sparse repertoire of narratives of disability from which disabled people have to draw (Smith & Sparkes, 2005, 2008b) as evidenced in the absence of narratives exploring enhanced well-being and the potential social adjustment of individuals with C-SCI via holiday-taking.
2.12 Social issues associated with SCI

Very little research exits on the practical benefit of improving the quality of life of disabled people (Oliver, 1996; Barnes et al., 2005) even though, over two decades ago, Hasler and Oliver (1982) reported that people with SCI were more concerned with the physical and social than individual medical or psychological issues. Of the social, Richards (1982) revealed that leisure and sport were amongst disabled people’s eight top priorities in life. Although literature (eg, Kleiber et al., 2002; Loy et al., 2003) has explored the positive effects of participating in disabled sport, it has examined very little of the restrictions of participation some disabled people face with view to overcoming them or, indeed, the potential of other forms of leisure, such as holiday-taking, for those whose physical functioning levels exclude them from disabled sport.

2.12.1 Restricted leisure opportunities

The leisure of most of the men with SCI in Creek et al.'s (1989) study was inhibited by factors such as higher levels of injury, single status, age, fatigue, a dislike of being ‘man-handled’, reliance on others to accompany them and even ‘root pain’. Sometimes called ‘phantom limb pain’, the origin of which remains unknown, root pain is viewed with scepticism despite some neurophysiological basis for it (Smith & Sparkes, 2008b). Many men also changed their leisure expectations because living life in a strict care-routine interfered with leisure activities, having, for example, to plan activities around bowel and bladder functions (Creek et al., 1989).

Although spontaneity was lacking, most men still continued to develop their leisure interests and friendships post-injury; however, this was generally not true with regard to holiday-taking following difficulties with physical access (Creek et al., 1989). Furthermore, those not in full-time education or employment had particularly restricted social contacts, which thus affected leisure activities, as did those with C-SCI due to: greater mobility and employment restrictions;
reliance on carers; and the type of leisure activity denied them as they were unable to play ‘disabled sport’ which, naturally, reduced opportunities to make social contacts. Although those with C-SCI were more likely to be living with other people for assistance, and thus had regular social contact within a domestic setting, no indication was given in the study whether this offered them greater opportunity to become more socially or travel-active. This was not the case, however, for the individual with C-SCI in Smith and Sparkes’ (2005, 2008b) study who had full-time care-assistants yet rarely communicated with anyone or left his home.

Finally, studies examining the positive role of leisure for disabled individuals have focused almost exclusively on sporting leisure activities which, like much of rehabilitation practice and mainstream society, generally exclude disabled women and those with C-SCI. Research therefore needs to extend to holiday-participation, and the barriers that must be overcome, if the full extent of ‘leisure’ and the subjective well-being and social integration of all disabled people are to be explored.

2.13 Summary
This chapter has presented important background information on disability definitions and terms, and outlined the development of disability theory. It compared the medical model of disability, which emphasises functioning limitations, with the later social model which argues that societal structures ‘disable’ individuals, not their condition. Tensions within the social model were then considered and it was concluded that, to accommodate the multiplicity of disability, the individual, personal, subjective and corporeal experiences of living with an impairment should be acknowledged alongside the more traditional, collective, political accounts of disability.

Next the medical condition and physical and psychological impact of C-SCI were explored. Depression and/or suicidal thoughts, gender and higher levels of impairment, along with life-
threatening medical complications associated with the condition and oppressive rehabilitation practices, affected an individual's ability to re-enter society and participate in leisure activities. In contrast, literature on the positive by-products of SCI was presented, yet it lacked detail and largely did not relate to those with C-SCI. Finally, the chapter discussed how the lived experiences of disability could be explored, in-depth, through narrative. It was suggested that counter-narratives could be offered as an alternative to the current metanarrative framed by the medical model that continues to dominate in society and rehabilitation practice and thus influences, limits and restricts disabled individuals.

The next chapter will explore the literature on barriers to tourism participation for mobility-disabled people in order to understand more fully the reasons for their restricted holiday-participation.
Chapter 3: Disability & barriers to tourism participation

CHAPTER THREE
DISABILITY & BARRIERS TO TOURISM PARTICIPATION

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3.7 Summary
CHAPTER THREE

DISABILITY & BARRIERS TO TOURISM PARTICIPATION

3.1 Overview of chapter

This chapter briefly outlines the categories of barriers to leisure and tourism participation for the general population, followed by their associated negotiation strategies. It then presents the categories, individual barriers and negotiation strategies specific to disabled tourists. Finally, it details the effect of each barrier on disabled tourists’ participation, but predominantly in relation to mobility-disabled tourists and, where possible, severely mobility-disabled tourists.

3.2 Background

Literature on barriers to tourism participation suggests that everyone is subject to constraints, the most significant of which are ill health, insufficient time, money or family-friends support network (Norman, 1995). Researchers in both leisure (eg, Jackson & Scott, 1999; Shogun, 2002) and tourism (eg, Turco et al., 1998; Daniels et al., 2005) have consistently drawn on Crawford and Godbey’s (1987) three categories of definitions of leisure constraints to determine barriers to participation in their fields. While the first category, intra-personal constraints, eg, anxiety or low self-perception, are associated with one’s psychological state which affects leisure preference, inter-personal constraints, eg family duties or lack of a suitable partner with whom to engage in the desired activity, are associated with one’s social interaction skills and can intervene between preference and participation. Lastly, structural constraints, eg, physical ability or financial or work commitments, influence participation but may be overcome if desire is greater than perceived constraints.
Literature on barriers to leisure was later refined by Scott (1991) who suggested that these constraints could be negotiated in order to facilitate participation. Constraints were also deemed to be hierarchical in respect to their order and importance, beginning with intrapersonal and followed by interpersonal and structural, the negotiation of which would follow the same structure (Crawford et al., 1991). Furthermore, Jackson (1999:196) noted that ‘people “negotiate around” constraints using a variety of strategies, achieving their leisure goals, but often in a way that differs from how their leisure would have been if constraints had been absent’. Finally, it was recognized that constraints are not static; they and their negotiation could change over time as a result of the social or historical context in which they are set (Jackson & Scott, 1999; Henderson et al., 2005). However, despite recent changes with the introduction of disability legislation in many countries, little has changed for disabled tourists across the globe since they still do not enjoy parity of opportunity as ‘there exists an economic, social, and cultural imbalance in the way in which persons with disabilities are viewed and receive services’ (Stumbo & Pegg, 2005: 200).

3.3 Barriers for physically-disabled tourists

Within a disability context, Smith’s (1987) seminal, theoretical study of barriers represents the first and, to date, most comprehensive and internationally-cited published work on barriers and constraints to tourism participation related to disabled people. As with the general population, three main categories of barriers were presented, although the author identified them as: environmental (external to the tourist); intrinsic (internal to the tourist and due to the tourist’s own cognitive, physical and psychological function); and interactive (the tourist’s response to environmental barriers).

Smith (1987) proposed that, while the combined effect of these constraints could either reduce the enjoyment of the tourism experience, or result in non-participation for any person, disabled people would be disproportionately affected by them, and so their sense of freedom would be
especially undermined. This was because intrinsic barriers were found to most negatively affect leisure enjoyment (Francken & van Raaij, 1981, cited in Smith, 1987), and since disabled tourists were far more likely to encounter a greater number of intrinsic, and also environmental, barriers, Smith (1987) hypothesized that their participation would be more affected. In addition, he suggested that severely-disabled tourists might experience even greater constraints and thus called for empirical investigation of this issue and all his other proposed barriers.

Subsequent work has corroborated most of Smith’s (1987) findings, although research examining severely-disabled tourists has been virtually non-existent despite widespread recognition that the level of disability is the greatest indicator of accessibility barriers (WHO, 2002). Any mention of severely-disabled individuals has tended only to allude vaguely to them with comments such as: ‘a person who used a motorized wheelchair and could not use his or her arms was apt to encounter more barriers than someone who used a manual wheelchair and had full use of his or her arms’ (Avis et al., 2005: 245). Thus, apart from a few notable exceptions (eg, Burnett & Bender, 2001; Darcy, 2002), research has largely focused on tourists with mild to moderate disabilities and, indeed, only on the issues and constraints affecting those who have already participated.

Furthermore, in Daniels et al.’s (2005) examination of the barriers in the website travel tales of disabled tourists, the various categories and themes of constraints and negotiation strategies were revealed to be interactive, inter-related and linear, and not hierarchical as previously suggested by leisure researchers, Scott (1991) and Jackson et al. (1993). In fact, an environmental, intrinsic or interactive constraint could arise at any time of the holiday and needed to be negotiated immediately for participation to continue. However, since Daniels et al.’s (2005) travel tales were retrospective and largely positive accounts of national and international holidays, no attention could be given to any pre-holiday constraints which might
have offered significant insight into the dilemmas faced by many would-be disabled tourists with no holiday experience.

McKercher et al.'s (2003) study nevertheless revealed how travel agents were often inhibitors of travel for disabled people during the actual planning stage of the holiday. Furthermore, Yau et al. (2004) and Packer et al.'s (2007) investigation of the holiday experiences of 86 Hong Kong residents with various visual and mobility impairments highlighted a whole range of barriers that needed to be overcome before tourism participation was possible for their disabled tourists. However, as holiday-taking in these studies was generally regarded as impossible with the onset of disability since it involved exchanging both physically and psychologically a ‘safe’ environment for an unknown one, the authors found that a six-stage process was first necessary in order to become, and then remain, travel-active. Details of this process are outlined below.

3.3.1 Process of becoming travel-active

According to Packer et al. (2007) and Yau et al. (2004), the first three ‘personal stages’ of becoming travel active were affected by early experiences of both disability and rehabilitation. Stage one, the ‘personal acceptance of impairment’, was essential in order to brave a re-appearance in public. Yet travel still generally remained difficult without financial, physical or psychological support from family who, having already provided motivation and confidence to travel, also made the best travel companions and enhanced the holiday enjoyment by generating feelings of security.

Without family support, the individual’s personality and nature of the disability were the deciding factor in deciding whether or not to take a holiday (Packer et al., 2007). Those who had become disabled at 50 plus were less confident about their travelling ability, having mainly experienced travel as able-bodied tourists, and were also found by Creek et al.’s (1989) to be the most dissatisfied with their overall situation. Conversely, those born with an impairment, or
acquired it in childhood, were more accustomed to disablement and were seen as more willing to travel (Packer et al., 2007). Ill-health, however, represented a primary obstacle to be overcome before holiday-participation was possible for anyone (McKercher et al., 2003).

Stage two was termed 'reintegration' into community life. As disabled people reconnected with the world outside by learning to function independently, or returned to paid employment, they soon desired the same opportunities as non-disabled people. This thus explored the idea of the lost pleasure of travel by rejecting the 'prevailing social attitude... that those with disabilities are not worthy of having anything but the sheer basics of life' (Yau et al., 2004: 952). Since confronting such prevalent stereotypes could be problematic, many therefore preferred the safety of travelling with friends and family or a segregated holiday for disabled tourists.

An evaluation of the 'risk and reward' of travel concluded the third of the personal stages. This stage was particularly difficult for severely-disabled individuals due to, for instance, the risk of possible uncontrolled bladder or bowel movements during flights, of not being able to exit the airport if wheelchairs were lost, or of developing health problems if dropped whilst being assisted. When the perceived risks far outweighed the possible rewards, travel was cancelled, and so this third stage needed to be revisited in order to proceed to the next 'public stages' of becoming travel-active.

Stage four involved 'taking action' to: gather information, plan the holiday and decide on strategies to cope with the journey and the new environment. Stage five, 'physically managing the trip', required testing planned strategies and also finding new ones to facilitate this and future holidays. Finally, stage six, 'post-trip reflection' of the holiday experience, determined whether the person would 'remain travel-active'. Positive first trips boosted self-confidence and travel continued, whilst negative ones - most common amongst those with severe disabilities -
had the opposite effect, often due to negative public reaction or being ‘over assisted’ by strangers. Consequently, some either stopped travelling or needed to revisit the whole process to rebuild their confidence and skills.

3.3.2 Literature on barriers to participation

Most research on the actual barriers encountered by disabled tourists tends either to use a framework consisting of Smith’s (1987) most frequently-cited category, environmental, (eg, Turco et al., 1998; Stumbo & Pegg, 2005; Bi et al., 2007), or exclusively highlights one or two environmental barriers (eg, Williams et al., 2006; Eichhorn et al., 2008; Lovelock, 2009). Of these, the two most frequently-cited are architectural (Darcy, 1998; Gleeson, 2001; Imrie & Hall, 2001; Burnett & Bender, 2001; Avis et al., 2005; Daniels et al., 2005; Bi et al., 2007) followed by attitudinal barriers (Burnett & Bender, 2001; Yau, et al., 2004; Avis et al., 2005; Shelton & Tucker, 2005; Bi et al., 2007). Yet, as Smith (1987) hypothesised, and Daniels et al. (2005) and Packer et al. (2007) subsequently confirmed, barriers to participation for disabled individuals are far more complex than most literature would suggest by its focus on environmental barriers.

Later, McKercher et al. (2003) condensed the barriers encountered by disabled tourists into two categories: ‘internal’ and ‘exogenous’. The first, they related to issues such as self-perception, the need for travel companions, the belief that travel is a right and ‘affordability’. It is debatable, however, whether the ability to afford a holiday is entirely ‘internal’ given the underlying social and political structures that create many economic barriers for disabled people. The second category, ‘exogenous’ constraints, included inaccurate information, the built environment, lack of encouragement to travel and communication challenges at home or abroad (McKercher et al., 2003). However, placing ‘communication challenges’ in this category does not, if one considers Smith’s (1987) interactive category, reflect the disabled person’s equal responsibility for overcoming cultural and communication barriers.
Arguably, therefore, Smith’s (1987) categories of barriers still offer the most comprehensive theoretical framework and widest scope for in-depth discussion of the full complexity of barriers and constraints within a disability context. Furthermore, as Darcy (1999) suggested, all Smith’s (1987) barriers ‘need to be addressed in the widest sense of access, if the ultimate goal of eliminating social injustice for people with disabilities is to become a reality.’ Thus, this chapter will predominantly use Smith’s (1987) three categories of barriers as a framework to examine the literature on constraints to tourism participation for mobility-disabled individuals.

3.4 Framework of environmental barriers

Smith’s (1987) largest and most cited category of barriers, ‘environmental’, highlights both social and physical constraints. It includes: attitudinal barriers; architectural barriers; transportation barriers; rules & regulations; and ecological conditions. With the exception of the latter, all environmental barriers are imposed by societal structures that inhibit tourism participation and inclusion in mainstream society. Subsequent research has paid less attention to Smith’s (1987) ‘rules and regulations’ and ‘ecological conditions’, where as two other environmental barriers that were acknowledged, yet not included, by Smith, have been widely-cited in published works as highly-significant environmental barriers. They are: ‘information provision and marketing’ (Turco et al., 1998; McKercher et al., 2003; Eichhorn et al., 2009) and ‘financial barriers’ (Burnett & Bender, 2001; Cameron et al., 2003; Bi et al. 2007). These will therefore also be included in the study’s examination of environmental barriers and will be addressed first.

3.4.1 Financial barriers

Financial constraints, alongside time constraints and social role responsibilities, represent the most significant barriers to tourism participation throughout the general population (Smith, 1987; Hughes, 1991). Although Hughes (1991:193-4) acknowledged that there is ‘a link
between disability and low income', Smith (1987) failed to include financial constraints in his category of environmental barriers as his intention was to foreground only barriers which disproportionately affected disabled people. Disabled people of working age are, however, twice as likely to be unemployed as non-disabled citizens (Manpower Inc., 2003) or, if employed, to earn on average 20% less than other employees (Rigg, 2003). Their lack of access to employment therefore restricts their leisure choices and their overall life experiences and opportunities (Smith et al. 2001; Mckercher et al. 2003).

Moreover, holiday-taking tends to be a far more expensive leisure activity for disabled people. A study by Cameron et al. (2003) revealed that disabled people in Australia spent between 30% and 200% more than non-disabled tourists on holiday. Instances of paying extra were also highlighted by Daniels et al. (2005) when some of the disabled writers of the travel tales recorded having to pay twice for accommodation due to travel agents' accessibility errors at the time of booking. Consequently, they needed to find and pay for another room at a different hotel whilst still being charged for their reserved, yet inaccessible, room at the first.

The lack of accessible, budget accommodation available especially affected wheelchair-users, as the larger and therefore more ‘wheelchair-accessible rooms’ tended to be at high-end, international calibre hotels (Yau et al., 2004). Most disabled tourists were thus reliant on families to finance holidays, which, in turn, restricted travel choice, feelings of independence and also the freedom to travel with friends (Darcy, 2002; Yau et al., 2004; Shelton & Tucker, 2005; Bi et al. 2007). Likewise, Hunter-Jones' (2003, 2004) cancer patients cited financial constraints as barriers to holiday-taking due to a lack of funds following periods of not being in work as a result of illness, and also the inflated cost of travel insurance imposed on them during this time.
However, those with the most severe physical disabilities tended to be worst affected financially (Cameron et al., 2003). Darcy (2002:65) explained that:

*The disproportionate lack of access to paid employment of people with high support needs ... and the resultant low incomes, radically constrains a person's ability to travel where even moderate costs are involved. This also restricts the travel choices and the frequency and duration of trips.*

Furthermore, since many severely-disabled tourists were unable to travel independently and generally required more equipment, additional financial issues arose with the added expense of transporting or hiring equipment and paying attendant costs (Burnett & Bender, 2001; Darcy, 2002). There appears to be little hope of improving the travel opportunities of severely-disabled individuals, because, as Darcy (2002) pointed out, these costs include not only paying the attendant per hour, or for the duration of the holiday, but also the attendant's travel, accommodation and meal costs. Moreover, in contrast with the more tangible issues of physical accessibility, 'the extra requirements for travel and the costs of travel for this group are not being addressed at the political level' (Darcy, 2002:69). Consequently, along with physical and attitudinal barriers, economic issues were regarded by many researchers as the most significant, socially-constructed factors affecting the tourism experiences of disabled individuals (Darcy & Daruwalla, 1999; Burnett and Baker, 2001; Darcy, 2002; Bi et al., 2007).

### 3.4.2 Information & marketing barriers

'Information is 'the lifeblood' of tourism' (Williams et al., 2006), but for disabled people to participate in mainstream tourism, specific and detailed accessibility information is essential (Darcy & Daruwalla, 1999; Whitford, 1999; Ray & Ryder, 2003; Williams et al., 2006; Packer et al., 2007; Eichhorn et al., 2008). However, readily-available tourist information tends to be both in text and photographic images directed exclusively towards non-disabled people (Fost, 1989; Ray & Ryder, 2003), ignoring the needs of disabled tourists (Darcy, 1998; Miller & Kirk, 2002; Ray & Ryder, 2003; Mckercher et al., 2003). Given the latest tourism research findings on this (eg, Murray and Sproats, 1990; Darcy, 1998; Stumbo & Pegg, 2005; Packer et al., 2007;
Eichhorn et al., 2008), little improvement appears to have taken place over the last twenty years since sociologists Creek et al.’s (1989) study of wheelchair-users first reported that this group: could not find the information needed to plan a holiday; had been inaccurately informed about access and thus had arrived at hotels without access or accessible facilities; and consequently had reduced satisfaction and therefore often stopped taking holidays.

Other research has revealed that on the rare occasion accessibility information was provided, it still lacked the most essential details. For instance, some European tourism providers’ access schemes failed to give accurate information about accessing their site or the accessibility of surrounding pathways (Eichhorn et al., 2008). Given that continuous, accessible pathways were ranked by disabled people more highly than other aspects of attractions (Israeli, 2002), the absence of such information created further barriers as people could not actually get to even the most wheelchair-friendly site inside (Marston & Golledge, 2003). The most frequently-cited information barrier was, however, the absence of specific accessibility details regarding accommodation. For wheelchair-users, the ‘most important information requirements involve the dimensions and organisation of space within the rooms. ...This type of information either is unavailable, is not provided accurately when requested or is misunderstood by the property managers’ (Darcy, 2002: 68). Yet, taking pot luck on arrival was considered too great a risk as hotels, and/or their facilities, might not be accessible, have vacancies, or be affordable (Darcy, 2002).

The use of hard-to-decipher international accessibility signage further exacerbated accommodation planning (Richter & Richter, 1999), as did the absence of photographs next to written texts or details corresponding to the type or level of disability. This was a serious omission since: ‘people may have the same disability but not the same level of functioning, [so] the need for tailor-made information is an important requirement’ (Eichhorn et al., 2008: 203). Such lack of co-ordination and co-operation to harmonise access standards thus forced
European disabled tourists always to spend their holidays always in the same, familiar region (Eichhorn et al., 2008).

Telephoning ahead to the service provider was only successful if the information provided was true and accurate (Turco et al., 1998; Frei & Madley, 1999). However, hotel employees were often ignorant of their own accommodation facilities in relation to the needs of disabled guests (Feiertag 1997), who therefore had to use a number of other sources to attempt to locate accessible information before travel (Cavinato & Cuckovich, 1992; Epstein, 1998). Although many frequently used high street travel agents (Epstein 1998), they could not obtain as reliable and detailed information as other customers because these agents were required to push standardised mass tour products, and had little understanding of their suitability for disabled tourists (McKercher et al., 2003). Some disabled people thus used specialised travel brochures (Turco et al. 1998; Ray & Ryder, 2003), but, potentially, this could have led to their taking segregated holidays and their continuing to be excluded from mainstream tourism.

The Internet offered greater possibilities of locating more detailed accessibility information than the other sources (Darcy & Daruwalla, 1999), although Williams et al.'s (2006: 71) study found that: 'the clear majority of the [Internet sites of the] UK-based hotels surveyed... failed to meet the needs of disabled tourists' as levels of web accessibility and relevant accessibility information were both low. Internet sites also generally lacked testimonials from disabled tourists (Ray & Ryder, 2003; Eichhorn et al., 2008) even though 'The most reliable sources of information... were considered to be personal inspection and information from another person with a disability'. This was especially true for mobility-disabled tourists who tended to rely far more on their own or friends' past experiences (Packer et al., 2007: 289).

Since severely-disabled people encountered far more accessibility barriers than other disability tourists in all sectors (Bi et al., 2007), they therefore had greater information needs, but
particularly in relation to accommodation (Burnett & Bender, 2001). For instance, they needed more space to accommodate their larger wheelchairs and extra equipment, such as hoists, battery chargers, commodes, shower chairs and respiratory equipment (Darcy, 2002), yet remained especially sceptical and apprehensive about the accuracy of any information provided, particularly on accommodation and attractions (Dottavio & O'Leary, 1986; Cavinato & Cuchovich, 1992; Turco et al., 1998; Darcy & Daruwalla, 1999; Ray & Ryder, 2003). Furthermore, since this group was especially constrained by financial barriers, (Burnett & Bender, 2001; Darcy, 2002), moving to a more expensive hotel with larger suites was not an option if their pre-booked hotel turned out to be inaccessible on arrival (Darcy, 2002).

Improving accessibility information is therefore essential. Furthermore, 'meeting differential informational requirements of all individuals adds to the power of tourism to reduce social exclusion' (Eichhorn et al., 2008: 206). Cavinato & Cuckovich (1992: 53) also viewed it as 'the most effective means for increasing opportunities for both the traveller and the service provider', even though the necessity of such detailed accessibility information might render the disabled market a difficult marketing segment to reach (Guzman, 1999). Even if the relevant information were readily-available, however, Ray & Ryder (2003) questioned whether this could offer the tourism industry the same economic returns as for other 'niche markets'. Nevertheless, Burnett and Bender (2001) recommended distinguishing between the needs of consumers with different levels of mobility-disability to enhance tourism managers’ market share so that separate tourist segments could be targeted in terms of mild, moderate or severe disabilities. Likewise, Bi et al. (2007) agreed that market strategies should target disabled individuals more on functioning ability than on income, age, gender or assistive devices. They overlooked the fact, however, that for some severely-disabled individuals, their ‘assistive devises’ – power (ie, electric) wheelchairs – often afford them their only ‘functioning ability’, and so it is crucial that providers are able to physically accommodate this very wide and heavy assistive device in order to accommodate the ‘functioning ability’ of the person.
Furthermore, whilst there is definite merit in understanding and catering for the needs of different groups, marketing aimed at specific levels of impairment of disabled people, as suggested by Burnett and Bender (2001), could inadvertently deepen feelings of social segregation and isolation. Moreover, to date, only the needs of those who have travelled are generally understood and can be targeted by marketers. Consequently, the travel needs of ‘non-travellers’, who are often those with the most severe disabilities, and without sufficient finances to travel, remain ignored and misunderstood. Potentially, this might lessen if the emphasis were placed more on striving to create an inclusive for all tourism industry catering, at once, for the needs of all.

Tourism scholars are nevertheless in agreement that the industry’s information provision and marketing strategy for disabled tourists must be reviewed (Israeli, 2002). Offering disabled people the same freedom of choice of information to select amongst the same alternatives as other citizens enjoy (Dattilo, 2002) must be one of the very first steps on the rocky road to tourism participation and social inclusion. Relevant, accurate information should therefore be available via mainstream publications rather than via those less far-reaching speciality submarkets (Cheng, 2002).

To ensure success, Darcy (2002) proposes that governments and the tourism industry co-ordinate the provision of accessibility information. Yet, as very little detailed research on the needs of disabled tourists exists (Shaw & Coles, 2004), how these two bodies are to acquire the quality and detail of information necessary is questionable. Although it is essential that disabled people are involved and consulted so that the details correspond directly with their greatly differing needs (Imrie & Kumar, 1998), neither these details nor the ‘value of qualitative comments by disabled people is currently ... utilized by organizations operating access schemes in Europe’ (Eichhorn et al., 2008: 199) nor, it would seem, by most researchers in tourism.
3.4.3 Rules & regulations

Organisational and institutional barriers throughout the tourism and hospitality sectors often inhibit or exclude disabled people from holiday-participation (Smith, 1987; Barnes et al., 2005). While many rules and regulations, policies and practices may unwittingly disadvantage disabled individuals (Schleien et al., 1996; O'Neil & Knight, 2000), some lead to overt discrimination (McKercher, 2003). For instance, Vladimir (1998) found that different reservation practices existed for disabled guests in some hotels when accessible rooms could not be reserved in advance because they were offered only on a ‘first-come, first served’ basis. Likewise, Feiertag (1997) noted that, on occasions, hotel staff refused to guarantee an accessible room so that their disabled guests did not know what they would find until they arrived, which, as discussed earlier, particularly inhibited travel for wheelchair-users (Darcy, 2002).

Wheelchair-users, observed Barnes et al. (2005), were also unable to turn up to some of London’s top tourist attractions, such as Madame Tussauds, without telephoning in advance to see if the ‘three wheelchair quota’ had been filled, which thus reduced both choice and spontaneity. In addition, the authors noted that wheelchair-users were generally discouraged from attending tourist attractions at peak times, and were sometimes turned away on health and safety grounds, although in reality, particularly in the hospitality industry, it was usually because their presence might be ‘bad for business’. Furthermore, the ticket sales policy of England’s National Theatre was revealed in an earlier study by Sygall (1985) to be both inappropriate and patronising when staff refused to sell tickets to two travel-independent wheelchair-users unless they were accompanied by an able-bodied chaperon. The enforcement of this policy seems to reflect the common misplaced notion held by the majority, including many able-bodied staff and policy makers, which infers that, irrespective of impairment or level of functioning, disabled people form one large homogeneous group and thus should be treated uniformly.
With a similar ‘take it or leave it attitude’ to a ‘one policy suits all’ approach, Mckercher et al. (2003: 465) revealed that the policies of ‘the retail travel sector... force agents... to push high commission, easy to book packaged tours that may not be suitable for the tourist with a disability’. The promotion of such hassle-free and time and cost-efficient mass products (Dube & Reneghan, 2000) thus meant that agents often lacked knowledge about non-mainstream options, or were unable or unwilling to investigate the accessibility of their standardised products or other independent travel options (McKercher, 2003).

Discriminatory practice on airlines was also evident in the absence of consideration for disabled people as there is no requirement for aircraft evacuation certification trials to consider mobility-disabled people (Galea, 2003). Although there have long been calls for a review of all transportation policies, along with their customer services (Cavinato & Cuckovivh, 1992; Abeyraine, 1995), more recent research has revealed that local, national and international transportation policies still continue to disadvantage disabled people and thus inhibit their holiday-taking (Stumbo & Pegg, 2005).

### 3.4.4 Ecological barriers

According to Smith (1987: 382), 'the popularity of many tourist locations is based upon their ecological uniqueness – a uniqueness that often results in lack of access for disabled people'. Nevertheless, the natural environment was a highly-desired holiday location for many disabled people (Ray & Ryder, 2003; Lovelock, 2009), with the top five motivations for travel amongst those with general mobility-disabilities connected to nature, from visiting lakes and mountains to tropical forests and wilderness nature (Ray & Ryder, 2003). However, as a greater number of barriers was likely to occur at natural attractions (Lovelock, 2009), travel to them was less frequent as these barriers were considered insurmountable for disabled tourists (Packer et al., 2002).
Naturally, mobility-disabled tourists expressed a greater desire than able-bodied tourists for motorised access to remote natural settings, although both groups generally held similar ecological concerns to protect the environment and so equally rejected increasing motorised access inside such areas (Lovelock, 2009). As Lovelock (2009) pointed out, however, his study sample was aggregated and so the specific needs and obstacles relating to different levels of impairment may have been masked. The natural environment - the countryside - was again cited as the preferred location for severely mobility-disabled people (Burnett & Bender, 2001). However, since these individuals self-defined themselves as severely-disabled, and did not disclose their disability, it is unclear whether this is a true reflection of their level of impairment and thus of the holiday preference of severely-disabled people. A reliable representation of the views of severely mobility-disabled people appears, therefore, not to have emerged on ecological barriers.

Other literature has revealed that for general wheelchair-users, obstacles within the natural environment might simply be the ‘dirt and sewage that sticks to wheels’ (Daniels et al., 2005: 926) or factors such as extreme weather conditions, hills, trees, tree roots and sand that inhibit participation (Smith, 1987; McKercher et al., 2003). Yet, the staging of the Barcelona Paralympics in 1992 demonstrated to the world how well accessibility measures could be put in place not only for public transport and the built environment, but also for the natural environment. Both the beach and the sea in Barcelona were made accessible for people with mobility-disabilities and wheelchair-users with large wooden panels secured in place over the sand at various points. Such panels began from the pavement, across the beach and continued to the sea. Wheelchair-users thus had the option to sit with others on the beach or continue to the water’s edge and take a boat trip. More recent research has revealed, however, that from other tourist-boat harbours, mobility-disabled tourists had ‘to travel through chest high water when disembarking from boats’ (Packer et al., 2007: 287), which would have excluded most wheelchair-users from taking a boat trip and, in particular, ventilator-dependent individuals.
Weather conditions inhibited holiday-participation for some disabled tourists. For instance, some wheelchair-users found even the relatively mild heat in northern European countries like Denmark took its toll on them (Daniels et al. 2005). Presumably, this was due to the effort of pushing themselves around all day in their manual wheelchairs which, even in gentle heat, would have become more taxing. Smith (1987) noted, however, that individuals with certain spinal cord injuries were particularly sensitive to hot weather conditions since they are unable to perspire to reduce their body temperature if they become too hot. This, he suggested, would significantly limit their travel options with regard to popular warm-weather holiday destinations. Similarly, in cold weather this group of wheelchair-users would run the risk of hyperthermia as core body temperature can not be maintained (NSEM, 2006). Even travellers with general mobility-impairments tempered their desire to explore cold natural environments involving ice or snow as these were felt to pose safety or mobility barriers (Packer et al., 2007). Smith (1987) thus suggested that whilst careful planning might reduce certain ecological barriers, others would be impossible to overcome unless assisted by a travel companion.

3.4.5 Public Transportation

Participation in tourism generally requires travel to and at the destination which can be hindered by an inadequate public transport system. However, many disabled people are often unable even to physically access the range of public transportation. (Cavinato & Cuckovich, 1992; Turco et al., 1998; Darcy, 1998; Taylor, 2000; Burnett & Bender, 2001; Daniels et al., 2005) due to poor design which, in turn, affects their initial holiday decision-making process (Packer, 2007). On holiday too, over 50% of all the constraints reported by the disabled tourists in Daniels et al.’s (2005) study were environmental, and many were related to transportation: planes, trains, boats buses and cars. In addition, inaccessible transport for cruise ship excursions made disabled passengers feel isolated on board ship as other holiday-makers departed on excursions. If they dared to disembark and venture out alone, they always felt
vulnerable in case they were stranded, unable to return to the ship due to a lack of accessible local taxis or busses.

Although there are a number of years until 2012 when large bus companies in the USA must become fully accessible with wheelchair lifts and ‘tie-downs’ to secure wheelchairs, it is likely that seating issues on buses, and a lack of sensitivity training for transportation employees, will still contribute to disabled people’s exclusion from holiday-taking (Stumb & Pegg, 2005). Furthermore, inadequate customer care, inaccurate travel information, poor design of bus stations, badly positioned bus stops and long waits, (Hine and Mitchell, 2001) appear likely to continue to inhibit disabled people from using buses and other public transport (Stumbo & Pegg, 2005).

Air travel presented a particular set of problems. According to Lipp and Keefe (2003), the two most essential elements to air-travel for disabled passengers were preferred seating and a ‘meet and greet’ service at the airport. Specific issues for wheelchair-users included: inaccessible, smaller regional aircrafts; inaccessible ground transportation and lavatories; too few seats with fold-up arm rests or cabin crew who were aware of them; and extra time on board waiting for the retrieval of wheelchairs from the luggage-hold (Woods, 1992). Some attempt was made to improve air travel for disabled passengers as all regional airports and airlines were required by 2000 to provide easy access to all aircrafts carrying 19 or more passengers, and those with at least 10,000 flights annually to install boarding bridges and ramps (Nelms, 1999). Yet, despite this legal requirement, and further calls for international action to address air transport barriers (Abenyraine, 1995) that pose ethical dilemmas with regard to health, security and accessibility (Richter and Richter, 1998), relatively little appears to have changed to date. Wheelchair-users still continue to report: no boarding bridges for certain flights; being lowered by hydraulic catering trucks from aeroplanes; and some airlines still not providing aisle wheelchairs to be able manoeuvre along the narrow aircraft aisles (Daniels et al., 2005).
Severely-disabled individuals were particularly affected by accessibility problems across the range of public transport. As a result, they left the confines of their homes far less than other disabled people (Grundy et al., 1999) and travelled far less frequently (Burnett & Bender, 2001; Darcy, 2002). Whenever they did travel, it was usually by private car or van for medical appointments or visits to family, rather than for holidays (Burnett & Bender, 2001). They were thus the least satisfied with travel (Darcy, 2002).

3.4.6 Architectural barriers

As with transport, many disabled people face difficulties in physically accessing built-up areas, tourist attractions and buildings, or using existing facilities within them (Smith, 1987; Darcy, 1998; Bi et al. 2007). Thus, as Creek et al. (1989) revealed, even the most active wheelchair-users were reluctant to stray from tried and tested places into ‘unknown territory’, and no longer considered taking holidays as they always ‘immediately hit a brick wall’ (Creek et al., 1989: 137) outside their own environment. Decades later, and despite various anti-discrimination laws, ‘Inattentiveness to, and the exclusion of the needs of disabled and other people is [still] evident in all stages of the design and development of the built environment’ (Imrie & Hall, 2001: 334), all of which also reflect a society’s attitude and respect for disabled citizens (Parker, 2001).

Wheelchair-users are still unable to access many art galleries, museums, concert halls, theatres, cinemas and places of accommodation (Barnes et al., 2005). For the latter, good accessible design for universal use for all areas of accommodation is essential (Fost, 1998; Dattilo, 2002) as, according to Lipp and Keefe (2003), the number one accommodation barrier is being given a room not close to amenities. However, since room and bathroom dimensions are most critical in order to accommodate the wheelchairs of severely-disabled tourists (Darcy, 2002), this seems to reflect more the wishes of those with mild to moderate disabilities. Nevertheless, accommodation was by far one of the toughest challenges for all disabled tourists because most
providers did only the bare minimum to comply with the law in terms of accessibility (Feiertag, 1997; Vladimir, 1998; Barnes et al., 2005). Smaller establishments found the law confusing and were therefore often unable to comply (Upchurch & Seo, 1996), and consequently did not take complaints very seriously (Walsh, 2003). This further inhibited disabled people’s participation as they were unable to access smaller, more reasonably-priced lodgings.

Whatever the case, better alterations to existing buildings, as well as general access issues, need to be at the heart of the architectural design of new buildings and facilities (Darcy, 1989; Avis et al., 2005). However, as cost-effectiveness is at the core of most building work, even newly-built buildings may still not be accessible or conform to accessibility requirements (Stumbo & Pegg, 2005). Additionally, many experienced builders and architects possess insufficient knowledge of the whole spectrum of disability which would render the same built area accessible for some whilst inaccessible for others. Such spaces have the power, therefore, to direct visitors either towards or away from them and their facilities (Imrie, 2001), symbolically welcoming or rejecting individuals and presenting themselves as harbouring attitudes of inequality and alienation (Stumbo & Pegg, 2005).

Thus, whilst buildings with steps and hand-operated doors at the main entrance physically restrict those with varying levels of mobility-disability and no, or restricted, hand movement (Gleeson, 2001), sight of entrance steps could possibly also stir similar feelings of rejection and discrimination as those experienced in the 1940s and 1950s by newly-arrived West Indian workers barred from finding accommodation by ubiquitous ‘No blacks’ notices. Consequently, Darcy (2002) suggests that if attitudinal barriers were addressed, those physical accessibility barriers which most studies highlight as most significant, could be resolved.

Yet very few studies offer much detail, background or solutions to either attitudinal or accessibility barriers. For instance, literature examining American tourists with ‘walking
difficulties' (eg, Takeda & Card, 2002; Card et al., 2006) chiefly reported in percentage terms that more accessibility than attitudinal barriers were encountered in eating and drinking establishments, accommodations, attractions and transportation. However, most of the barriers were in eating and drinking establishments, and the least in attractions. Bi et al.'s (2006) study of Chinese disabled travellers revealed similar results except that the relative perception of the importance of barriers in attractions and accommodation were reversed.

Daniels et al.'s (2005) website travel tales nevertheless provided some details of accessibility barriers. The multitude of accessibility barriers encountered by wheelchair-users included: flights of stairs and individual steps; streets with rain channels fashioned into pavements; pavements with no curb cut-outs and inaccessible attractions, site layouts, lifts, restaurants, hotels, dining rooms, and bathrooms in terms of dimensions and wheelchair manoeuvrability. Barriers to accessing the built environment were also found to include broken services on roads and pavements which restricted movement and limited or cancelled the effectiveness of wheelchairs (Gleeson, 2001).

Although income limited travel choices for disabled people (Darcy & Daruwalla, 1999; Cameron, 2003), a number of scholars (eg, Burnett & Bender, 2001; Avis et al., 2005; Bi et al., 2007) agreed, along with the WHO (2002), that levels of physical functioning offered the greatest indication of barriers encountered. Severely-disabled tourists were found, therefore, to have rated accessible environments and activities most important in their choice of holiday destination (Burnett & Bender, 2001) even though their preferred destination appeared to be the not-so-accessible countryside.

Furthermore, Burnett and Bender (2001) found that around 72% of their mobility-disabled travellers reported they would travel more if hotel rooms accommodated their needs, such as having lower shag-pile carpet on the floor, less furniture, extended motorised curtain pulls,
wider hallways, the correct direction for doors to open, and light switches and telephones nearer the bed. Such ‘physical details’ would indicate that these needs once again relate to those with mild to moderate disabilities. Suggestions for best-practice within the European tourism access schemes included ‘professionals visiting facilities, checking accessibility’ (Eichhorn et al., 2008: 202), yet who these ‘professionals’ were and how they assessed sites was unclear. Nevertheless, like Bennett (2002) and Kelly and Nankkervis (2001), the authors recommended that this process could be improved by involving disabled people. Finally, it was proposed that a new international labelling system of symbols indicating accessibility throughout the built environment needs to be created as many of the current symbols used by providers were neither defined nor understood by all (Eichhorn et al., 2008). Suggestions of symbols for this new labelling system were, however, not included.

Although much of the literature has focused on inaccessible accommodation, Daniels et al. (2005) emphasised that, to ensure an overall pleasurable holiday experience, good accessible design for all stages of the tourism experience was necessary. Whenever this was lacking - or nature-based attractions, theme parks or cultural and historical sites were only partially inaccessible - individuals felt that a reduced entrance fee should be offered (Turco et al., 1998; Stumbo & Pegg, 2005). Furthermore, whilst some argued that detailed site accessibility information and multiple site photographs should be available on the attractions’ websites as a form of compensation for not being able to visit the entire site (Stumbo & Pegg, 2005), Israeli (2002:102) maintained that:

For most tourists, a certain trade-off exists, whereby a lower level of one attribute can be compensated by a surplus in another attribute...[but for disabled tourists, accessibility attributes] cannot be compensated for by a surplus in any other attribute.

Such a site would therefore not be revisited (Israeli, 2002; Daniels et al., 2005) just as negative experiences and feelings of helplessness would result in future non-participation (Bedini, 2000).
With regard to historic sites, Goodall et al. (2005) revealed that the need to reconcile conservation of the revered historic environment with full physical access exacerbates problems, especially for those with the most severe mobility-disabilities. It would appear that conservation interests override those of disabled tourists as long as other legislation takes precedence over the DDA (1995). The authors acknowledged some parts of heritage sites must remain inaccessible for conservation reasons, although, like Israeli (2002), they suggested that that offering alternative, intellectual access in the form of photographs and multimedia presentations of inaccessible areas still does not compensate. Thus, further improvements were deemed essential because:

"physical access is critical in the tourism case – the site visit being of paramount importance to the quality of the tourist experience.... [The DDA's]Reasonable adjustments are acceptable to disabled tourists, but, because they fall short of inclusive environments, disabled persons will continue to face a degree of social exclusion and suffer discrimination in areas of discretionary consumption such as leisure and tourism."

(Goodall et al., 2005:76)

3.4.7 Attitudinal barriers

Fear of public reaction often inhibited holiday-participation, although feelings of alienation and being ‘an outsider’ away from one’s usual environment are not exclusive to disabled tourists (Pearce, 1982). In fact, Hunter-Jones’ (2003, 2004) study reveals cancer patients’ perceptions of negative public reaction to the often temporary physical side-effects of cancer treatment, and Stephenson (1995) outlines the Afro-Caribbean community’s fear of being conspicuous in an ‘all white’ country-side setting away from their usual urban environment. However, Murphy et al.’s (1988: 239) comment that ‘all users of wheelchairs know that when they are in public places, they are commonly noticed by everyone and acknowledged by nobody’ illustrates the constant paradox of disability wheelchair-users face both locally and away on holiday with regard to attitudinal barriers.
In general, disabled tourists sensed that they were viewed as incompetent as they were often pitied, excessively praised or given unneeded physical assistance (Kennedy et al., 1987, cited in Smith, 1987). Such prevailing negative attitudes towards disabled people (Goffman, 1963; Barnes et al., 2005) tended to exacerbate feelings of alienation resulting in reduced public outings (Smith, 1987) or the decision to forgo holidays as, constantly, 'you get the feeling everybody’s looking at you' (Creek et al., 1989: 137). Even legislation can not easily change ingrained attitudes as Tregaskis (2004; 146) found almost a decade after the introduction of the DDA (1995) when the disabling attitudes towards disabled people at a leisure centre were described as 'insidious and pervasive'.

Most of the literature on attitudinal barriers has focused not on the attitudes of the general public, however, but on those of tourism service providers. It highlighted two issues: firstly, the consistently unreliable accessibility information they provide and, secondly, their negative, condescending attitudes towards disabled people (Turco et al., 1998; Burnett & Bender, 2001; McKercher et al., 2003; Lipp & Keefe, 2003; Bi et al., 2007). As indicated earlier, these were found to present even greater travel obstacles than physical barriers (Packer et al., 2007) with attitudinal barriers described as 'the most limiting barriers encountered' (Bi et al., 2007) and the hardest to overcome (Schleien et al., 1997; Smith et al., 2001; Darcy, 2002). Consequently, over 66% of the American mobility-disabled travellers in Burnett & Bender’s (2001) study declared that they would travel more if they felt more welcome at places of accommodation.

Furthermore, most staff working in travel agents were uninterested in learning more about disabled peoples’ needs, while some believed that any impairment, particularly a mobility-impairment, excluded people from holiday-taking (McKercher, 2003). An inability to empathise with others without shared experiences (Williams et al., 2006) and/or a distinct lack of disability education and training tended to account for negative attitudes throughout the tourism industry (Duruwalla & Darcy, 2005). Nevertheless, negative personal attitudes towards
disabled people appeared more pronounced and difficult to change than societal ones (Daruwalla & Darcy, 2005).

According to Avis et al. (2005), gender and age are significant in assessing the degree to which disabled travellers experience attitudinal barriers, with young females most affected. This, the authors suggest, might be either a matter of perception of more barriers, or that young women are more sensitive towards attitudinal barriers than men or older, more experienced disabled women. It is possible, however, that, like the rest of society, tourism staff tend to treat younger women differently (Conway & Vartanian, 2000) - as sexual 'play-things' when able-bodied and as asexual and invisible when disabled (Lonsdale, 1992). However, the most severely-disabled tourists encountered the most attitudinal barriers irrespective of age or gender in all sectors except in attractions, perhaps because staff at attractions generally displayed negative attitudes towards disabled tourists regardless of functioning levels (Bi et al., 2007).

Thus to combat such attitudinal barriers, tourism providers need opportunities to acquire a deeper knowledge and understanding of disabled people and their accessibility needs via simulation experiences and direct face-to-face interaction with them (Darcy & Daruwalla, 1999; McKercher et al., 2003). Moreover, further research is needed to enhance understanding of such a major barrier to holiday-taking for disabled people (Eichhorn et al., 2008), just as society as a whole needs to become more aware of disabled people's needs and expectations (Yau et al., 2004).

3.5 Framework of intrinsic barriers

As indicated earlier in the chapter, the process of becoming travel-active as a disabled person depends on far more than merely an absence of environmental barriers. It depends on a combination of 'personal initiative, accurate evaluation of one's own capabilities, the ability to collect reliable information, managing the trip, manage [sic] oneself, and reflect [sic] on
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experiences’ (Yau et al., 2004: 958). Thus, despite the heavy focus on the more tangible environmental barriers whose removal, many academics stress, will offer the industry great potential for profit, barriers to participation are not simply an issue of physical access and/or current social and cultural conditions (Packer et al., 2007; Daniels et al., 2005; Yau et al., 2004). They equally include many intrinsic and interactive barriers (Smith, 1987).

Just as the level of disability is the greatest indicator of accessibility barriers (WHO, 2002), it is possible that intrinsic and interactive constraints may equally vary according to the level of disability and personal situation (Smith, 1987; Clift & Page, 1996). Daniels et al. (2005) revealed that around half of the barriers encountered by disabled tourists in their study were a mix of intrinsic and interactive constraints and, of these, slightly more intrinsic barriers were cited. This is hardly surprising since intrinsic constraints are generally regarded to be the greatest obstacles to holiday participation (Smith, 1987; Murray & Sproats, 1990). They are internal to the tourist and may be directly related to the impairment or arise as a result of it, such as familial over-protection (Yau et al., 2004; Packer et al., 2007) or reduced educational opportunities, although health-related problems, social ineffectiveness, a lack of knowledge or physical/psychological dependency may have an greater impact on participation (Smith, 1987).

3.5.1 Health-related problems

Health-related problems associated with certain impairments, such as prolonged exposure to hot or cold weather for individuals with C-SCI, could significantly limit participation in cooler, wetter climes (Creek et al, 1989) and at popular warm-weather destinations (Smith, 1987). Other health issues, such as depression and secondary cancer, also inhibited travel post-diagnosis for many cancer patients as did fear of not being able to cope if unwell away from their familiar network of support (Hunter-Jones, 2003; 2004). Consequently, although holiday motivation generally remained unaltered following ill-health, timeshare options and inclusive package holidays, particularly for rarer overseas travel, were preferred due to the perception that
these would provide better security for health (Hunter-Jones, 2003, 2004). Although ill-health was the prime barrier to participation for disabled people (Mckercher et al., 2003), interest in new types of holidays actually increased for cancer patients, leading Hunter-Jones (2005:87) to conclude that ‘illness, even when serious, was not in itself found to act as the sole barrier to participation’.

3.5.2 Psychological/physical dependency

Disabled people often become psychologically dependent on others to overcome physical and social obstacles for them; unwittingly, family members and rehabilitation providers’ attitudes or actions reinforce this dependency (Smith, 1987). Thus problems arise because:

*Many of the barriers that are faced by people with disabilities require personal initiative, creative thought, risk taking, and perseverance in action. These qualities do not develop fully in an atmosphere of psychological dependency.*

(Kennedy, 1987:72, cited in Smith, 1987)

As for physical dependency, although no reasons were specified, one of the travellers with SCI in Daniels et al.’s (2005) study expressed concern before the holiday about his body being able to physically manage an eleven-hour flight alone. Others recounted different physical barriers they faced when, for instance, they fell off a portable shower bench and were forced to crawl for almost an hour into the bedroom to telephone for help (Daniels et al., 2005). Although their lack of psychological dependency afforded them the freedom and privacy to spend the night alone in a hotel bedroom with an en suite, their physical dependency still ensured that they stayed in the type of accommodation where immediate physical assistance would only be a telephone call away.

Physical health and psychological factors equally inhibited cancer patients’ holiday-participation (Hunter-Jones, 2003). For instance, nausea and fatigue due to treatment, coping with a colostomy bag, poor resistance to infection, as well as anxiety about the various physical
side-effects of treatment, negatively affected participation. Furthermore, a mix of a lack of energy, confidence, and self-belief, together with feelings of anger, loneliness, vulnerability and despair with regard to their illness, further inhibited participation. Conversely, for physically-disabled individuals, acceptance of their condition, together with an ability to physically manage daily living tasks, promoted travel interest and success (Yau et al., 2004). However, due to the limitations of physical function, many severely-disabled people were not physically-able to take holidays if not accompanied by an assistant (Burnett & Bender, 2001; Darcy, 2002) on whom they then often became psychologically-dependent to plan and book their holidays (Burnett & Bender, 2001).

3.5.3 Lack of knowledge

Over two decades ago Creek et al. (1989: 138) suggested that: 'more work needs to be done... to enable people with physical disabilities to have greater knowledge and gain greater confidence in being able to set about a holiday'. Yet, a lack of travel knowledge has continued to affect essential holiday planning activities (Daruwalla & Darcy, 2005). Whether or not this was a consequence of inadequate educational opportunities for disabled people, a lack of knowledge of accessible tourism information, and/or how to locate it, this severely inhibited their ability to participate (Smith, 1987; Packer et al., 2007). It also rendered them especially cautious of international travel (Shaw and Coles, 2004). For instance, they did not know what types of facilities to expect abroad, where to find assistance, how to use the accessible facilities provided at establishments, and even failed to understand the consequences of booking a hotel based on information supplied in a brochure twelve months out of date (Daniels et al., 2005). Yet, this knowledge deficit also extended to travel agents (McKercher et al., 2003) and to 'carers' who often lacked knowledge of local leisure opportunities (Matthews, 1990) and, presumably, of tourism opportunities as well.
Likewise, cancer patients’ participation was affected as they and their families lacked knowledge of holiday opportunities for people with serious illnesses; thus it was suggested that dissemination of suitable holiday information should take place during patients’ rehabilitation period (Hunter-Jones, 2004).

3.5.4 Social ineffectiveness

Since the process of holiday-taking generally involves social interaction with others, effective social skills play an essential role in an individual’s ability to manage the whole holiday experience (Smith, 1987). Social difficulties often arise for disabled individuals, however, as they commonly encounter:

> Parental overprotection, segregated (disabled only) social experiences, and inadequate feedback about inappropriate behaviors during the developmental period...

(Smith, 1987:380)

Thus, Yau et al. (2004) noted that many disabled individuals had become increasingly passive and possessed virtually no life-goals or expectations. Consequently, most who had taken a holiday had first been motivated by family members (Yau et al., 2004; Packer et al., 2007). Conversely, overprotective parents tended to have a negative influence on an individual’s decision to travel (McKercker et al., 2003), while even a simple lack of encouragement from families could result in non-participation (Yau et al., 2004). Apart from having the courage to take risks and to venture out into the unknown, participation was therefore dependent on having the social skills to build a social support network of people willing to assist when one’s first choice of family members as travel companions was unavailable (Yau et al., 2004).

In contrast, younger cancer patients, having lost contact with friends their own age after their illness, lacked enthusiasm for holiday-taking as they resented being dependent on family for their travel companions (Hunter-Jones, 2004). When mobility was impaired, female cancer patients tended to be more reluctant to travel (Hunter-Jones, 2004), reflecting the assertion that
physical ability, together with other factors, such as sexual orientation, race and marital status, particularly affects women's self-concept and thus their leisure participation (Goodale, 1992; Henderson et al., 2005). As a specific group of women, however, the leisure constraints of disabled women become magnified in society (Britt, 1988; Henderson et al., 1995) even though these constraints are thought to be fluctuating and not fixed because: 'Being female and having a disability are socially constructed and historically mediated categories of experience (Harris and Wideman, 1988, cited in Henderson et al., 1995: 18). In this sense, gender appears to belong to environmental barriers, although another school of thought would contend that 'gender', particularly in relation to sex and sexual attraction, is more nature than nurture (Ridley, 2004) and so would view it more as an intrinsic barrier.

### 3.6 Framework of interactive barriers

Finally, interactive barriers, namely skill-challenge incongruities and communication barriers, focus on the disabled tourist's behaviour in relation to environmental barriers and the skills necessary for successful interaction with others, such as service providers and travel companions, to overcome them (Smith, 1987).

#### 3.6.1 Skill-challenge incongruities

Although a lack of skill or ability might be considered internal to the individual, Smith (1987) viewed skill-challenge incongruities to be predominantly interactive. He acknowledged that individuals might have certain reduced skills due to their impairment, but these, in themselves, were not barriers to holiday enjoyment provided that the activity was tailored to an individual's skill levels. With little suitable or reliable holiday accessibility information available (Mckercher et al., 2003), both skill and persistence were needed to plan a holiday (Smith, 1987). Disabled travellers therefore generally undertook research on the Internet to confirm accessibility, and contacted overseas Tourists Boards for local arrangements before travelling (Daniels et al., 2005). Yet, whenever holiday planning or any holiday activity was considered
to exceed skill level, worry or anxiety could inhibit participation or a pleasurable travel experience (Smith, 1987; Darcy, 2002). Smith (1987) further suggested that if individuals felt insufficiently challenged, participation might be constrained due to boredom. Conversely, when the initial holiday-planning became too difficult, some abandoned their travel plans, although most found that experience facilitated future planning (Yau et al., 2004).

- **Coping with physical barriers**

Daniels *et al.* (2005) noted that the cumulative stress of dealing with constant accessibility barriers on holiday resulted in disabled travellers often becoming emotionally overwhelmed. Reactions then became distorted when, for example, they could become enraged or tearful on sight of an inaccessible room. Thus, to continue the holiday, psychological strength and determination were required, together with the ability to accept that, although obstacles would arise with rooms, transport or excursions, they would find a way to participate and continue the holiday.

Some disabled tourists relied on a travel companion/third party to negotiate environmental barriers (Daniels *et al.*, 2005). Others, who tried to negotiate barriers themselves, needed to be assertive and to find coping or innovative strategies (Yau *et al.*, 2004). In contrast with the general public whose holiday ‘participation [was] dependent not on the absence of constraints but on the negotiation through them’ (Jackson *et al.*, 1993:1), if disabled tourists were unable to find solutions, particularly with regard to wheelchair problems, the negative experience made them less enthusiastic about future trips (Yau *et al.*, 2004). This therefore confirmed Israeli’s (2002) findings that even one barrier might be significant enough to end the holiday prematurely or prevent future participation.

Since wheelchair manoeuvrability was essential to holiday success, wheelchair-users needed the skills to negotiate barriers caused by strangers in crowded airports, streets, ship gangways and
even lifts (Daniels et al., 2005). Manual wheelchair-users devised strategies to counter obstacles with assistance from travel companions, such as: being helped up a curb or a step; packing luggage so that the companion could carry it whilst pushing the wheelchair; and being able to access the bathroom by asking the companion to remove the wheelchair, and returning it when required (Daniels et al., 2005).

- **Coping with face-to-face interaction**

Additional barriers arose from face-to-face interaction with strangers or travel companions. Presumably, to avoid causing offence to companions, few travel companion constraints were reported in the travel tales in Daniel et al.'s (2005) study. Travellers did, however, record their ability to cope with companions' pulling out of the holiday last minute, or to manage complaints from companions about their lengthy bathroom routines (Daniels et al., 2005). Taking holidays with companions thus involved substantial compromise as well as negotiation of destination, length of time away and dates of travel, which would particularly apply to severely-disabled tourists as a travel companion would always be required to assist them on holiday (Darcy, 2002; Yau et al., 2004).

Furthermore, the ability to deal with service providers with an 'it can't be done' attitude and to be able to persuade them to co-operate, was considered equally crucial to holiday satisfaction and success (Daniels et al., 2005). However, without these interactive skills, travel could become an extremely negative experience having to endure, at times, inferior/discriminatory service, strange looks or even being totally ignored (Yau et al., 2004). This paradox of being simultaneously conspicuous and ignored (Murphy et al., 1988) was evident on a cruise ship when one of Daniels et al.'s (2005) wheelchair travellers, who was determined not to be isolated in a cabin, only just managed to squeeze past the cleaners' carts left regularly in the narrow corridors. Disabled tourists therefore found that they either had to accept or challenge such
situations, or persevere when, for example, hotel staff refused to change an unsuitable room or, during the planning process, travel agents constantly warned of inaccessibility.

New or inexperienced travellers tended to protest most about having to negotiate barriers and to make compromises which later could affect their desire to travel again (Yau et al. (2004). Barriers were also not so easily negotiated by individuals from certain cultural backgrounds. Chinese travellers, for example, displayed a cultural reluctance to ask for help for fear of burdening others (Yau et al., 2004), although requesting assistance was not always necessary as unsolicited acts of kindness and physical assistance came from strangers and tourism staff of both Western and Eastern cultural backgrounds in Daniels et al.'s (2005) study. Again, while tourism staff’s attitudinal barriers were the most commonly-cited barriers in much of the largely quantitative literature on barriers (eg, Card et al., 2005; Bi et al., 2007), the most frequent individual theme that emerged from the disabled tourists’ travel tales in Daniels et al.’s (2005) study was the positive impact that tourism service providers’ negotiation of barriers had on holiday enjoyment. This was followed by an appreciation of tourism staff’s willingness to manoeuvre manual wheelchairs along forest trails or over rough and uneven ground to reach the tourist site.

3.6.2 Communication challenges

The final interactive barrier, communication challenges, refers not only to barriers related to foreign languages, cross-cultural difficulties and inappropriate social skills on holiday, but also to cognitive, speech and hearing impairments (Smith, 1987). As communication is a two-way process, the author considered the non-disabled person to be equally responsible for endeavouring to understand and respond appropriately to the person with the impairment.

Although research examining disabled tourists appears to have failed to address communication barriers, fear of language problems should medical assistance be required were found, as
previously indicated, to limit cancer patients' holiday plans to English-speaking destinations (Hunter-Jones, 2004). Nevertheless, even in the UK, many cancer patients still relied on a third party, usually a family member, to communicate with local healthcare professionals (Hunter-Jones, 2004). Arguably, this illustrates how deep psychological dependency can become following serious illness and/or changes to the physical self.

3.7 Summary
This chapter first presented an overview of the categories of barriers to leisure and tourism participation for the general population. It then focused predominantly on Smith’s (1987) categories of barriers for disabled tourists, and presented a critical review of the literature in relation to the various barriers, which later provided a theoretical framework that informed the collection of primary data.

Most of the studies focused on environmental barriers, and in particular on accessibility and attitudinal barriers, although a small number of more recent studies highlighted the impact of all three of Smith’s (1987) categories of barriers. They revealed that almost half of all the constraints encountered were a mix of intrinsic and interactive barriers. There remains, however, an absence in the literature on constraints faced by those disabled people who have never participated in tourism (Daniels et al., 2005), which confirms what was indicated in chapter one - that a gap exists in tourism knowledge as only ‘the presences’, and not ‘the absences’, represent ‘the truth’ about issues of participation. In short, although there is a ‘distinct lack of academic research looking at tourism from the eyes of those excluded from it’ (Hall, 2000: 136), research examining disabled people has focused exclusively on those who have participated, however little or unsatisfactorily, and failed to engaged with those who have never participated.
Furthermore, scant work exits on severely-disabled tourists even though this group is said to encounter the most accessibility barriers (WHO, 2002) and to experience complicated travel arrangements (Darcy, 2002). It is thus possible that they might also encounter the most interactive and intrinsic barriers which, in turn, would demand additional skills and/or knowledge to manage a holiday. This might explain why, according to Burnett and Bender (2001), severely-disabled people are the least satisfied with their travel and therefore travel the least. As such, they are also the most likely never to have participated in tourism.

As work on disability and tourism is still largely exploratory in nature, and in the form of quantitative surveys with data represented statistically, very little information, or detail, is available regarding the causes of the barriers, how they interact or inter-relate and the potential solutions to counter them. A greater variety of data gathering and dissemination is therefore called for, particularly as disabled people are seldom given a voice with direct quotations in published studies, even in works with qualitative methods (Daniels et al., 2005). Even when direct quotations are used, no sense of the full impact or causes of the travel barriers is conveyed as they are not presented within the context of the disabled person’s life history or everyday life.

Findings from the literature may also not be representative of all disabled people. For example, the travel tales in Daniels et al.’s (2005) study posted on the travel website were written by ‘can-do’ types of disabled people who had already successfully participated. The authors suggested, therefore, that analysis of interviews would allow for a clearer understanding of the travel pleasures, expectations, barriers and outcomes of disabled people. Thus, in an attempt to redress the gaps in the literature, qualitative research in the form of in-depth interviews was undertaken with a group of severely-disabled individuals with C-SCI. They were encouraged to talk at length and in-depth about their lives and experiences and issues regarding
(non)participation in tourism. Details of this and a discussion of the whole research approach are presented in the next chapter.
CHAPTER FOUR

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CHAPTER FOUR
RESEARCH APPROACH

4.1 Overview of chapter
It is often contended in social science inquiry that ‘ultimate truth... will never be reached’ (Rosengren, 2000: 5) and that there is no right way to arrive at this only ever partial human knowledge (Feyerabend, 1975; Smith, 2009). Yet, if any legitimate form of human inquiry with plausible outcomes is to be produced, researchers must demonstrate that there has been a serious and rigorous process behind the research outcomes. Central to this process is reflexivity, ‘a turning back on oneself’ (Davies, 1994:4), since few social researchers’ work is entirely unconnected to their personal history (Bochner, 1997) whether acknowledged or not. The importance of employing a critical and analytical stance towards the topic, and oneself, throughout the research process can thus not be underestimated if one is to defend the research process effectively (Letherby, 2000). This chapter will therefore endeavour to do this by addressing what Crotty (1998) describes as the four essential and interconnecting stages of the research journey, namely: the epistemology, theoretical perspective, methodology and methods. Each stage will inform the other in an attempt to build an accountable, robust research approach so that a deeper understanding of the research problem and outcomes may be offered. The chapter will conclude by detailing the reasons for, as well as the merits, risks and challenges of presenting the fieldwork data in narrative form.

4.2 Epistemology: social constructionism
Tourism research has been, and still is, dominated by ‘value-free’, positivist work that contends ‘objective truths’ about the social world can be ‘scientifically’ discovered (Morgan & Pritchard, 2007). This thesis takes an alternative approach to ‘knowing’ the social world (epistemology) in the form of ‘social constructionism’. In contrast to positivism, this stance, whilst not
'necessarily opposed to "science"... has a more sceptical view of how science operates' (Banister et al., 1994; 9). It contends that human beings actively construct meaning or truths based on their knowledge and experiences of a particular phenomenon, such as disability, within a given cultural, historical, linguistic and ideological context (Moses & Knutsen, 2007). In this respect, truth is not simply subjective as 'theory [evolves from] experienced reality' of the phenomenon, thus constructionism can be seen to be able to bring together elements of both subjectivity and objectivity (Crotty, 1998: 44).

Whilst 'social constructivism' privileges, in typical psychological mode, the individual's construction of social knowledge, 'social constructionism', in a more sociological fashion, emphasises collective constructed meaning (Searle, 1989) typical of Foucault's work in the 1980s on knowledge, power, the body and discourse. Thus social constructionism demonstrates how, in a normative body hierarchy (Young, 1990), the presumed personal inadequacies in relation to 'impairment' and 'disability' are socially-constructed (Thomson, 1996). Social constructionism was therefore deemed the more appropriate epistemology for this study as its emphasis on how groups create meanings and realities, whilst also fostering a moral, critical spirit (Banister et al., 1994), mirrors the thesis' emancipatory philosophy. Since this goal is not just to explain but to critique the social world, the presentation of collectively identified issues in relation to C-SCI and (non)holiday-taking should add weight to the possibility of informing change.

Alongside epistemology is one's ontology, or 'concept of reality or being', which equally underpins the research's theoretical perspective or 'worldview' (Crotty, 1998). A 'relativist' ontology was adopted in this study as it recognises that the nature of reality – or, indeed, the reality of disability - is dependent on human consciousness and relative to time and place. Yet, in seeming contradiction, the study does not deny the existence of structural truths or corporeal
body truths (Thomas, 1992; 2004) that exit outside the mind. This is because the body is not simply a socio-historic construct, thus:

People need to realise that not all is social construction, ideology or discourse, all people have bodies and our bodies are often fragile and feel pain. ...Language and metaphor may well be vehicles for making sense of bodily sensations and actions, but this is not the same as the suggestion that bodily experience solely exits at the level of language. (Best, 2007: 169-70)

This allows, therefore, a small element of ‘realism’ to creep into a fundamentally relativist approach. However, this need not be incompatible with a social constructionist epistemology as, according to Guba and Lincoln (1994), subscribing to the idea that some things exist in the world independently of human consciousness, does not infer that meaning exists independently of consciousness. Thus this ‘near-relativist’ ontology can, in fact, complement a social constructionist epistemology. Together, they are able to offer an understanding of the ways in which the dominant knowledge and reality of disablement is historically and culturally situated and tied up with issues of structures, power and language, as well as acknowledge the bodily experience of impairment which inform the way disabled people live their lives and experience holiday (non)participation.

4.3 Theoretical perspective: critical inquiry

Understanding how the researcher views the social world under investigation – that is, his/her ‘theoretical perspective’ or values - is important since it justifies not only the choice of research but its approach and also builds its conceptual and analytical frameworks (Brunskill, 1998). Key to understanding the theoretical perspective selected is the process of reflexivity (Silverman, 1998) outlined in chapter one. To ignore or underestimate the researcher’s identity, experience of and assumptions about the social world and the impact these have throughout the research - on the selecting, shaping and understanding the research topic - would also deny the positive effects that insight, empathy, sensitivity, connection and rapport with participants bring to the research process (Kvale, 1996).
Weber (1949) was one of the first to explore how one's values might impact on research, yet over half a century later, there is still a tendency for social inquirers to remain detached, 'objective' and writing themselves out of the research (Morgan & Pritchard, 2007). Such a view predominates in tourism inquiry still. Yet Reinharz (1992) distrusts such researchers and feels their work to be incomplete and even dishonest because, as Mills (1959:204) commented, social researchers are part of the social world, and so, as 'no one is outside society, the question is where he [sic] stands in it'.

As outlined in chapter one, my personal experience led me to view society as fundamentally sexist, racist and discriminatory towards those who are different from the dominant group. Furthermore, during my voluntary work with disabled people, I witnessed, and still continue to witness, the degree to which current socio-cultural-political structures affect the social inclusion and holiday-taking of individuals with C-SCI. It was a wish to highlight this social inequality that I embarked on this research journey with the intention to openly critique and challenge the status quo. In line with the emancipatory goals of disabled scholars (eg, Shakespeare, 1994; Oliver, 1996; Barnes et al., 2005), critical inquiry was therefore selected as the theoretical perspective for the thesis because, unlike interpretivism, it seeks to change the current situation, not merely reflect it (Horkheimer, 1937). Thus, common to critical inquiry approaches is an understanding that:

all thought is fundamentally mediated by power relations that are social in nature and historically constituted ...; that language is central to the formation of subjectivity, that is, both conscious and unconscious awareness; that certain groups in any society are privileged over others, constituting an oppression that is most forceful when subordinates accept their social status as natural, necessary or inevitable; that oppression has many faces, and concern for only one form of oppression at the expense of others can be counterproductive because of the connections between them; that mainstream research practices are generally implicated, albeit often unwittingly, in the reproduction of systems of class, race and gender oppression.

(Kincheloe & McLaren, 1994: 139-40)
It is regrettable that tourism scholarship has largely failed to engage with critical inquiry and the industry’s disabling economic and cultural structures (Morgan & Pritchard, 1998). As such, in tourism research:

*Questions of critique of the system of domination that gives rise to the human condition under study, the extent of the researchers’ political commitment to emancipatory social change, dialectics – the interplay of theory and practice, and the account taken of historicism – the determination of economic forces in history are simply not found.*

(Botteill, 1999:10)

Ateljevic *et al.* (2007) thus call for more radical camps, such as critical inquiry and feminism, to be adopted in qualitative tourism research which, according to Hollinshead (1997:15), ‘must always begin with the perspectives, desires and dreams of those individuals and groups who have been oppressed by the larger ideological, economic and political forces of a society or historical moment’. Critical tourism research should, therefore, be more about making a difference than simply marking the difference (Aitchinson, 2007) if the knowledge generated is to enhance social justice (Ateljevic *et al.*, 2007). Yet, in championing quantitative empirical research, tourism inquiry has neglected the building of theory, which is a primary objective of social science (Schuett, 1996; Delanty, 1997; Silverman, 1998) since theory is *the lens that tells social scientists where to look for data and how to interpret them* (Hornig Priest, 1996: 52) in order to understand more than just the ‘positives and presences’ outlined in current tourism theory. Rosengren (2000: 5) observes:

*New theories and hypotheses always have to be tested, and in the long run, many theories will be forsaken for lack of empirical support. But meanwhile surviving hypotheses and theories may be used... to explain the world in which we live, to try to understand and interpret specific phenomena at the individual and societal level.*

Central to the understanding and analysis of C-SCI and holiday (non)participation are the individual, social and societal theories of disability (Barnes *et al.*, 2005) and the environmental, intrinsic and interactive barriers encountered by disabled tourists (Smith, 1987) which were explored in the previous two chapters. In an attempt to redress the gap in theory-building in
tourism, this thesis also seeks, and partly in an inductive manner, to build on and develop existing tourism theory on severe disability and (non)engagement in tourism.

Although social critics are not a modern phenomenon as they have been around since Socrates or earlier (Walzer, 1989), the term ‘critical social inquiry’ or ‘critical theory’ has been primarily associated with the Frankfurt School for Social Research established in the 1920s for the study of Marxism. Originally based on Marxist theory, critical inquiry has always had a more practical, transformative than a contemplative purpose seeking ‘to liberate human beings from the circumstances that enslave them’ (Horkheimer, 1982: 224). However, with regard to challenges to social inequality, Botterill’s (2001: 207) study of PhDs in tourism found that:

The characteristics of a Marxist inspired social science are virtually absent from this set of tourism studies. Critiques of the system of domination that give rise to the human condition under study are not often found in studies of tourism.

A materialist approach informed this study, however, with an exploration of both the absence of experience, as well as the experience, of holiday-taking for individuals with C-SCI. In so doing, a ‘space for an absent subject, and an absent experience...’ (Morris, 1992:159) set within an emancipatory philosophy was therefore created in tourism inquiry.

4.3.1 Critical inquiry & disability

Most criticism levelled at contemporary critical inquiry, much of which was shaped by Habermas, lies in its emphasis of power relations embodied in everyday communication and language at the cost of attending to material structures (Dux, 1991). This view is reflected by many of today’s critical inquirers who, although not all are (neo)Marxists, are still ‘of the left’ politically (Walzer, 1989: 26) and thus wish to stress socio-political structures. Amongst these are the disabled activists (eg, Shakespeare, 1994; Barton, 1996; Oliver, 1996) who - like Marx, the man of action and not just of ideas and theories about social oppression - still attend to the real-life experiences of people and actively challenge oppression via political means. It follows,
therefore, that new critical theories, such as the social model of disability focusing entirely on oppressive structures, emerged as a result of social movements following earlier (able-bodied) critical theorists’ neglect of the oppression of disabled people and other disadvantaged groups.

However, many disabled feminists contend that both the disabled people’s movement and disability theory are, like critical theory, one dimensional as they have been dominated by men (Morris, 1991; French, 1993) - and indeed, white, heterosexual men - neglecting the double or multiple forms of oppression, such as gender or race, which exit alongside disability. Like Habermas, they wish to stress the multi-layered power relations of discursive practices, and argue that the ‘personal is political’ (Morris, 1991) and that this, and the experience of the restrictions of the body, are equally vital to understanding the concept of disablement (Fine & Asch, 1985; Morris, 1991; Thomas, 2004). However, as discussed in chapter two, many of the male disability activists, who advocate a strict materialist approach, fear that the inclusion of the above will subvert attention away from the goal of changing oppressive political and economic structures (Barnes et al., 2005) because, thus far:

_The achievement of the disability movement has been to break the link between our bodies and our social situation, and to focus on the real cause of disability, i.e. discrimination and prejudice. To mention biology...has been to risk the oppressors seizing on evidence that disability is 'really' about physical limitation after all._

(Shakespeare, 1992: 40)

All this serves to highlight the breadth and complexity of disability. However, since a comprehensive theory of disability which recognises all these multiple forces at work has, to date, not been created, much of the theorising, experience and the analysis of impairment/disability has operated at three separate, and often competing, levels. They include the _individual level_ - a person’s everyday, personal experience of disability/impairment; the _social level_ - the social-construction of disability which, via institutions such as the welfare state, mainstream education and healthcare, categorises and stigmatises disabled individuals;
and finally the societal level - the power, interests and political/economic systems of dominant social groups which oppress disabled people (Turner, 1987; Layder, 1997). Thus, to understand the full complexity of severe disability and (non)holiday-taking, inquiry needs to be multidimensional (Smith, 1987).

Given that such debates and epistemological insights/methods have been largely absent from the tourism domain, this study will be one of the first pieces of work to bridge the gap between tourism and disability studies. It will address and draw links between all three levels of disability while ensuring that ‘key concepts, such as power,... be integrated at all levels of analysis’ (Barnes et al., 2005: 36). Power, as Foucault observes, is all about language, about the dominant discourse, since to construct a society, and knowledge, in terms of those who are able-bodied, and those who are not, brings with it a power inequality between these groups. Words and terms define and limit, but language has the power to resist also. Certainly, the discourse of the social model of disability resisted the earlier medicalisation of disability and thus influenced the DDA (1995), the UK’s long-overdue disability legislation (Thomas, 1999).

4.3.2 Critical consciousness

‘The culture of silence’ to which many oppressed people belong does not easily fit with the notion of ‘critical consciousness’ since oppressed groups, like those with C-SCI, are often unaware of the oppressive reality of their situation in order to be able to take charge and change it (Freire, 1972b). They are also unaware that they have no voice and tend to adopt the dominant power’s voice, language, position and, since they are ‘prohibited from being’ anything other, even internalise the myth of their inferiority (Freire, 1972b, 30). In this way, they are prevented from transforming their situation without help as oppression sparks fear, apathy and a lack of awareness; yet, just as Marx proposed, no one can liberate somebody else; only people joined in solidarity can liberate one another with, according to Freire (1976: 157), a methodology that is ‘dialogical, problem-solving and conscientising’. In other words, a process
of enlightenment and critical thinking needs to take place, through dialogue, so that the silenced and socially-excluded individuals with C-SCI may reflect upon the problem of holiday-participation - the causes, consequences and potential solutions - before transforming it via ‘a dual process of critical reflection and action’ (Freire, 1972a: 64-65). This naturally raises the matter of participants being engaged with struggle and change because, while some may choose to do so, others may find it damaging. This therefore highlights the ethics of engaging in emancipatory research addressed later in the chapter.

Furthermore, when the goal is social change, it is to be expected that criticism levelled at critical inquiry is that it is often utopian and rarely affects change (How, 2003). Nevertheless, Mills (1970) stressed that whatever its eventual outcomes, critical research can play a significant role in society through its critique of oppressive power relations and in shaping public debates on key social issues. To realise serious social change, however, involves a long, difficult process, often enhanced by a cross-disciplinary and multidimensional approach (Layder, 1997; Filmer et al., 1998). It always begins, though, with the ‘awakening of the consciousness of the oppressed’ (Freire, 1972a) and, in relation to C-SCI and holiday-taking, of the consciousness of other stakeholders’ too.

In order to awaken consciousness and to engage in critical thinking, Freire, the Marxist and educationalist working with Brazil’s poor, illiterate non-voters, advocates that ‘the educator’ engages with ‘the students’ as equal partners so that both take responsibility for learning from and teaching the other to grow in critical consciousness (Crotty, 1998). Only through dialogue do the oppressed come to learn that their situation is not ‘a dense, enveloping reality or a tormenting blind alley’ (Freire, 1972a: 81) or ‘fetters or...insurmountable barriers’ (Freire, 1972a: 72), but a challenge that can be met. This spirit of co-operation informed the study’s methodology so that, through dialogue, greater critical reflection of the barriers to holiday-taking could develop, which might then inform both my action and that of the participants. That
said, epistemological and methodological challenges, language, silences and internalisation of
the dominant voice of disability poses unique challenges to a researcher working towards an
emanipatory partnership between participants.

4.4 A blended methodology
Although the terms ‘methodology’ and ‘methods’ are often used interchangeably, they are,
however, quite different. Methods are the specific practical procedures used to gather and
analyse data. They are informed by the methodology, a ‘bridging conceptual framework’ that
illuminates the researcher’s theoretical perspective and links it to the appropriate methods
which, in turn, seek to elicit the desired outcomes of the inquiry (Seale, 1998; Rosengren, 2000).

As indicated earlier, much tourism scholarship has been dominated by predominately male-
orientated, ‘impartial’, ‘scientific’ quantitative research which obscures the voices of those not
belonging to the dominant group. This has been especially evident when the research lens has
examined tourism and disability, producing a marginalisation of disabled people in the research
process as the questions, approach, method, analysis and dissemination employed largely
produced ‘simple and sterile’ ‘facts’ and statistics about disabled people for the able-bodied
majority (Lowych et al., 1992:30). Such marginalisation in the research process has resulted in
disabled people being frequently represented as voiceless statistics, or written about as ‘them’ as
opposed to ‘us’ and our common humanity and rights of citizenship to be able to take holidays.
At best, an extremely partial insight into disabling effects and, at worst, a superficial and
occasionally inaccurate view of the realities of disability and holiday-participation has thus
emerged in the literature.

In contrast with the above, this study employed an entirely qualitative approach to be able to
provide ‘deeper’ understanding of social phenomena than could be obtained from purely
quantitative data. Furthermore, by adopting a blended qualitative methodology, the lived
experiences of individuals with C-SCI could be placed at the centre of inquiry so that rich, in-depth data based primarily on their thoughts, feelings, personal experiences and perceptions of (non)holiday-taking could be generated (Fontana & Frey, 1994). This was achieved by transforming the research process and approach from a traditional researcher-centred one to placing the participant at the centre of it where the power lay with the participant to decide, for example, when and where data were collected and how long the sessions would last. The blended methodology was considered appropriate for this as it used both a feminist standpoint, which promotes an enabling, emancipatory research approach, and also elements of narrative inquiry, which is able to highlight the personal experience of members of a marginalised group to capture both the individual and collective story (Richardson, 1990; Smith & Sparkes, 2008b). Complimenting social constructionism and its emphasis on collectively-identified issues, the collective narrative can thus add weight to the possibility of informing change.

A discursive approach formed the third and final part of this blended methodology and will be discussed first since knowledge or ideologies are, first and foremost, expressed and reproduced in discourse and language and are the social representations of groups (van Dijk, 1993). Thus phenomena such as disease or disability are made visible through discursive practices and so constructed by discourse (Prior, 1989). In any culture at any given time in history, the dominant ‘discourse’, observes Hall (1997:44):

*rules in certain ways of talking about a topic, defining an acceptable and intelligible way to talk, write or conduct oneself, so also by definition, it ‘rules out’, limits and restricts other ways of talking, of conducting ourselves in relation to the topic or constructing knowledge about it.*

Influenced by Foucault’s (1976) work on medicine, discourse and power, disability can been seen to be created by the ‘disablist’ language - and practices - that surround it. As such, disabled tourists are equally influenced by the discourse of the tourism community and how they are represented or absent from its discourse. Yet, despite recognising the impact of language and power on people’s lives, discourse theory has been often criticised for its
preoccupation with how meaning is produced through the details of language, and how
terminology, syntax, patterns or even omissions shape, reflect and control knowledge of the
social world, rather than focusing on powerful structural factors which oppress or exclude
individuals.

4.4.1 Critical discourse approach

Due to an over-emphasis on the details of language, Hall (1997:51) thus contends that
discursive approaches have failed to properly indicate the 'influence of the material, economic
and structural factors in the operation of power/knowledge'. Drawing on critical theory from
Marx, Habermas, Foucault, Bourdieu and others, a more politically aware 'critical discourse
approach' (CDA) that focuses on societal structures which oppress disabled people (Fairclough
& Holes, 1995) was, therefore, considered better suited to the study's theoretical perspective.
Nevertheless, a CDA is also able to facilitate an additional layer of critique through a study of
disablism at both a micro and a macro level. It may consider, although to a lesser degree, how
and what is said by the culturally-dominant group to inform, influence, limit and oppress
disabled people or, in dialectical terms, what is absence from discourse to gain further insight
into power relations (Wodak & Meyer, 2001) which affect holiday-taking.

A CDA locks into interpretivism and the concept that, as Derrida (1977) argues, and Delanty
(1997) observes together with Ricoeur and Habermas, there is no objective truth or knowledge,
only socially-constructed interpretations based on the historical and cultural context of the
discourse. This could be seen to clash with critical inquiry since the latter seeks primarily to
inform change by exposing the reality of inequality of opportunity based on the current
knowledge and experienced reality of the groups who live it. Yet, despite this apparent
disparity, a CDA can still be considered an effective methodology for critical inquirers as it is
able to expose the most prominent concerns of critical inquiry, namely the power abuse of
institutions and elite groups whose structures and practices - and language - inhibit or exclude
severely disabled people from mainstream society and tourism. Moreover, according to van Dijk (2003), a CDA takes an explicit socio-political position and its hope, if occasionally illusory, is for change through critical understanding or, if not change, at least resistance to social injustice.

4.4.2 Feminist standpoint

At the core of all the many different feminist perspectives is an explicit commitment to challenging oppressive power relations (Crotty, 1998). A Marxist-feminist approach specifically advocates structural change, believing women’s oppression to be ‘the product of the political, social and economic structures associated with capitalism’ (Tong, 1995: 39). Although this approach compliments the study’s critical inquiry and focus on the social model of disability, it falls short of an examination of the way ‘inherited discourse’ can oppress women by exposing ‘the visible effects on women’s lives of seeing, hearing our wordless or neglected experience affirmed and pursued further in language’ (Rich, 1990:483). Many feminists thus applaud critical theorist Habermas’ shift from societal structures to communication and an intersubjective view of ethics and dialogue, even though others object to his associating key concepts like citizenship or public sphere with the male gender (Fraser, 1985; Benhabib, 1992).

Despite such tensions, all feminist perspectives strive to know the world differently from how it has been known before (Crotty, 1998). They have an openly moral and political commitment to social change, offering ‘a practical achievement, not an abstract “stance”’ (Stanley & Wise, 1990: 27) and a commitment to ‘intellectual and political struggle’ (Harding, 1987: 185). Thus, complimenting the thesis’ open commitment to the social inclusion of individuals with C-SCI, a feminist standpoint is also unashamedly political and far from value-free, contending that ‘no researcher practices research outside his or her system of values and that no social science method can ensure knowledge is produced independently of values’ (Brunskill, 1998:46). Furthermore, it offers opportunity for inclusiveness as disabled and able-bodied feminists alike
(eg, French, 1993; Assiter, 1996) demonstrate in their concern for other oppressed groups such as gay people and different racial groups.

For decades disabled scholars have advocated that disability research must have an approach based on reciprocity and empowerment (Lather, 1987; Abberley, 1991; Oliver, 1996). This concern for others is also demonstrated in feminists’ non-threatening, egalitarian approach towards their research participants. Such an approach is highly relevant for working with individuals with C-SCI as they often have little opportunity for social interaction and to express themselves. Many may thus lack the confidence to gather and offer ideas counter to those circulating in mainstream society or even to participate in research. It is crucial, therefore, that participants feel comfortable with the research process and not be intimidated by an overly formal, academic, researcher-dominated approach. The practice thus needed to be participant-friendly so that, in their current ‘culture of silence’ (Friere, 1972b), they were able to let their voices be heard in order to tease out fresh understanding of the issues affecting their participation in tourism. A feminist standpoint was therefore deemed particularly relevant as it embraced ‘enabling’, egalitarian forms of research and an inclusive, accessible practice which operates in a more caring, open, trusting, empathetic participant-involved and reflexive manner, paying continual attention to ethical issues (Arksey & Knight, 1999).

Furthermore, in contrast with the minority of social scientists who have sought only relatively recently to include the self as central to one’s understanding of the topic (Letherby, 2000), feminist researchers have always openly drawn on their own experience and used it as a resource to enhance the research process (Knight, 2002). By investing time in sharing similar, personal experience with participants, they are able to create rapport, even friendship, in order to facilitate further sharing and deeper knowledge (Oakley, 1981).
Apart from a shared experience, many feminists also stress the importance of participants and researcher being of the same social standing (Riessman, 1987). Some, however, (eg, Abbot & Wallace, 1997) spread their net wider and contend that research should include both men and women's views on issues of gender and power, whilst others (eg, Roberts, 1981; Assiter 1996), along with critical theorist Freire (1972a, b, 1976), argue that one does not have to be a member of the oppressed group under investigation to be committed to its emancipation or to take the group's views seriously. In fact, they claim that a collaborative, committed approach, which this study strives to adopt, can be a particularly powerful one. Nevertheless, striving initially to build rapport with participants is key (Kvale, 1996), and particularly so with severely-disabled individuals, so that they are able to relax and feel comfortable sharing sensitive or potentially embarrassing information. Despite having no personal, lived experience of C-SCI, my prior knowledge of the condition and clients' daily lives gathered from earlier periods of voluntary work at NS home, as well as my engaging appropriate interpersonal skills, helped create a 'connection', or rapport, with numerous participants which enhanced interaction throughout the research process.

Inspite of the merits of employing a feminist standpoint, it must be also acknowledged, however, that, just as traditional social research perspectives' truths are historically gendered, and thus socially-constructed, any other 'truth' will be open to personal choice and change (Letherby, 2000). Thus, if a traditional methodology rendering 'objective' knowledge is only ever partial as it evolved from a male perspective (Davies, 1999), or indeed from an able-bodied perspective, criticism can be equally levelled at a feminist methodology for simply replacing masculine knowledge, theory or practice with feminine ones. However, the research process employed here, as well as later 'issues' regarding the research and researcher/participant voices and egalitarianism, provide a counter-balance to such claims. Consequently, it would not be a case of simply replacing one with another. Moreover, despite its peripheral academic status compared to more traditional ones (Maynard, 1997), a feminist methodology has much to
Chapter 4: Research approach

contribute to social science research and, in particular, to emancipatory and disability scholarship as disabled, male researchers in disability studies, such as Shakespeare (1994), have testified in their employment of it.

4.4.3 Elements of narrative inquiry

Since all knowledge is relative (Smith, 2009), a decision was made prior to fieldwork to invite participants to tell personal stories about their lives in order to illuminate their experience of C-SCI and (non)holiday-taking. In addition, and in keeping with a feminist standpoint by setting holidays in the context of their daily lives and their ‘life history’, it was hoped that this would put participants at ease and enhance understanding of the participants, the issues of travel (Chamberlayne, Bornat & Wengraf, 2000; Crossley, 2003) and their social world (Chase, 1995). Thus elements of an approach of what was to be known, retrospectively, as ‘narrative inquiry’ were instinctively adopted and created the final part of this blended methodology. This proved highly effective because, as I was to learn post-fieldwork, the broad concept of narrative inquiry holds that people lead storied lives (Sarbin, 1989), they think in ‘story forms’, and they relate to others, and bring meaning to their lives, through stories (Taylor, 1989; Josselson, 2006; McAdams, 2006; Smith & Sparkes; 2008a, b) and, importantly, they can ‘do things’ with stories (Atkinson & Delamont, 2006).

Moreover, story-telling helped established a closer connection between the research participants and me because, as I listened to their stories, it became clear to them that I was genuinely interested in them as individuals because, unprompted, they then often offered further stories. Importantly, this demonstrated that they did not feel that they were being used simply as a vehicle to supply details that only the researcher deemed important. This ‘natural’ way of imparting information and non-threatening approach (Josselson, 2006; Smith & Sparkes; 2008b) delivered at participants’ own pace proved particularly effective for individuals with C-SCI as injury had often slowed their speed of speech. Furthermore, narrative inquiry worked in
harmony with discursive and feminist approaches, acknowledging that the culture to which participants belong provides them with vocabularies, meanings and interpretations to understand, shape or limit their stories (Gubrium and Holstein, 1995) of their lives and holiday experiences.

However, although narrative inquiry reflects culture, it simply offers an interpretation of the social world and not, as critical inquiry demands, a critique of it in order to affect social change. As such, disabled scholars call for research on disability no longer to be ‘of the positivist and interpretive research paradigms, but the disablism ingrained in the individualistic consciousness and institutionalised practices of what is, ultimately, a disablist society’ (Oliver, 1996: 143). Nevertheless, narrative inquiry has the potential to reveal a great deal about the social world as the stories participants tell are informed and constrained by the historical and cultural context in which they are set (Chase, 1995) and, according to Atkinson & Delamont (2006), may even have the potential to inform social action.

Although Botterill (2001, 2003) advocates the ‘emancipation’ of tourism research design and methods so that researchers are be free to choose between ‘scientific’ and other kinds of knowledge, such as life histories or ancient myths, story-telling approaches have been underused in tourism research (McCabe & Foster 2006). This is curious as accounts of travel and holidays are amongst the most frequently heard private and public/media stories in Western society and ‘the natural attitude of the touristic account of experience is a narrativistic attitude’ (McCabe & Foster, 2006: 212). Thus, by encouraging participants’ natural instinct for story-telling to come to the fore - and by engaging with other academic disciplines and perspectives (Mishler, 2006) – it was hoped that a deeper, multifaceted and more complex picture of C-SCI and holiday (non)participation could be drawn.
Finally, the fact that multiple methodological perspectives underpinned this study, the latter of which evolved more retrospectively than causally, need not undermine its legitimacy, but demonstrate rather, how a methodological approach can develop whilst engaging with the research process and may be the richer for it. Conversely, methodological pluralism might be judged as methodological anarchy offering no ‘standard’ or authority against which contributions to knowledge can be judged. However, since the social world is a complicated entity, it might be prudent that ‘we keep our options open’ as no one methodology holds the secret of uncovering the truth (Feyerband, 1975: 20; Smith, 2009). A blended methodology may, therefore, potentially offer an even richer insight into such a complex research problem as C-SCI and non-participation. It must also be acknowledged, however, that established practice in tourism still seems to prefer one type of ‘truth’ over others, and that its influence is insidious since it is this against which others are judged whilst, ironically, remaining relatively immune from scrutiny and critique itself.

4.5 The methods adopted

Empirical research was conducted at NS Healthcare Corporation, California. Data exploring the experience of holiday (non)participation for individuals with C-SCI were derived from the ‘official’ period of data collection at NS in March 2006 although enriched by many years previous interaction with a number of the research participants. As the word ‘client’ is used interchangeably with ‘individual with C-SCI’ at NS, and ‘attendant’ for ‘care-assistant’ and sometimes nurse, they will be similarly employed in the thesis.

NS is a private company consisting of eight detached, family-sized houses located in different residential areas. The company was originally set up in 1982, predominantly for clients with high-level C-SCI and reliant on state benefits, as a bridging gap from acute hospital care to living independently, with assistance, in the community. However, many clients often choose
to live long-term at NS. The company won national recognition when the US Government recommended that NS be used as a States-wide model of C-SCI rehabilitation

4.5.1 Access to vulnerable populations

Gaining access to vulnerable research populations can, naturally, often be problematic. Numerous, fruitless attempts were made to gain access locally to Wales’ National Centre for SCI at Rookwood Hospital in Cardiff. It was hoped that contact could be made through the hospital with staff and former and current patients with C-SCI. However, all my letters and telephone messages for the SCI ward’s head social worker remained unanswered. This left me ‘in limbo’ for many months since my request to discuss the research project had neither been granted nor refused.

The lack of response eventually resulted in my having to travel half way around the world to conduct the fieldwork. More importantly, however, it meant that the ‘voice’ of those already socially-excluded individuals with C-SCI had, once again, been silenced and excluded; and excluded from the process of deciding for themselves whether or not to be part of a research project with an emancipatory philosophy. It was also regrettable that an opportunity to explore the experiences of local Welsh people with C-SCI had been lost and, with it, the possibility of presenting, post-doctorate, the ‘Cardiff findings’ to policy makers at the Welsh Assembly Government in the hope of informing change locally. Nevertheless, my goal remained unchanged which was: to embrace the marginalised and historically-silenced group of individuals with C-SCI, and to give them ‘a voice and representation in the social, political, and academic arena...’ (Creswell, 2007:37).

To avoid further delay, I was advised by a colleague engaged in research with the NHS that, due to increasingly lengthy NHS ethical approval procedures, a great deal more time would be lost if I approached other NHS SCI hospitals in the UK. A decision was therefore made to engage
personal contacts at NS in the USA where I had previously undertaken voluntary work with individuals with C-SCI. A telephone call was made to NS director, ‘Mia’, and once details of my proposed research project had been fully explained, access was granted to any clients and staff interested in taking part in the research. Given that ethics were considered central to the study, ethical approval was implicit in NS director’s consenting to the research by providing access to clients.

Although initially disappointed by the lack of response in Wales, two years later in April 2008, as I presented a very brief overview of my research at a Tourism and Social Exclusion Seminar at UWIC, Cardiff, I was heartened to learn publicly that my American fieldwork data could and had ‘travelled’ home. Attendee and invited key-speaker, Vanessa Webb, Director for The Blind, Wales, requested that I send her my research findings, when completed, so that she might look at the possibility of implementing for individuals with visual impairments some of the practical suggestions relating to C-SCI and holiday-taking outlined in my presentation.

4.5.2 Confidentiality & anonymity

Since voluntary participation is not possible without informed consent, I sent Mia a letter following our telephone conversation to present to all parties at NS who had volunteered or indicated an interest in participating in the project. I offered background information, explained the type and purpose of the research, what the data would be used for, and also informed participants that they would be free to withdraw from the project at any time without explanation. Confidentiality and anonymity would also be assured and they could choose, or would be provided with, a pseudonym. Later, when I met with the participants, no one seemed concerned about this, however. Post interview, some even suggested keeping their first names which, nevertheless, were not used in the study.
Occasionally, however, I was concerned about confidentiality during the fieldwork as sometimes staff or other clients were present at a client’s interview or would unexpectedly appear during part of it. Since, for health and safety, most clients’ condition necessitated that they were at least within ear-shot of staff twenty-four hours a day, they never seemed disturbed or surprised by such interruptions. Although I always asked, they never wished to reschedule, insisting that they were completely comfortable speaking in front of people they knew. Len clearly demonstrated this when he spoke frankly in front of staff about the restrictions of living at NS. In fact, it was I who needed to adjust to the unexpected presence of others during interviews, so I took my cue from the participants, and had to learn to shut out any distractions or feelings of self-consciousness.

4.5.3 Research sample

Although the main focus of the research was clients’ experience and perception of (non)holiday-taking, a number of attendants who had accompanied clients on holidays (four) or day trips (two) were also interviewed as they were an essential part of clients’ daily lives and, thus, any holiday. Views of three different groups (travellers, non-travellers and staff) therefore contributed to the study and offered the possibility of comparison and contrasting perspectives, and also provided insight into the ‘discourse’ formed in interaction.

Although the research sample was opportunistic in nature, a cross-section of client-volunteers was initially requested during my initial telephone conversation with Mia. This was to ensure a full range of C-SCI (C7-C1) was represented, including those who had acquired the condition through disease, should there be any marked differences. This was achieved with respondents’ levels ranging from the lowest, C6/7, to the highest, C1, with the majority at C2 and ventilator-dependent, while two respondents had acquired the condition through disease: polio and muscular dystrophy. Consideration was also given to, and achieved, with regard to differences that might arise due to: age (early twenties to late fifties); gender (four females and eight
males); ethnicity (Caucasian, Hispanic and African-American); and socio-economic background (two multi-millionaires, one salaried employee and the majority on state benefits with ‘disposable incomes’ falling well below a hundred pounds a month).

In addition, it was hoped that a percentage of interviewees might be independent of NS as it was felt that this might yield more frank discussion, particularly amongst staff. Of the six staff, three were no longer working for NS and one had never been an employee. Five of the twelve participants with C-SCI were now also independent of NS. Nevertheless, all participants talked very openly, seeing the interviews as an opportunity to bring out into the open long-standing issues that needed to be addressed. When data saturation occurred eliciting the same responses from non-travellers and also from staff with no client-holiday experience, it was decided that the same numbers of non-travellers and staff as travellers (6) would be used for individual interviews, which brought the total number of interviews to eighteen.

Without exception, all clients at NS defined themselves as non-holiday-makers (non-travellers) and felt it most unlikely that they would ever take a holiday. Either they had never had a holiday or had not taken one since they had lived at NS. A few, however, had taken a day trip but had never stayed away overnight. Thus, whilst accessing any number of non-travellers - or staff with no client-holiday experience - presented no problems, the opposite was true for those who had taken holidays (travellers) as it seemed that holiday-participation for those with C-SCI was extremely rare. In fact, in over forty years of working with thousands of individuals with C-SCI, Mia was aware of only five people, and all former clients, who had taken holidays, and just three other staff, besides herself, who had ever accompanied a client on holiday. The sixth traveller, another former client, was accessed by chance via a visiting ventilator specialist after a conversation was struck up between us whilst waiting to see separate clients at NS. This ‘snowballing’ effect occurred again naturally when, unprompted, both clients and staff introduced me to other individuals with C-SCI or other staff. Thus, around forty persons
eventually contributed to the overall study, although the number of in-depth interviews remained at eighteen.

4.5.4 Ethical considerations

Ethical issues were key to the underlying process and, through engagement with feminist theory, concern for clients was placed at the forefront of all of the decisions made throughout the research process. Since the fieldwork was conducted before UWIC’s ethics approval process was introduced, no application form was required to be submitted for approval to the university. Furthermore, in the USA, Mia’s prior knowledge of my previous interaction with NS clients and staff meant that no formal rules or restrictions were imposed on me during the fieldwork. Nevertheless, Mia informed me at the end of my fieldwork that she had quietly monitored her clients’ reaction at the start of the research process, and had been reassured by speaking with them that they were both comfortable and happy with the interviews. As indicated earlier, this was reflected in the way numerous staff and clients’ offered to introduce me to other individuals with C-SCI in and outside NS. In addition, telephone calls were received from a number of travellers following their interviews giving further information and offering to take me to meet other contacts.

However, despite having no formal restrictions imposed on me, I was constantly conscious that I was interacting with very severely-disabled and socially-vulnerable individuals. As such, important ethical decisions needed to be made throughout the research process. Even before leaving for the USA, a decision was made not to refer to a possible follow-up piece of fieldwork spent observing a number of clients planning and taking a holiday in case this could not be arranged, or financed, and would cause upset and disappointment. Equal concern was expressed to supervisors in Cardiff about the impact that even discussing holidays might have on such vulnerable individuals in case it should distress them and reinforce feelings of difference and social exclusion. Consequently, it was decided that, to gauge the situation before
holiday-taking was mentioned, clients would first be encouraged to tell any 'stories' they wished about themselves, their lives and their interests. Part of the later decision to present their data in narrative format thus evolved from the successful outcome of this decision.

Ethical considerations were also embedded throughout the narratives as unexpected incidents called for on the spot ethical decisions to be made both before and during a number of interviews. Illustrating the study’s on-going engagement with ethical considerations, I thus talked in Len’s narrative about whether or not, or indeed how, to wake him for his pre-arranged morning interview for which he and staff had spent hours getting him ready. In Susan’s, I mentioned how I responded to an unexpected personal request from her, and in Lynette’s, whether or not, with Lynette’s permission, I should take a matter concerning a NS manager to the director. Additional ethical dilemmas arose post-fieldwork when deciding which data should and should not be included in the narratives which will be discussed at the end of the chapter.

4.5.5 Pilot study

A two-part pilot study initially conducted in Cardiff, and then in California, offered me the opportunity: to reflect on the appropriateness of the research design; to conduct some initial data analysis to inform and refine questions used in the main data collection; and also to prioritise its content (Seale, 1999). Pilot interviews were recorded with four wheelchair-users: two male British manual wheelchair-users, one male (severely-disabled but not C-SCI) British power wheelchair-user, and one female American manual wheelchair-user employed at NS. Of the four, only one of the British manual wheelchair-users had taken holidays, although he had not done so in years after suffering skin sores during a long-haul flight on his last holiday and thus spent the entire two-week holiday in hospital.
Only the power wheelchair-user's interview was delayed by over forty minutes whilst he was being assisted with a personal task. He was also the least vocal and forthright, although he began to relax when reminiscing about past holidays when he was less disabled. This gave me an indication of how interviews might and actually did, proceed with NS clients. Furthermore, the more abstract questions such as 'what does the word “holiday” mean to you?' were excluded from the main study as none of the pilot participants responded well to them. However, all enjoyed discussing past holidays and describing their dream holiday even though they insisted that it could never be realised. This introduced a more naturally-occurring conversation-style to the interview which put them at ease and elicited some unexpected material, especially from the more confident participants. Specific travel issues that were common to all informed questions used in the main interviews which were also discussed with Mia before fieldwork began. They included: physical access problems, comments from the general public, unhelpful and unwelcoming tourism providers and incorrect access information from disability organisations.

4.5.6 Data collection methods

Data were derived from non-participant on and off-site observations, small group conversations and discussions, and individual, pre-arranged in-depth interviews. These constructed a specific type of research relationship characterised by sharing personal and private experiences (Birch & Miller, 2002) and facilitated understanding of issues connected with holiday-participation.

The goal of the interview was to understand the inner person and individual experience of barriers to holiday-taking in a more authentic, less exploitative way than other traditional methods (Seale, 1998). Oliver (1996) warned, however, that interviews where the researcher is presented as an expert and is unable to reformulate questions in a more appropriate way can be oppressive, making disabled participants feel inadequate and giving them the impression that the problems they experience here, or in life, are generally due to their own limitations. From the outset, however, I informed participants of my research approach which placed them at the
centre as experts of their situation, and I asked them, the experts, to explain specific words and terms to do with their condition or environment, whilst I used non-academic language and as many American or NS terms, such as 'vacation', 'attendant', 'client', 'Access' (cab) and 'power wheelchair' as possible, for ease of communication.

Furthermore, there was always an opportunity during interviews for 'free talk' and additional comments or observations to be made by participants which brought greater depth and richness to the data whilst allowing me to further assess their values, attitudes and emotions (Clark et al., 1999). Empathy was thus further developed as participants often felt able to disclose personal information, although this did not mean that I became so involved with the personal that any negative aspects or behaviours were ignored or unreported as balance, rather than neutrality, was constantly sought (Chisnall, 1996).

The employment of on and off-site non-participant observation of participants' interactions with others and with me, and the details of their daily tasks and healthcare, often confirmed or offered deeper insight into what had been verbally reported. In addition, this placed information about (non)holiday-taking in the context of the management of their daily lives, and compensated for either what had not been said or was too difficult or embarrassing to say. Observing some of the most personal parts of their lives was both an emotional experience (Lacey, 1967) and a privilege. It allowed me to observe their - and other people's - reactions and not to rely solely on what had been disclosed about, for instance, being washed or fed by an attendant because I was able to draw on direct evidence of the eye, and the other senses, to witness such events and reactions first-hand (Denscombe, 1998).

Although claims are made that the validity of the data can be checked and the strengths and weakness of the different methods can be balanced out (Denzin, 1970), whether one can ever arrive at 'the truth' through the use of a number of data collection methods - or 'triangulation' -
is nevertheless contested. Whilst Hammersley (1992) believes that the 'right' methods can get at the truth, Smith (2009) argues that all that different methods offer are different, partial views of the same phenomenon since ultimate truth can never be reached, only versions of it. Thus, rather than employing different methods in the hope of arriving at the 'whole truth', it was more important in this study that the methods used overlapped and complimented one another, allowing as much time as possible to be spent in the presence of the participants. Most important, however, was that the methods employed would place the participants at the very heart of the research process and facilitate an effective, alternative way of looking at issues of travel and severe disability in tourism research.

4.5.7 Interview procedures

All interviews were recorded, with permission, using a Dictaphone and generally lasted between one and five hours, sometimes with long breaks, or even days, in between to accommodate participants' needs. Since a feminist approach to interviewing is based on establishing rapport, reciprocity and egalitarian research relationships (Oakely, 1981; Finch, 1984), participants generally determined the times and/or locations of their interviews and how our meetings would proceed, although Mia initially coordinated my first meetings with the non-travellers. This was not entirely unexpected as I knew from past experience that clients tended towards being passive and thus not inclined to make organisational, or any, decisions for themselves.

A flexible, relaxed approach was essential throughout the fieldwork (Rubin & Rubin, 1995) as interviews were often delayed or postponed when participants had, for example, forgotten about the interview, fallen asleep, needed to be fed or washed or because their accessible transport had arrived late. Furthermore, in line with clients' wishes, interview venues were changed last minute and also, with no forewarning, interviews were terminated prematurely to accommodate participants' needs, such as hospital appointments. Yet this 'unpredictability' offered further insight into their everyday lives and the impact this might have on travel.
For the interviews and conversations to flow, warm, authentic exchanges, peppered with humour and genuine interest in participants was essential (Rubin & Rubin, 1995). This appeared even more important for most of the non-travellers whose social isolation meant that they were unused to interaction with others and, therefore, less confident. Fortunately, my previous contact with NS clients, and with a few of the research participants, enabled me to quickly (re)establish empathy and rapport with them. For instance, we would usually begin by reminiscing, and often laughing, about funny things that happened the last time we met, or remember people who were no longer at NS.

Often, and much to their delight and encouragement, I would greet Hispanic clients in Spanish and continue chatting until I had exhausted my limited command of their language. This relaxed approach helped allay one Hispanic non-traveller’s concern before the interview that he may not have anything of relevance to say as a non-traveller. Like the pilot study’s power wheelchair-user, he and some other non-travellers initially lacked confidence and needed reassurance to expand their one or two-word replies during the interviews. To offer encouragement, I would nod, use encouraging or appropriate facial gestures and words, rephrase or ask further questions, share information and always listen very attentively (Charmaz, 2006). This, together with my explanation that both the experience of holiday-participation and the absence of holiday-experience were needed to provide a deep insight into the full issue of C-SCI and holiday-participation - assured them that what they were saying was of great interest, and that their views were as important as those of any traveller.

As for the travellers, my experience of interaction with them or others with C-SCI played a relatively small part in the interviews (Finch, 1984) as they were generally more confident, assertive and asked more questions, particularly about the purpose of the research. As a result, I was able to engage more in ‘active interviewing’ (Holstein & Gubrium, 1997) where both they and I actively contributed to making sense and meaning of (non)holiday-taking. Thus,
interviews flowed easily with travellers who even steered the discussion at times. In contrast, I needed to work much harder in the interviews with most non-travellers, firstly in order to encourage them to speak and, secondly, to pay as much attention to what was not being said, yet implied, as said. Nevertheless, both interview scenarios were intense, absorbing experiences and yielded much rich data.

Although I was not an ‘insider researcher’, my previous voluntary work at NS allowed me to conduct insider type research in the sense that I was familiar with the environment, the equipment, the medical condition and some participants, and knew what type of questions to ask and ‘how to hear’ (Rubin & Rubin, 1995) their replies – in particular, the despair or familiar whining about their situation and issues related to their highly-specialised, internal world with its special terms, or even their voices in competition with the noise of the ventilator and words sometimes muffled at the end of sentences as they ran out of breath. Generally, however, how and what a researcher hears is determined by the approach taken, reflexivity and reciprocity which naturally also played a part in my ‘hearing’ the participants. As soon as possible after each interview, conversation or observation, I noted down all my thoughts, feelings and observations (Patton, 2002) and endeavoured to recover any information that was unclear or not recorded. This sometimes meant returning another day to ask if I had accurately represented what participants had said and/or to ask them to repeat certain parts so that their words could be reported directly.

Although participants were happy to deal with any query or questions of accuracy in face to face interaction with me, no one took up my offer at the end of the fieldwork to send them their typed interview transcript in order to confirm its accuracy. A number even laughed at the suggestion, stating that trust was not an issue with me. Others seemed disinterested in it declaring that it would be ‘too involved’ getting someone to hold the transcript and turn the pages. If they received it by email, however, they would have had to be computer literate which
some were not, and those who were, preferred to spend their time watching television. Given my previous experiences with clients, I had half expected this reaction with regard to the effort it would entail for them and so accepted their decision gracefully. It also revealed how much this form of research actually demands what Ellingson (2009) terms ‘a strong researcher/participant relationship’ built upon trust, honesty and empathy. However, three members of staff, who agreed to read their transcripts, were sent theirs. They all confirmed accuracy which offered a strong indication that the other transcripts would be equally accurate. In addition, during telephone calls made to NS post fieldwork, staff offered further or explanatory information as well as corrections of spellings of drugs or local agencies.

4.5.8 Interview particulars

Of the eighteen interviews, three staff and two travellers were interviewed and recorded using a speaker-phone since they lived long distances away in different States or other parts of California. Fortunately, the lack of visual cues during the telephone interviews resulted in little more than occasional, unnecessary repetition when silence fell. This usually occurred as I was not able to see ventilator-dependent participants draw breath to speak. As a result, I incorrectly assumed that the silence meant they had not heard the question. This soon corrected itself though as I was aware of how ventilators functioned and soon became accustomed to the rhythm of participants’ speech and their drawing of breath. Prior knowledge also of their need to regularly reposition themselves in their wheelchairs to avoid skin sores, and the familiar, mechanised sound that accompanied the manoeuvre, assured me that any sudden, lengthy breaks in conversation were due to this. Naturally, with their mouths on the wheelchair’s central control-piece, participants were unable to speak, so I took my cue from them and waited for them to start talking again so that they did not feel rushed to complete the manoeuvre.

Even in face-to-face interviews, empathy, understanding, patience and, again, embracing moments of silence were important since sitting positions needed to be changed regularly and
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the speed of speech was dramatically reduced for ventilator-dependent participants and also for those former ventilator-dependent participants who needed, consciously, to draw breath. Likewise, knowledge of the potential dangers of C-SCI, such as over-heating, acquired during voluntary work and whilst reading about the condition for the literature review proved useful. For example, during Susan’s interview, I noticed how flushed her face looked and asked her to buzz immediately for assistance as I was aware that over-heating could produce potentially fatal medical complications. All this thus exposes some of the issues researchers face when conducting research with such medically-vulnerable individuals.

4.5.9 Interview type and questions

As discussed earlier, my identity and view of the world impacted not only on how the fieldwork was conducted, but also on the type of data collected (Charmaz, 2006). As someone who had experienced and challenged sexual discrimination, I was interested in, and focussed discussions on, the participants’ experiences of and reactions and solutions to discrimination particularly in relation to holiday-taking. Questions were therefore largely based on: the theoretical framework of barriers for disabled tourists/people outlined in the literature review; the thesis’ research questions; the findings of the pilot study; and also on the current interview exchange or earlier observations, conversations and interviews with others. Moreover, questions explored different discourses relating to the individual, social and societal discourses of disability which thus brought different aspects into focus to ‘explain’ non-participation.

As discussed earlier, to put participants at ease, I tended to start interviews in a relaxed, conversational style using ‘guided conversations’ (Chisnall, 1996) and asking open-ended questions like what kinds of things they enjoyed or looked forward to on a weekly, monthly or annual basis before then enquiring about any issues they might have encountered in public spaces. Yet, speaking for most participants involved a great deal of physical effort. Thus, while I favoured more informal ‘conversations with a purpose’ (Lofland & Lofland, 1971; Burgess,
1984:102) - but realised that even the most unstructured interview is still subtly structured (Collins, 1998) - I then employed a semi-structured style. This was to conserve their energy and also to encourage the less confident to speak as the more unstructured and 'open' I left the interview, the more daunting it became for some non-travellers to begin to speak or to elaborate their points. I therefore began to ask a series of short, generally open-ended questions, so that in practice there became, as Denscombe (1998) suggests, an overlap of both a structured and unstructured approach.

Besides asking questions based specifically on each participant's individual holiday experience and life history, for consistency and comparison, many similar questions were posed (Wisker, 2001) and, whenever required, the same well-received information was offered to help clarify certain questions or assist participants expand their answers. Participants were generally only prompted to comment on the issues they did not mention which key studies in the literature review or other participants had singled out as significant. It was hoped, therefore, that this process might result in an element of inductive theory from 'naturally occurring' data (Hammersley, 1992).

4.6 Post fieldwork

In spite of earlier concerns about discussing holiday-taking, interviews were generally well-received. In fact, clients' spirits appeared to have been lifted because they had been the centre of attention for something other than care-giving or negative public attention. Moreover, being encouraged to voice their thoughts and opinions was a new confidence-building experience for many as was interaction, at length, with anyone. As such, clients often responded when being thanked for their contribution by equally thanking me, or with words such as: 'Sure, it's been fun'. Since most clients had no personal contacts, if they wished, we often chatted long after the Dictaphone had been turned off and, again, when I always returned to say 'hello' a day or so later so that they would never feel they had been 'discarded' after the interviews. To reinforce
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this, all participants were sent on my return to the UK picture postcards and 'thank you' cards with individual messages and my contact details.

Unexpectedly, the interviews also had a somewhat motivating effect on some participants as Mia informed me at the end of the fieldwork that several clients had begun thinking about holidays. Three travellers also requested information from me about accessibility issues in parts of Europe, and two non-travellers declared, post-interview, their intention to try and arrange a short two or three-day local holiday. The final assurance about conducting the interviews came on my return to the UK when I met up with the British power wheelchair-user from the pilot study, and he announced that he was hoping to arrange his first holiday in years. Eight months later he returned to share with me photographs and tales from his first ever holiday abroad – Florida, USA – demonstrating the power of dialogue and that critical 'thinking ... does not separate itself from action' (Freire, 1972a: 65).

4.6.1 Data analysis

'Analysis is about the search for an explanation and understanding, in the course of which concepts and themes are likely to be advanced, considered and developed' (Blaxter et al., 1996: 185). Although analysis is never a separate process but a continual one informing further data collection (Miles & Huberman, 1994; Hammersley & Atkinson, 1995; Coffey & Atkinson, 1996), serious, in-depth:

analysis begins after the interviews have ended and been transcribed. Many analyses of qualitative data begin with the identification of key themes and patterns. This in turn often depends on the processes of coding data. ...All researchers need to be able to organise, manage, and retrieve the most meaningful bits of our data.  

(Coffey & Atkinson, 1996:26)

Furthermore, just as there are no rules or rigid procedures regarding how to record, code, index, analyse and report fieldwork, 'organisation, reflection, commitment, thought and flexibility are essential to data analysis as they are to data collection' (Burgess, 1984:183).
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Sorting the large amount of data acquired from each of the NS interviews into relevant themes required good management and skill (Coffey and Atkinson, 1996). Before transcription took place, each interview was played several times and notes were made as ideas for new avenues of analysis occurred. By ‘listening beyond’ the words of the participants, I was able to pick up echoes of the experience of others with C-SCI and thus identify the themes that also made them the ‘stories’ of a group (Bertaux-Wiame, 1981).

The vast amount of additional data acquired from fieldwork notes, on and off-site observations, informal discussions and conversations, as well as my thoughts and concerns recorded about them, further extended the long and complex process of analysis. As is customary with much in-depth qualitative material, data were coded by hand on paper and divided into the relevant columns of categories. However, before this took place, ‘data reduction’ was necessary. In relation to the conceptual framework, significant parts of interview transcripts and fieldwork notes were highlighted and words or phrases in relation to key themes placed in the margins next to them (Miles & Huberman, 1994). Data were coded and analysed by content for emergent themes (Weber, 1990) relating primarily to Smith’s (1987) categories of environmental, intrinsic and interactive barriers for disabled tourists. These overlapped at time with disability theory’s individual, social and societal barriers (Barnes et al., 2005) which were equally important in the analysis since the thesis seeks to contribute to contemporary tourism research by developing tourism theory in addressing the absences from and negatives of tourism as well as the denials, delusions and risks often necessary for participation.

The second phase, ‘data display’, entailed an ‘organised, compressed assembly of information that permits conclusions to be drawn and action’ (Miles & Huberman, 1994: 11). Charts were drawn up with names of participants at the top and key themes at the side so that information contained within was condensed and easily accessible in order to make justifiable conclusions. Finally, the third stage, ‘conclusion drawing and verification’ (Miles & Huberman, 1994) took
place which involved noting regularities, patterns, providing explanations for the data and highlighting possible configurations. Conclusions were finally verified by returning to my fieldnotes and interview transcripts and tested for their plausibility and validity by engaging with the theoretical literature on disability theory and barriers for disabled tourists. Although some additional barriers affecting holiday participation emerged from the study, they could still be analysed in relation to the theoretical framework of the aforementioned categories as well as overlapping themes such as power and discourse (Barnes et al., 2005). A link between concepts and data was thus able to emerge.

4.7 Presentation of data in narrative form

Prejudice and common stereotypes which emphasise ‘deficiencies’, not capacities, of disabled people appear to be as widespread in the tourism community as they are in the wider community. Consequently, disabled people are largely perceived by researchers as ‘problems’ to be solved rather than as individuals with lives, personalities and goals of their own (Mount & Zwernik, 1988). Research methods reflect this stereotype by reducing the reality of disabled people’s lives down to quests for simplistic generalisations (Booth, 1996). Thus, ‘disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life’ (Oliver, 1996: 141). Since most tourism research examining disability operates in this way, often with greater concern for the economic needs of the industry than those of disabled people, it was decided that the study’s ‘findings’ would be presented in narrative form as ‘[n]arratives are a window upon society’ (Williams, 2004: 280). Since they are also regarded as the principle format by which individuals’ lived experience is made meaningful to themselves and those outside their social world (Gabriel, 2000), they could be an important vehicle for challenging preconceived beliefs about severe disability and holiday-participation. Furthermore, just as a blended methodology was first taken to examine the inter-disciplinary nature of the study, a blended
method within narrative inquiry was adopted, in part so that the details of experience could be appreciated as much by the general as the academic reader.

The potential of narrative has been increasingly recognised in the social sciences, particularly in work on disability (eg, Marks, 1999; Thomas, 1999; Swain & French, 2000; Smith & Sparkes, 2005, 2008a, b; Todd, 2006; Goodley & Tregaskis, 2006), illness (Frank, 2004) and earlier by Williams (1984:180) in his work on chronic illness and 'narrative reconstruction as political criticism' which suggests how people use narrative to 'repair ruptures between body, self and world'. Within disability narratives too, Goodley et al. (2004: viii-x) testify that life story:

...tells us much about individual and collective, private and public, structural and agentic and real and fictional worlds. Stories occupy a central place in the knowledge of societies... Narratives are always politicised, structured, culturised and socialised. ...Narratives may be our best hope of capturing structures that continue to shape, divide and separate human beings.

It is, however, an anathema that very few tourism researchers employ narrative methods when 'the role of narrative is fundamental in the construction of tourist experience... [to] make sense and meaning out of lived experiences and to present them in an interesting way to new hearers' (McCabe & Foster, 2006: 212). It is perhaps even more surprising that there appears to be an absence of narrative in any tourism research exploring disability when the potential for narrative in both these areas has been recognised. Nevertheless, there has been a recent resurgence of interest in narrative by other social scientists since the heyday of the Chicago School. This has been due primarily to feminist and critical race theory scholars. Narrative methods have provided their readers with access to excluded voices and the perspectives and experiences of oppressed groups who lacked the power to make their voices heard through traditional academic discourse (Booth, 1996). Likewise, in this thesis, an informed, principle decision was made to use narrative methods (Sparkes, 2002) to give the socially-excluded participants with C-SCI a much needed voice.
As mentioned earlier, another equally important reason for presenting the data in twelve separate narratives of non-travellers and travellers evolved partly during fieldwork in the USA, and partly from discussions with friends and colleagues post-field work in the UK. This thus illustrates how: 'research cannot be tightly prescribed, and that all phases of the process may change or shift after researchers enter the field and begin to collect data' (Creswell, 2007:39).

The common denominator on both sides of the Atlantic was a combination of general negativity and ignorance about C-SCI and holiday-taking which illustrated how individuals with C-SCI were still being 'prohibited from being' (Friere, 1972b: 30) anything other than what common cultural myths about them perpetuated in the metanarratives of the media and healthcare practioners (Smith & Sparkes, 2005, 2008b).

From their comments, it was clear that few, if any, alternative narratives of disability were available to them to draw upon and challenge their preconceived ideas. However, it was a revelation on the occasions I offered stories, or 'counter-narratives', of travellers with C-SCI. As outlined earlier in the thesis, these are the antithesis of the usual, dominant narrative and 'are tools designed to repair the damage inflicted on identities by abusive power systems' (Nelson, 2001: xiii). Listeners remarked how these stories changed their views about the hopelessness of life with C-SCI. Some of the listeners who were non-travellers were even inspired to begin to believe that holiday-taking might be possible for them. This thus proved the power of storytelling - and particularly of counter-narratives- to caste people with C-SCI in a new light and change common misperceptions.

### 4.7.1 Benefits of narratives

As a result of such unexpected, positive responses to the stories I told during and post-fieldwork, it was decided to present the fieldwork data using a narrative format. Additionally, it was considered necessary to go beyond the standard presentation of academic research findings in order to reach multiple audiences who were still influenced by the dominant discourse of
disability. Data thus had to be presented in an accessible format to reach a wide audience of: clients, family and friends of clients, staff, tourism academics and providers, and hospital rehabilitation programme planners and policy makers. Since people think in and relate to and, just as I had done, pass on information in ‘story form’ (Smith & Sparkes, 2005, 2008a,b), and indeed enjoy reading/hearing stories, narratives seemed the most appropriate and accessible vehicle to impart such potentially emancipatory information.

In addition, narratives could provide essential background information and a multilayered lens through which C-SCI and holiday (non)participation could be illuminated, as opposed to offering random points that fail to convey the connection and complexity of the issues and barriers. Moreover, by considering the aforementioned stakeholders in the presentation of the findings, a natural link was made with the ‘practical suggestions’ regarding C-SCI and holiday-taking to be offered in chapter seven of the thesis.

It should be stressed, however, that the study’s adoption of a narrative form is quite different from the approach taken by narrative inquirers whose distinct epistemological and interpretivist stance (Smith & Sparkes, 2008a) differs from that of this critical research. Moreover, since ‘lives are available to us only in words’ (Denzin, 1989), narratives were used in this thesis as an alternative method of presenting primary data. Thus the use of narrative here differs only in the presentation not in the collection, retrieval and analysis of data of more traditional critical research.

4.7.2 Risks of using narratives

The narratives presented in the next two chapters of the study drew on elements of participants’ daily life and life history in order to set the issues of holiday (non)participation in context of their lives. Thus, far from being an ‘easy option’, using narratives involved working with an extraordinarily large amount of data even before the complex process of writing via a
multilayered lens could begin in order to produce coherent, ‘readable’ narratives interwoven with theory-relevant themes. Yet, despite such a long and involved process, presenting data in narrative form carries risks due to a general lack of peer recognition.

As the near absence of publications in tourism journals from researchers using narrative methods testifies (Westwood, 2007), some of the risks involved are that the narratives might be read as ‘fiction’ rather than relevant ‘facts’ acquired via a rigorous research design. Due to this and other traditional views on research methods within the academic community, I was advised by a senior academic and experienced PhD supervisor to employ a more conventional PhD format and to place my narratives in the appendix of the thesis. This was rejected, however, as, contrary to the proposed approach, it would involve marginalising participant voices whilst privileging the researcher’s role and interpretations.

Most of the criticism levelled at narrative methods, such as issues of unrepresentativeness, lack of objectivity, verification, partiality and unreliability, emanates largely from those scholars entrenched in traditional, positivist research methods (Charmaz, 2006). Yet, surveys or questionnaires using large numbers of disabled people often produce only ‘surface truths’ and are no more ‘reliable’ than other methods as they too depend on personal recall and what is said in relation to how questions have been phrased (Veal, 1997). Furthermore, these methods help reinforce the medical model of disability, emphasising individual deficits because, by not fully engaging with disabled individuals, their ‘limitations’ come to the fore rather than the limitations of the traditional methods used (Booth, 1996). Thus, on political grounds, narrative methods can be seen to directly challenge the medical model of disability as ‘they form a bridge between individual and society by giving access through people’s lives to structural factors of their social world’ (Booth, 1996: 239).
Another risk involved with narratives is how narratives are written, because if the researcher-writer is not an experienced or skilled narrative writer, ‘the message’ which the narrative form is supposed to convey with great effect is likely to have less impact or even be lost (Smith & Sparkes, 2008a). Yet, because of the paradoxical nature of disability, disability stories can also be ‘difficult to tell as well as to hear’ (Zola, 1981: 356), with either too much or too little meaning being conveyed. Often, therefore, ‘to understand lived experience, we need narratives, stories of unfinished, muddled, in-the-midst-of experiences whose only certainties are the beginnings or turning points’ (Wikan, 2000:234).

Furthermore, the decision to pepper the narratives with sizable extracts of participants’ direct speech could be considered, at times, to jar with the overall style of the narrative and so risk reduced impact on reading. Yet it is hoped that what is being presented by these previously unheard voices might be found to be infinitely more compelling than the hows of style, particularly since what is being said might be so different, unexpected, challenging and potentially disturbing or emotional that readers would become fully engaged in content.

Finally, despite the rigor and risks that are involved in producing narratives with elements of life history, the act of challenging traditional methods of presenting data sits more comfortably with emancipatory research like this, since it carries with it an inherent understanding that to critique or potentially change the status quo often involves risks. Nevertheless, Ellingson (2009) calls for the research community be open-minded and willing at least to appreciate, if not like, ‘other ways of knowing’ and representing data.

4.7.3 Type of narrative

Writing about people’s lives offers a distinct set of challenges which have rarely been articulated or confronted in much qualititative research. For instance, narrative inquiry offers a series of styles from which researchers can choose. Although it does not privilege any one type
of narrative over another, researchers who present their data in narrative form nevertheless tend to align themselves with one of two very distinct types of narratives (Smith & Sparkes, 2008a). The first is the traditional ‘realist’ tale which uses quotations from interviews and frequently interrupts the text to link themes from participants’ quotations to theory (Smith & Sparkes, 2008a). This results in a highly academic and, for most readers, inaccessible narrative.

The other type - eg, an ‘autoethnography’ where the researcher him or herself is the focus of social inquiry exploring, for instance, his/her own experience of disability - is more ‘creative’ and accessible using fiction, plays, poetry and so on. The narrative is kept whole with no theoretical interruptions asserting that a good story is in itself analytical and allows readers to make their own interpretations (Smith & Sparkes, 2008a). Likewise, another form, such as an ‘ethnographic creative non-fiction’, offers the impact, emotion and accessibility of a fictional format, yet the content is entirely based on facts retrieved from recorded interviews and documented observations (Ellingson, 2009). The facts may not be presented in the order in which they occurred, but they are not the researcher’s own creations. Again, whilst the actual words of the participants might not be presented, their essence is nevertheless represented which produces a consistency of style and enhanced ‘readability’ for different audiences (Ellingson, 2009).

Apparently, few narrative inquirers ‘cross over’ to represent their work in the other’s format (Smith & Sparkes, 2008a). The concept of ‘crystallisation’, however, offers the possibility of using multiple writing styles to present similar and different aspects of research data to reach different audiences at different times (Richardson, 2000; Ellingson, 2009). In this way, the same data could, for example, be written using an academic style and language with medical jargon for a specific journal and, also, to reach segments of the general public, in a more accessible style and language (Ellingson, 2009). However, since my goal was to reach the broadest possible audience at the same time - to enhance the possibilities of ‘concentric circles
of witness’ (Sparkes, 2002), so that when one person becomes informed, he/she informs the next person and so on - I chose to blend elements from both of the above narrative types. Thus, the narratives needed to be kept whole to allow as full a picture of the complex, multifaceted experience of disability and holiday (non)participation to emerge which is rarely, if ever, painted in tourism literature. Furthermore, theoretical interruptions of a realist tale would affect the overall sense, flow and impact of what needs to be conveyed (Smith & Sparkes, 2008a) as well since as risk losing authenticity as unelaborated narratives are more true to individuals’ experiences (Booth, 1996).

Equally important was that information should be conveyed in a clear, direct and, hopefully, engaging way if inclusive knowledge is to be provided. The academic language of a realist tale was rejected as it could render it inaccessible for many of the target audience. Yet, in contrast with the creative non-fiction type, direct quotations from participants played an important role in the narratives in order that these previously silenced voices would be heard and their ideas conveyed in authentic, personal speech rather than academic prose. With regard to ‘reliability’, the emphasis on the participants’ own words also made it more difficult to misrepresent data (Sedgley, 2007).

4.7.4 Potential of narrative

By attempting to offer the audience direct ‘interaction’ with participants through participants’ speech, life history and daily life, it was hoped that readers would make the imaginative leap into a world beyond their own experience so that the common tendency to label disabled people either a victim or a hero might be reversed (Booth, 1996). Moreover, the travellers who might traditionally have been perceived as heroes illustrated the paradox of disability by revealing themselves as victims also as they had been physically, emotionally and financially ‘abused’ by new partners. There was a similar grey area for non-travellers who, traditionally, would have
been represented wholly as victims to be pitied rather than as they actually were, fellow human beings with the same basic needs, fears, desires and qualities. Moreover, when the disabled person is no longer the subject of impersonal, abstract theory within the narrative (Booth & Booth, 1994), the power of drawing readers in through emotional engagement with the individual cannot be underestimated (Uzzell & Ballantyne, 1998; Sparkes, 2002) as:

*Imagining what it is like to be someone other than yourself is the cornerstone of our humanity. It is the essence of compassion, and it is the beginning of morality.*

(McEwan, cited in Cooke, 2005)

Thus, in contrast to how analysis is, or is not, applied within the different types of narrative camps, this study's analysis and discussion of the themes and issues of the narratives will be offered separately in chapter seven after the narratives have been presented, intact, in the previous two chapters. By providing an analysis of the narratives, albeit in a separate chapter, the demands of scholarship can therefore be met as an opportunity for the narratives to be disputed has still been provided (Farber & Sherry, 1993). Perhaps the most compelling argument for delaying the analysis until after the narratives have been read is, however, provided by Sparkes (2002: 36-37) who argues that:

*The best nonfiction writers do not tell us how we should think about something, how we should feel about it, nor what emotions should be aroused. They simply present the concrete details. ...Cognitive research indicates that humans remember best what enters the brain in an envelope of 'emotion'. If it is true that facts and details are stored along with attendant emotions in a system of cross-files throughout the brain, we writers must recognise it and use it to our advantage.*

Finally, with little more than politically-correct 'lip service' still being paid to disability issues (Shakespeare, 2005), the aftermath of the ADA (1990) and the DDA (1995) demonstrates that people can not be simply 'instructed' to think or act in a different way. Rather, they need to discover the reasons 'why' for themselves. Often, it is only by being moved, by being given the freedom to gather their own thoughts, to form their own interpretations and to come to their own conclusions can true critical reflection, and the possibility of emancipatory action, be realised.
Chapter 4: Research approach

My intention was never to lead the audience to a specific conclusion, or course of action, as different people will see or need different things from the narratives. The objective was to stimulate a response on one or more levels - emotional, intellectual, moral or practical - so that readers might respond proactively and of their own accord for the better. Naturally, this presents the researcher with a series of challenges in the style and tone of writing, and also the thorny issue of voice, be it the researcher’s, the participant’s or both.

4.7.5 A matter of voice

Issues raised about the social exclusion of disabled people are, observes Barton (1996:14), not only to be ‘engaged with at a societal or policy level, but also at an individual one. ...An important way to begin to seriously engage...is to listen to the voices of disabled people as they are expressed...’ Thus, contrary to customary feminist and narrative inquiry practice, I endeavoured to silence my own voice as much as possible in order ‘to give voice’ to the participants whose voices were all but absent from tourism literature. Moreover, their silent and silenced voices perpetuate the myth that people with C-SCI, especially those who are ventilator-dependent, are physically or mentally incapable of speech or anything else.

However, despite my desire to suppress my voice, it must be acknowledged that as the writer of the narratives, my voice or ‘presence’ is embedded throughout the narratives. Indeed, as Booth (1996) observes, in writing the narratives, I needed to edit material and connect different parts of the same or different interview in order to form a coherent whole or to develop a particular theme. Nevertheless, it was important always to stay loyal to the actual words spoken by participants (indicated by italics), although when staff’s accounts were either too lengthy or repetitive, I sometimes edited and reported these accounts using my own words in between smaller quotations.
Regrettably, my voice was more evident in the narratives of some of the non-travellers who had less to say about holidays or, indeed, anything else. Nevertheless, their interaction with me and others was in stark contrast with that of the more socially-confident travellers, and thus offered greater scope for observational material. The challenge then was to translate these observations into words. Unlike the descriptions of traditional research narratives, I decided to draw on all the senses to paint as true and vibrant picture of participants’ daily life as possible. Yet, from a strict feminist, egalitarian approach to research, in offering this observational detail, the power had uncomfortably shifted back towards me, the researcher-writer, because, with far less direct speech to draw from, my and/or staff’s observations became fore-grounded in the narratives. Again, as Iles (1992) points out, however, the issue of power is always apparent in all of the narratives, first in my selection of pieces of information/discourse to omit or include, and then in the order of their presentation.

To compensate for this, I tried to avoid using an omnipotent, authoritative voice or even an overtly interpretive one. Instead, my voice was to appear more like that of a documentary-maker conveying the ‘facts’ as directly as they were presented from different participants. This practical, logical documentary-style allowed me to organise important information under subheadings in order to break up long narratives, and to guide readers easily through the vast amount of information before they reached their own conclusions. It also allowed me to explain specific C-SCI terms or issues used by participants that might be unfamiliar to many readers. Additionally, I was occasionally able to situate myself in the narratives by using my documentary-maker’s eyes and reactions to describe personal interactions with participants which could offer readers insight into how other members of the general public might also feel during interaction with an individual with C-SCI.
4.7.6 Reworking the narratives

Although it was clear from my engagement with reflexivity earlier in the thesis that I was an ‘interested and sympathetic observer’, I still endeavoured to offer as true and balanced picture as possible of the participants and the realities and practicalities of life and travel with C-SCI. Not only did the integrity of the research demand this, but if change is to be realised, the real ‘warts and all’ and practical issues of C-SCI and holiday-participation must be fully exposed. Furthermore, as stated previously, for genuine change to take place, the impetus needs to come from the readers of the narratives without their being ‘instructed’ by my interpretations of the data presented. However, any naturally-occurring analyses or interpretations that participants made whilst speaking were automatically included in the narratives as it was their lived experienced of severe disability and their thoughts and perceptions as ‘experts’ I wished to foreground.

Yet, despite my intention not to interpret the narratives, during the process of writing, some of my own analysis - although only ever presented as an interpretation - unconsciously started to creep in and appear as the dominant analysis/interpretation of an omnipotent narrator. I therefore ‘reworked’ the narratives to take out as much of my own overt interpretation as possible because, in contrast with the other types of narratives where, for different reasons, the researcher’s voice is the most dominant and important, these narratives were not about the researcher, but the participants. Thus I changed, for instance, the opening sentence of Maria’s narrative as I had inadvertently instructed the reader how to view her when I first wrote: ‘Tiny in statue she may be, but Maria is hugely inspirational...’ The rewritten opening sentence began with a brief physical description of Maria - ‘Fresh-faced, pony-tailed and diminutive, Maria looks years younger than she really is’ - followed by accounts of the challenges she had met in her life and then the audience was left to draw its own conclusion at the end of the narrative.
Chapter 4: Research approach

The rewrites brought further challenges, however, as finding the right balance of tone, information and ‘interpretation’ proved more problematic than expected. Having striven to take out as much of my own interpretations as possible, some of the reworkings left the narratives sterile, with reduced emotional impact and, perhaps, for some readers, reduced clarity. I concluded, therefore, that besides giving full voice to all the participants’ interpretations, I also needed, on occasions, to compromise and allow my own ‘summing up’ to come through in order to guide the less empathetic readers to piece together what had been presented in the narrative. Thus, the sparse and almost cryptic rewrite of non-traveller Nancy’s conclusion - ‘Yet, with hindsight, the more I began to understand her silence’ - was later rejected. The longer, original conclusion was reinstated which tied all the loose ends together by posing questions based on information already presented throughout her narrative:

I respected her silence even more with hindsight. Perhaps she may have felt some embarrassment or even pain at the ‘injustice of it all’. Or was her silence simply because she had turned yet another unfortunate page, and the art class and very occasional day trip, just like her living as part of a family, were now things of the past, no longer part of her conversation or of her increasingly socially-isolated world.

Finally, as indicated earlier in the chapter, ethical considerations pervaded every part of the research process, including the (re)writing of the narratives. Compared with quantitative researchers’ working with numbers and statistics, as a qualitative inquirer dealing with a vulnerable research population, I had expected I would face many more ethical dilemmas. I did not, however, expect the following ethical dilemma to arise. When the same information about the parent of a non-traveller kept surfacing during several staff interviews, yet this information was unknown to the client, I risked dishonesty if I withheld the information when presenting the results. Therefore, in the first and overly interpretive draft, I reluctantly included this information. It read:

On several occasions it was suggested to me, but never to [the client], that the house fire death was a way to stop contact so that [the client] would not call any more and try to arrange for his/her parent to see him/her.'
Chapter 4: Research approach

No one at NS doubted that [the client] believed that his/her parent had perished in the house fire as the frightening voices in his/her head immediately followed it. I began to wonder though whether, even at the risk of unbearable rejection a second time round, [the client] had also silently questioned the legitimacy of the house fire as its timing had coincided with his/her request to meet his/her parent. Certainly, years earlier I had been exposed to [the client’s] quick-wittedness, intelligence and thoughtfulness, and how much more there was to this client than the label of being ‘difficult’.

Although presenting what knowledge I had acquired during fieldwork was important to the integrity of the research, I remained uncomfortable with the first draft as my overriding concern for, and commitment to, this or any participant’s well-being was greater. Indeed, protecting participants from psychological or emotional harm is of great importance (Lee, 1993) if they are at risk of harm where ‘research gives rise to false hopes, uncalled for self-knowledge, or unnecessary anxiety’ (BSA, 2002:4). Yet, narrative inquiry demands that once researchers tell a story, it is ‘uncontrollable and unpredictable’ as no one can know how a person will react to or use the narrative; thus, although there are clearly both ethical and moral implications here, narrative inquirers just have ‘to live with’ this uncertainty and the consequences of ‘tellability’ (Smith & Sparkes, 2008b). Nevertheless, the decision was made to withdraw the above information in the rewrite in case it would cause the client any harm should the narrative be ever read. The whole approach adopted in this study can thus be seen to make many demands on the researcher because, even if the researcher is well-prepared, other challenges - ethical or otherwise - can emerge out of the blue and force the researcher to grapple with the unexpected.

Based on the previous decision, a final ethical decision was made to destroy unused data that could be considered harmful to any participant three years after completion of this thesis. After all, research objectives 2 and 3 reflect the principle reason why this qualitative data was to be presented in narrative form: to give voice to participants in the hope of providing them, and other clients, with a broader repertoire of narratives of disability to draw upon that might inspire critical thinking and potential action towards a more positive and fulfilling way of life.
4.8 Summary

This chapter has discussed the research approach used to achieve the research objectives outlined in chapter one. It explored the four core research elements identified by Crotty (1998) and detailed their relevance in this research. They included: social constructionism (epistemology); critical inquiry (theoretical perspective); a critical discourse approach, feminist standpoint and elements of narrative inquiry (blended methodology); and in-depth interviews, non-participant observation and narratives (methods). Justification was then provided for the selection of narrative within a disability studies and critical tourism context, although the use of narrative differed only in the presentation not in the collection, retrieval and analysis of data of more traditional critical research. Finally, the challenges of using narrative were explored with regard to voice, interpretation, emotion and ethical considerations.

Next, the narratives of six non-travellers and six travellers will be presented respectively in the following two chapters.


### CHAPTER FIVE

**NARRATIVES OF NON-TRAVELLERS**

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CHAPTER FIVE

NARRATIVES OF NON-TRAVELLERS

5.1 Overview of chapter

This chapter presents the narratives of six non-travellers with C-SCI written from data collected via interviews, discussions and non-participant observation. All are clients at NS home in California and, although some have taken an occasional day trip or even a holiday as a disabled child long ago, all now define themselves as non-travellers. Thus, through an exploration of their socio-political culture, past events and painful experiences as well as their current situation, the narratives hope to illuminate issues surrounding their collective non-participation in holidays. The narratives of participants who, on a sliding scale, appear most convinced of their fixed status as a non-traveller will be presented first, opening with Nancy and concluding with Maria. For immediate clarity relating to each non-traveller, however, a brief overview of the individual’s personal history is provided at the outset of each narrative next to the person’s name. It includes: ethnicity; gender; age at the time of interview; the cause of C-SCI; age at which C-SCI was developed/sustained; and level of C-SCI (C7-C1).
5.2 Nancy (Caucasian female; 26; car accident as small child; C2 ventilator-dependent)

As I entered the computer room to meet Nancy, there was not even the expected sound of typing. Only the rhythmic puffs of three ventilators exploding into the silence at various intervals could be heard. Nancy, wearing a red baseball cap with ponytail dangling over the back strap, was sitting on the far side of the room with her back to the door and the two other clients in the room. All three were completely engrossed in their computers.

As I approached, I caught a very faint odour of urine in the air, presumably from the urine bags on their wheelchairs. Nancy was slowly typing a letter with the aid of a thin, rubber-ended mouth-stick that struck the keypad silently and securely, never slipping off one task button onto another. Although she was expecting me, she did not acknowledge my presence or greeting. Instead of moving to another room to talk, she just continued typing in a slow nodding-like fashion. She stretched her head up to look at the screen and down again to position the mouth-stick onto the keypad which she was able to reach only because it was perched just below chin-level on top of a large, pink pillow on the desk in front.

Background

According to NS director, Mia, 'Nancy came to NS as a very disgruntled adolescent soon after her [single] mother remarried. Nancy resented her step-father as she had been used to living alone with her mother and ruling the roost since her car accident as a very small child'. When her step-father moved in, she found that she no longer had the only say in her mother’s life or the running of their household. Because of the friction this caused at home, her mother made arrangements to move her daughter out. This left Nancy feeling that she was being unceremoniously kicked out of her own home.
Nancy thus arrived at NS as a very angry, upset teenager. Mia was so concerned about a breakdown in the mother-daughter relationship that she immediately tried to counsel her new client. She did not want Nancy to view her coming to NS as being abandoned by her mother for a new man, but rather as a natural process of growing up, of needing to be more independent and consequently leaving home. Nancy eventually settled in at NS and, as Mia asserted, is generally thought to be: ‘quite easy-going on the whole, though at times ...she can also be demanding and very picky about how things are done which causes tension’.

Interaction

Nancy’s voice was a surprise; it was incredibly soft and sweet and also rather child-like, which did not quite fit her age or her large, adult appearance. I began to wonder whether her voice had changed much since the day she had arrived at NS as that unhappy adolescent. When I asked her about the computer she was using, she smiled sweetly and responded very enthusiastically, explaining how it all worked. However, instead of my enquiry being taken as an ice-breaker, she turned it into a computer lecture that seemed to last an age.

After her explanation, Nancy decided to demonstrate her typing skills. She painstakingly typed with her mouth-stick the same phrase over and over again until she deemed it worthy enough to show me as if seeking my praise, pupil/teacher or even child/adult-like. She appeared to convince herself that I was as technologically-minded and as interested in computers as she. As a result, she failed to take the bait to move off the subject, even for a second, whenever I tried to talk about her other interests. It was as if she were in a little world of her own unable or unwilling to pick up the signs that I would like to talk about other things after, of course, she had finished her letter. However sweet she sounded, she was clearly in control of the situation and her captive audience of one – me, and it soon became evident that she was more interested in ‘demonstrating’ than letter-writing.
Chapter 5: Narratives of non-travellers

As time went on, it started to look less likely that the letter was ever going to be finished as her computer lecture/demonstration routine continued again as I stood next to her in silence. Then, just as I was about to suggest we perhaps meet somewhere else for a chat another time, she looked up and said: ‘See him, *Todd, that guy over there, he’s got a head-set control for the computer. Ask him about it. He’ll show you how it works. I’ll have finished this to show you by the time you come back from talking to him’. (* This brief interaction with Todd is outlined at the end of Nancy’s story)

Leisure/holidays

After speaking to Todd I returned, as requested, to Nancy for my third and final computer session. It was then that I managed to discover that computers were now her only interest and activity in or outside the house since giving up her weekly art class at NS head-office. All she was prepared to say about her decision to leave the class was: ‘I don’t go any more there. I don’t like it’. Staff later intimated that she was one of the most talented mouth-artists they had ever known. When I attended the art class a couple of days later, I noticed how her beautiful landscape mouth-paintings stood out from all the other paintings adorning the walls of NS head-office. Staff explained that due to a falling out with the art instructor, Janet, during a day trip to Disneyland, Nancy could not be persuaded to return to the activity she loved so much and for which she showed such talent.

Nancy was equally unwilling to be drawn on the subject of holidays or day trips other than to say that she just did not like them and that they should not be part of a rehabilitation programme. She declared that she had never taken a holiday, and did not want to either; as for taking ‘day trips, yes some, well a couple maybe, but I don’t go any more. I don’t like going out...because of all the stares you get - as if you’re an alien. It makes me uncomfortable.’ And that was all she would say on the subject.
Chapter 5: Narratives of non-travellers

Staff account of day trip

I asked staff about the occasional day trip just a few clients had taken. Apparently, these trips are very rare and only financially possible due to some of the staff’s personal contacts whose businesses or associates are willing to provide a number of free passes or entrance tickets to attractions. Likewise, they are only possible because some attendants give their time free of charge to accompany clients.

To make the trip to Disneyland possible, Janet’s son-in-law’s company had provided a number of the free passes as well as vouchers to eat at a good restaurant there. Janet felt that most of the clients who went had an enjoyable time even though there was only one wheelchair accessible ride working that day out of a possible two. The ride was designed for very young children and was located in the aptly named section of the park, ‘Small World’. The ride which was out of action would not have been accessible to power wheelchair-users, however.

Attendants were impressed that, on the whole, clients did not complain that their ride was meant for little children or that they each had to wait patiently amongst all the children in the hot sun for almost three hours to go on this one ride: ‘They had to wait so long as there was space for only one of their power wheelchairs at a time on the ride, and if they didn’t wait in line for the ride to end, they would miss their turn and only opportunity to go on a pleasure ride that day.’ Yet, even after their ride, clients still had to wait around in a group until every one had had a turn because there were not enough attendants to accompany each client. No ventilator-dependent client could be left unattended at any time of the day or night in case the ventilator malfunctioned. Thus, for their own health and safety, they needed to stay in the group all day.

Nancy was not at all happy with this arrangement. She resented having to stay in a group as if she were a child on a school trip. She complained to staff that this restricted her and she wanted to be alone, with attendants, to be able to choose what she wanted to do at the time she wished.
At lunch, too, clients had to sit altogether in the restaurant as each attendant needed to feed a number of people at the same time, including herself. The final straw came for Nancy when she asked the attendant to use the suction machine to clear away her saliva before she ate - and she wanted it done there and then at the table. Janet explained to her that this was not the appropriate place to do that as 'the feelings of other diners paying good money to eat there also needed to be taken into consideration.... People would not feel comfortable eating when someone is using a noisy suction machine to bring up saliva and other secretions on the next table to them'. She therefore insisted that this be carried out in the restaurant’s ‘restroom’.

Nancy challenged Janet’s decision immediately, stating that she needed the suction done right away and that it was also her right not to be disturbed and to be able to choose where she wanted it to be carried out. She argued with Janet for quite a while and clearly expressed her anger when she could not get her way and had to head for the Ladies with the attendant. As a result, on return from Disneyland, instead of thanking staff for making this day trip possible, she typed a highly critical, ‘nasty, venomous letter’ to Janet about the trip and the lunchtime incident in particular. After that, she cut all contact with the art class as Janet was in charge, and declared that ‘she would never go on any day trip with anyone ever again because of the way she’d been treated that day’.

Janet passed the letter to Mia who commented on how hurt and upset Janet had been by its ‘venom towards her’. No one else has ever seen the letter. Janet sent a written reply to persuade Nancy to return to the art class, trying to explain, again, the issue with the suction machine from another’s point of view.
Chapter 5: Narratives of non-travellers

Occupational therapist manager, Chris, explained that Nancy’s rejection of future day trips, based on just one negative incident, was rather common amongst clients:

Generally, clients are depressed, angry or unmotivated. The less they do, the less they want to do. One [client] just recently described his life as ‘a living Hell’ to me…. But when they go out, they’re all very fearful of things going wrong or being hurt, so if there are problems, they generally will not go [out] again. Also they will only go if a certain care attendant accompanies them because of bad relationships with others…. They curse, even spit in attendants’ faces, the real nasty ones, but they were nasty before their injury. Care attendants also don’t want to go anywhere outside work with them either because of the way they’re treated, but if they do, they have to fix everything when things go wrong because clients are so dependent… and passive. And clients worry… about departure and return times, their care routines being disrupted, so they would never contemplate two day trips on the trot. Sometimes they are embarrassed to be fed like a baby in public…. Many are self-centred and demanding and don’t want to stay in a group on day trips with other clients [as] they want to be independent…. [Yet] they are also frustrated when they try to be independent and find out information for themselves as the person they have called puts the phone down on them thinking no one is there just as they are taking time to draw breath to speak. It’s so frustrating for them…. They try again but then give up.

Former NS nurse, Liv, noticed how frustrating also it was for clients to go out in public:

There was…fear because the [wheel]chairs are so big and there is the ventilator…. People assumed that, somebody so physically-disabled that they can’t move or can’t even breathe by themselves, then there has to be a mental impairment. …I think people are very scared when you’re with a quad. Even people in healthcare will talk to you, the nurse, and not to the person [with CSCI]. So many times, as a nurse, I would only make eye contact with the client so that they [the healthcare workers] would realise, don’t talk to me about him, talk to him.

The future

Nancy has not wavered from her decision to give up the classes and the day trips; neither has she ever mentioned the restaurant incident or the letter to anyone, including me. I respected her silence even more with hindsight. Perhaps she may have felt some embarrassment or even pain at what she might have considered the ‘injustice of it all’. Or was her silence simply because she had turned yet another unfortunate page, and the art class and very occasional day trip, just like her living as part of a family, were now things of the past, no longer part of her conversation or of her increasingly socially-isolated world.
At Nancy’s request, I dutifully headed across the computer room to find non-traveller Todd, C2 and mid-forties, to ask him about his computer head-set control. I learned later that he had been shot as a young man by his girlfriend’s jealous ex-boyfriend but that she had left him immediately after the shooting. Apparently, before injury he had been a successful businessman... rather in the style of an American ‘Arthur Daly’ as members of staff suspected he might still be doing a little ‘business on the side’, selling suspect CDs abroad.

As soon as Todd heard my accent, he looked up with a glint in his eyes, grinning from ear to ear. Fortunately for me, he was not the slightest bit interested in talking about computer technology. Neither, unfortunately, was he in answering anything else I asked him. He was the only one who was going to ask any questions around there, and soon started firing them at me one after the other: ‘Hey, where are you from? Where’s that? Is that a city? How do you spell ‘Cardiff’? Can you type it into my computer for me? Hey, look, there’s a castle there... in Cardiff. Where is it? What’s the name of this castle? How big is it? What else is there in Cardiff?’

Since he had shown such enthusiasm for this foreign place, I endeavoured, again, to ask him about his own home town and his travel interests and experiences. It was useless. He either completely ignored me or ‘replied’ by asking me yet another question about Cardiff until he became so absorbed in the coloured pictures of the city on his computer that he seemed to forget that I was standing next to him and stopped talking altogether. I knew I had been dismissed at this point, so my thoughts returned to Nancy on the other side of the room. I quickly headed for yet more computer-talk from her.

It was unfortunate that Todd’s obvious enthusiasm for discovering new places of interest on the Internet had not extended to exploring them through travel or with me in conversation. There
had been nothing remotely like a two-way conversation or interaction between us. As with Nancy and rather a lot of clients, it was his way or no way. With hindsight, having had some very unusual requests from clients in the past, my swift departure from Todd may have been fortuitous. For all I knew, he could soon have tired of the pictures of Cardiff, looked up at me again with that familiar glint in his eyes, and thought, ‘Bingo: Cardiff, dodgy CDs - link person!’
5.3 Jose (Hispanic male; 29; gun shot injury at 17; C2 ventilator-dependent)

Described by staff as 'a sweetheart' and 'a real sweetie', Jose came to NS in 1995, just one year after he sustained a gunshot wound which left him with a C2. He had been shot in a random 'drive-by shooting' as he and his friends were on their way home after a party. He was just seventeen.

Born in California of Mexican parents, Jose is proud of his Mexican roots, although he has only once been to Mexico when he was twelve to visit family. Other than that, he has never taken a holiday pre or post-injury. Thus, when Jose was asked if I could come and speak to him about holiday-taking, he agreed but also voiced concern. It seemed he feared he might not have anything to contribute as he had never even taken a day trip, yet added with a chuckle: 'But tell her, if she wants to take me on vacation, I'll go!'

Interaction

When Jose saw me at his bedroom door, he greeted me with a warm smile and the words: 'Hi, come on in'. Just like the last time I saw him, he was lying in bed under a crisp white sheet pulled up to his chest. He was not wearing a top, so part of the distinctive, thick, black calligraphy tattoo on the top of his right arm could be seen. Again, like last time, he was watching television but immediately asked if I would switch it off and then thanked me for doing so. His smile broadened as I said in Spanish 'de nada' - 'you're welcome' - and we continued in Spanish until I'd exhausted all the Spanish I knew, although he kept on praising me and wanting to teach me new words each time I tried to switch back to English.

Despite the fun greeting, I was still not sure whether he really remembered me. To my surprise, he replied: 'Of course I remember you. So why's it so long since you were last here? Where've you been? You know, you remind me of Liv, a Scottish nurse who used to work here. Oh, I told
you that last time? I did?’ We laughed. I recalled how Jose had told me on the first occasion we met that I reminded him ‘in every way of Liv’ who had left NS many years ago when she married and moved to another State. Although I had never met her, I told him that Mia had arranged for me to speak to her over the telephone some time that week about her trip to Las Vegas with two former clients. On hearing that, Jose’s eyes lit up and he said: ‘Please say hi from me, if she remembers me’.  

I promised Jose I would relay his message. Yet, before I left that day, he reminded me again to say hi to Liv from him. When I later spoke to her, she was ‘flattered’ that Jose had remembered her, yet choked that he might think she had not remembered him. Then, in my newly acquired role as ‘NS messenger’, I promised her that I would give Jose her best wishes and her email address which former client and traveller, Don, had already asked me to get from her. This became quite a pattern whilst I was at NS. I seemed to be constantly relaying messages and information about travel and many other things from one client to another and even to staff.

**Background**

According to nursing-manager Monica, Hispanic, Middle Eastern and Oriental families generally have more contact with their relatives at NS than white and African-American families, even if it eventually tails off: ‘For example, Jose’s mother, father and two sisters are nice people, and for the first five or so years [they] used to visit every week, but there does not seem to be much contact now’. Mia confirmed that this was a very common pattern with relatives, and calculated that over ninety-five percent of her clients were left with very little or no contact with their loved ones. In the case of female clients and their pre-injury partners, however, virtually a hundred percent had no further contact.

Liv had her own theory on why Jose, unlike many of the clients, did not appear to exhibit any anger, bitterness or any kind of ‘why me’ attitude about his injury or lack of contact with loved
ones. She had noticed that clients injured in their ‘mid years’ generally found it much harder to accept their new lives compared with those who were injured at a much younger or older age. These, she believed, did not seem to miss a working life or romantic relationships so much because either they had not yet experienced them or had already done so and felt less intensely about them.

Mia suggested that Jose’s laid-back approach to everything made for a peaceful life, yet also resulted in low expectations for the future as:

Jose’s happy to continue living at NS rather than using it as... a bridge between acute hospital care and independent living, with assistance, in the community. As Jose was injured so young, he’s never been interested in a job. He does have a high school diploma, and attended a computer class for a while, but didn’t like attending college. He likes being alone... and talking to people online...about relationships.

According to Mia and other experienced staff, this general lack of drive tends to be quite common amongst clients who have finally accepted their injury. Staff recognised that most people experience several ‘reaction stages’ following injury. Frequently, the first is denial that their condition is permanent, followed by anger and then depression. This may often be accompanied by constant requests for assistance with suicide. Finally, some attain a form of acceptance which is generally followed by apathy and emotional as well as physical dependence. Occasionally, though, acceptance is accompanied by a desire to turn their lives around. Not everyone goes through all these stages, however, or in that order. Some, it seems, remain at one or other of the stages.

Jose about himself

Jose told me that the two things he most enjoyed are ‘chatting to people on the Internet and going to bars’, but never with other clients. Likewise, he would never go on day trips with clients: ‘I don’t mix with other clients’. Ignoring his partying days before injury, he insisted:
I'm a loner; I've always been like that. I even prefer to go to the mall by myself and the movies' which he last did about a month ago accompanied by an attendant. Other than that, he has not been outside NS - or hardly out of bed - in over a month.

The only social contact Jose enjoys at NS is with the Spanish-speaking staff, especially the Mexican house-keeper who cooks him spicy, Mexican meals. He likes speaking Spanish with her and the fact that, given enough warning, she will substitute his favourite childhood food - enchiladas and tacos- for anything he dislikes on the week's menu.

**Holidays**

Jose mostly watches television alone in his room. Sometimes he watches 'the travel channel' and sees many beautiful holiday destinations on screen, but describes how any ideas he has about taking a holiday are 'just thoughts in my dreams when I'm on a beach in Cancun [Mexico]'. When asked if he would like these dreams of holidaying in Mexico to become a reality, he sighed, looked down at his body, and replied:

*Like this, no, because it's complicated being in a wheelchair...and I would worry would my wheelchair fit through doors. Regular ones are thirty inches but that's tight and some are smaller. ...all those kinds of things, like the ventilator etcetera as this needs to be charged... and I'd have to pay a nurse to go with me and take care of me, probably two because one could rest at night.*

Television brought Jose the only holiday information he ever saw such as 'Vegas commercials, beaches in Cancun commercials'. Yet, as these never included wheelchair-users, nor mentioned anything about accessibility, he concluded: 'Tourism, I think it's not for me; like this, no'. Furthermore, he believes that:

*Some clients might say "no" to the offer of a trip or vacation because people might be staring at them, or the wheelchair, ... and they might feel depressed, like seeing everybody [else] in the swimming pool or on the beach. When people stare, they feel bad, probably feel they're an alien or sub-human or something, you know, like, weird they feel.*
These ‘weird’ feelings, he guessed, would be even more acute away from home. He explained that, locally, things were generally fine when he goes out because only children direct negative comments at him such as: ‘Oh mom, look at THIS!’ or ‘How do you go to the bathroom?’ Local places were also generally accessible with ‘only some spaces... not wide enough for power chairs’. Leaving the security of his largely accessible neighbourhood seemed rather daunting. However, he felt that if travel for pleasure had played a part in his rehabilitation programme, he might feel differently today and ‘perhaps have more confidence’ to explore the unfamiliar.

Although Jose described his dream holiday as ‘Mexico, the beaches there, staying there, watching the blue water, the white sand, chatting, laughing, eating and drinking’, he would never consider going there. There might not be a language barrier for him in Mexico, but he admitted: ‘I wouldn’t feel comfortable so far away... and it’d be kind of scary probably’ travelling to a place where there might not be a specialist C-SCI unit in the local hospital. If he went to another part of the world, where he did not understand the language, he would be even more concerned if he needed medical help: ‘That would be a ten on a scale of one to ten for me not to go. See, when you’re a walking person, you don’t think about that. But in a wheelchair, you’re worried about your health if you don’t speak the language and are far away from home. That’s our problem.’

The future

Since Jose was very fearful of taking long holidays far from home, he thought a short trip would be more suitable if he were able to go away in the future: ‘Maybe I’d go to Vegas, about three hours from here, and then come back the next day or something. A short trip, yes, just to see if it’s possible... just to relax and to get away from it all... enjoy myself, have some drink, see some shows’. His preference would be to fly there, but felt travel by road would be easier because: ‘You’d need [an accessible] car to transport you to and from the airport in Vegas, so
maybe it'd be better go by car to Vegas' and not have to worry about finding accessible transport the other end.

Jose’s thoughts soon returned to concerns about healthcare. He concluded that he would not even be able to go to Las Vegas:

I've only got ‘Medi-cal’ insurance; I think it would be easier to stay in California as I think if I go outside this State for medical care, hospitals, I don't think Medi-cal would cover me as [there are] different laws in different States.... So, if I could give advice to law-makers, that's what I would suggest - [extend] our medical cover!

Until these issues are resolved, Jose believes that even the shortest trip away, let alone his dream holiday to Mexico for 'the beach, the Summer, partying, relaxing', will forever remain 'just thoughts in [his] dreams'.

5.4 Susan (Caucasian female; 26; polio at 6 weeks old; C2 ventilator-dependent)

Whenever I think of NS and its many clients, it is always Susan who first comes to mind. The world may judge her ‘difficult’, and she certainly would win no popularity prize from staff or client, yet she is definitely one of life’s colourful characters.

Background by staff

Susan came to live at NS at the age of twelve, and on numerous occasions has asked NS director the same curious question: ‘Mia, will you be my mother?’ Before arriving at NS, Susan had lived her whole life inside medical institutions and had no memories of, or contact with, her family. She had come from a very large but poor family and her parents were constantly moving house. She acquired a C2 through the disease of polio which she contracted at just six weeks old on the day her parents were moving house again. All the children were asleep in the back of their big Station Wagon car during the long overnight journey. Susan had been put to lie down on the back seat with her two year-old brother who had just been vaccinated against polio that day. While on the move, she caught polio from him as the vaccine given to protect him contained a little polio which was inadvertently passed on to his baby sister lying next to him.

As Susan’s parents had no funds or home to care for their new baby, they left her at a hospital. Apparently, on the couple of occasions they visited her, they were made to feel so guilty by the hospital staff because they were not looking after her themselves, that they stopped visiting completely and abandoned her. Mia explained:

*She never knew her family. They were gone by the time she could talk and think for herself.... She is very smart, though she has not fulfilled her potential as she has not channeled things in the right direction. She has no friends in or out of NS, no motivation. And she is difficult. Well, she’s not the most difficult; she’s ‘average to difficult’ sometimes, which gets her lots of attention - which is what she wants.*
Interaction

Susan often stays in bed all day and watches TV alone in her room. She has strained relationships with staff and clients and, at times, can be very offensive, swearing and directing racist slurs at them. Her generally brusque manner of speaking even extended to me, a virtual stranger, when she barked orders at me to ‘switch on the light’ in her room, ‘turn the TV channel over’ or ‘go tell them to come here’ without a single ‘please’ or ‘thank you’.

I got to know Susan better when she talked to me about her background whilst preparing a speech for a forum. The forum was to raise awareness for the need for greater financial assistance from the State so that people with high-level C-SCI could live more independent lives in the community. Several days before the event, Mia asked as many clients as possible, past and present, to attend the forum and, if possible, to think about making a short speech so that their voices and needs would be heard by those with influence.

As I watched the clients gather around Mia to hear about the forum, it was clear that Susan was the most outspoken, even though it was mostly in the form of negative quips, to the side, about Mia’s expensive sports car. Partly because of her ‘feistiness’ I decided to go, with Mia’s permission, to Susan’s room later to ask if she had thought about making a speech. She had not given it a thought, but when I offered to type up her speech, if she wanted to make one and dictate it to me, she readily accepted. The other reason I chose Susan was because I had learned from staff that she had no family, friends or even staff from whom she could or would want to ask a favour, and I did not want this to prevent her from preparing a speech if she so wished. We agreed that I would come to her the following day at 11am.

When I arrived the next morning, Susan was still in bed fast asleep, unwashed and unfed as she has been watching television all night. Attendants looked embarrassed when I mentioned the appointment, but were not to blame as they had not been told by Susan that she needed to be
ready by 11am. I was used to waiting for clients for a whole host of legitimate reasons, but this time I felt slightly irritated. It looked as if she just could not be bothered to remember or keep the appointment even though we were going to work together on something that might affect her and other clients’ future.

When she was finally ready for me an hour or so later, no apology or explanation was forthcoming, nor had she given any thought to what she might say. Yet when she started to speak, her speech tripped off her tongue so effortlessly that I had a hard job to keep up with her without interrupting her flow. She did, however, stop herself from time to time to ask questions, and to comment on my things.

First, she was intrigued by my hand-writing and wanted me to show her, slowly, how I formed the letters, something she had never had the opportunity to learn to do in all her twenty-six years. Then she could not keep her eyes off my wooden pen, complimenting me on it several times. In between ideas for her speech, she would fix her bright, blue eyes back on the pen and ask to see it up close. She would then return to her speech only to ask to see it again a few minutes later, this time to see how it twisted open and closed. Her eyes sparkled each time I did it, but I realized how inappropriate it was to give her a pen she could not even hold, so struggled with myself to resist offering it to her.

**Susan about herself**

After our late start, all Susan’s little magpie interruptions, plus a discussion about being ‘good friends’ following her request that I be her ‘big sister’, her speech was finally ready. Although we had discussed its structure, and she had needed to be steered back to the subject several times, the words and ideas were all her own. She then practised reading it aloud:

*I contracted polio at the age of six weeks and went to (a) children’s hospital in Texas. There I was in a coma for nine months and my family had to fight for me to be kept alive against the doctors’ wishes.*
At the age of two and a half I was moved to California to an acute hospital where I remained until the age of twelve and a half when NS rescued me. Coming into the NS Home's environment, I had a lot of work to be done on me. For example, at the hospital there was only time for us to get a hair wash - or even a shower - once a week, and my teeth on arrival at NS were lime green. My hair was so long, dirty and knotted that it gave me the appearance of little orphan Annie, and so it had to be immediately cropped short. At the age of twelve and a half I was still wearing moth-bitten clothes that I'd worn as a five year-old. As you can see, NS basically saved my life.

I am now in my twenties and am a high school graduate and have watched NS expand its life-enhancing business. The nurses and clients here have helped me grow as a person. Though I haven't lived a stable childhood, psychological therapy has helped me put that behind me. It took me years to accept the love and support of a very dear friend - NS. NS has given me all this and more. In short, it was like opening a Christmas present a couple of weeks early when I first arrived at NS.

As any young person, I have plans and dreams for the future. I plan to go to college and major in advertising so that I may one day achieve a job in this field. In order to realise this goal, I must obtain my independence. Independence means living on my own in the community with my own staff and being able to handle my own finances, healthcare, and transportation needs. All of these programmes must be installed in order for people with disabilities to be able to succeed in every day society. As a red-blooded American woman, I have the right to fulfill and achieve my goals as any other citizen of the United States. With the proper State funding I can realise my dream to be a useful and independent member of society - like any other person.

Susan in public

On the morning of the forum, and my last day with NS clients for that particular visit, I found Susan sitting around a large circular table at the front of the forum hall nearest the stage. She was the only female amongst six male clients at this table. She did not know most of them, but judging from her facial expression and lively manner, she found them rather attractive. When I approached, I was taken aback when she lifted her head up high and puckered up her lips as a signal for me to bend down and kiss her on the cheek. As I did, I whispered 'good luck' in her ear and checked she had her speech with her. Although she looked very relaxed and not at all nervous, I still reminded her to read it as slowly as she had practised, so that every word would count. She nodded happily so I left quickly to find a seat as the forum was about to begin.
When the forum got under way, it became evident that Susan was not only the youngest but also the only female client to make a speech. She was also the only client to have prepared a speech and received the loudest applause of all speakers, staff or client. The next day, she again was the only client to have been quoted in the newspaper. This 'difficult' character's words had brought positive public attention to NS's goal for its clients. Susan had also, for the first time ever, extended a gesture of appreciation to NS staff by recognising them as allies. Equally astonishing was how she even thought to acknowledge me in her own way at the forum. Just as everyone was waiting for her to start speaking into the microphone, which the officially-assigned person was holding along with her speech, Susan called for me by name. She wanted me to come up and hold the speech for her, and she would not start until I had come all the way from the back of the hall. She may never have uttered the words 'thank you' after our appointment or after I had typed up her speech, but this small, yet unexpected, parting gesture said much more.

**Holidays**

Four years later, I returned to NS. On entering Susan's house, I immediately asked where she was. An attendant pointed and accompanied me to her room, but seemed rather reluctant to knock the door. She appeared nervous about the reaction she might get, so told me to knock while she kept out of sight behind me. Fortunately, Susan looked happy to see me again as she beamed when I poked my head around her door to ask if I could come in for a chat. As usual, she was in bed in the middle of the day with the television on, but immediately stretched up her head and puckered up her lips for me to bend down to receive and give a kiss. Although the sun was streaming through the window, she had a couple of woolen blankets on top of her bed clothes which had been pulled right up to her neck. She was oblivious to how very flushed her face was with beads of perspiration above her upper lip, so I asked her to buzz immediately with her mouth-piece for assistance. An attendant came within seconds and spotted the problem before we even had time to explain. She immediately drew the curtains, took off all the
bedclothes and switched on an electric fan which she pointed directly at Susan's face, and came back several times to check that she was cooling down sufficiently.

Yet, even as all this was going on, Susan had again noticed something of mine. This time, my jeweled, claret-coloured velvet bag caught her eye and she immediately asked to see it up close. After she had inspected the bag both inside and out, she asked if I had bought it in London. I replied that I had bought it on holiday in Portugal. She smiled but asked nothing about the country or holiday. Nevertheless, I seized the opportunity to tell her about my research project and then asked if I could come back and talk to her about 'vacations'. She laughed and replied that she had never taken a holiday in her life - she hardly knew what they were - and there was no chance of her ever going on one because:

*It's simple, the number one problem is lack of money, and then there's the big question of my medical insurance which only covers a radius of sixty miles. So it's impossible.... I'd love, really love to go on vacation, but it's impossible. I don't have the money for national medical insurance or even for insurance for the State of California! Our biggest problem is medical insurance and we wouldn't dare go anywhere without it.*

Susan decided she wanted to talk to me there and then, so I stayed. She was fixated on the issue of insurance, and seemed very agitated talking about it, but would not be steered away for a second to consider other travel issues. It felt as if she were giving a party political broadcast on medical insurance, so when, at last, there was a slight pause, I tried to change the subject and ask her about local day trips so that she might eventually calm down. Her face softened when she thought and then talked about her only ever day trip. It was the trip to Disneyland Janet had organised on which Nancy had also gone:

*Oh, my trip to Disneyland was fantastic and the ride I went on was perfect. Everything was wonderful.... I came back so happy that I will remember it for ever! You know, my dream [vacation] would be to go London... because I want to visit Windsor Castle.... I've always wanted to see Windsor Castle, always. And I hear it's better for quads over there [UK].... You know, with technology and everything. And if I went, I'd never frigging come back!*
Interaction with staff

After my previous visit, Susan had not, as she had indicated in her speech, attempted to go to college or to live independently in the community. There had, however, been other changes. Mia explained that Susan had tried yet failed to find her family, but: ‘A couple of years ago, she managed to track down her mother. She never came to visit Susan, but Susan would always contact her and speak to her over the phone. [Sadly], not long after Susan started asking her mother to meet up with her, she got a telephone call informing her that her mother had been killed in a house fire’. Mia continued:

Not long after the house fire, Susan reported that she was hearing strange, frightening voices in her head which brought her a great deal of new attention.... Her relationship with staff became more strained. She shut herself away from everyone in the house and would just talk back to these voices in her head in front of us.... She became quite disturbed, and it was pretty frightening for everybody, so we suggested she should see someone from Mental Health to discuss the voices. But, you know, as soon as this was suggested, the voices disappeared.

The future

Before I left Susan that day, I mentioned that I might see her later in the week if she intended going to the art class. I thought this was doubtful because I had been told that there was usually a very low turnout for the class. Nevertheless, to encourage clients to go out and take an interest in something, NS arranged for a number of attendants to be available every Wednesday, free of charge, to accompany those clients who wished to attend its free art class on the other side of town at head-office. To my surprise, Susan nodded and said: ‘Sure, see you there Wednesday’.

When Wednesday arrived, Susan pulled up in an ‘Access’ taxi and wheeled into class with her Mexican assistant walking behind carrying a number of bags and blankets. She was all dressed up although the attendant had applied Susan’s make up a little too copiously for such a young, pretty face. Ten minutes later Susan announced that, although she would be back, she could not
stay for 'the whole class', as she needed to get something at the shopping mall. Speaking about the mall, she added: 'The most common thing at the mall is [that] they think I'm retarded. One time, a lady called her husband over to look at “this poor little thing”, patted me on the head and placed twenty dollars on my lap. Sometimes I've had people cry when they see me!'

Having put in a brief appearance, Susan set off for the mall, just a ten-minute walk/‘wheel’ away - with an assistant provided free of charge only if she attended the art class. If anyone could find a loop-hole or ‘play the system’, Susan could...and had. When she returned several hours later, she popped into class again for five minutes to show her face - and her two purchases: a leopard print top and, her favourite, a small, white, fluffy toy dog with a pink collar. The top could have been chosen by any young, ‘red-blooded American woman’ her age, but the fluffy toy, perhaps only by a small child. Yet Susan adored the dog, and the more staff exclaimed and fussed over it, the more she brimmed with pride.

My very last sight of Susan was of her wheeling away from us towards the ‘Access’ taxi with her little toy dog sitting in pride of place on her lap, as if it were a real dog. It belonged to her; something to love, yet it was inanimate and could not give her what she really craved. At that very moment it seemed, at least for the foreseeable future, that her much talked about desire for independent-living, study, travel - and that visit to Windsor Castle - presented an equally remote possibility of fulfillment.
5.5 Alex (Caucasian male; 38; prop gun accident at 18; C2 ventilator-dependent)

In 1988, drama student Alex became injured whilst rehearsing at the Beverly Hills Playhouse. He was practising a scene with a prop gun when it discharged with a live bullet leaving him with a C2. Twenty years on, and ever the articulate and handsome actor with a mop of curly, dark hair, Alex’s passion for acting has not diminished. He has worked locally as an actor on the rare occasion a small part for a wheelchair-user has come his way. Otherwise, he leaves NS only for hospital appointments.

Background

When Alex became disabled, his divorced father gave up work to take care of him at home single-handedly. Fifteen years later, Alex voluntarily admitted himself into a nursing home to allow his father to return to work and resume a ‘normal’ life. According to Mia:

*This was an extremely unusual and thoughtful way to behave for a client. You see, it’s almost always the other way around... it’s the other person who has to get out of the situation with the quad. Even the most dedicated and loving families or partners... find they can’t cope anymore.... But the nursing home he came from was for elderly people... most had dementia, and Alex was a young, intelligent man sharing a bedroom with an elderly man with dementia and living, well just existing, in that environment.*

It was from that nursing home that Alex came to NS and discovered a new way forward. He also found love with one of the Hispanic house-keepers at his house who, in line with NS policy, was then moved to work at another NS house. This policy was introduced to protect everyone as, in the past, some staff who had formed personal relationships with clients found it all too pleasant and convenient to have a ‘love interest’ at work. They tended to spend less time with other clients, yet outside working hours they made little or no effort to meet up with their client-partners. These relationships were always with male clients and could also be sexual, as it is sometimes possible for clients to have some form of involuntary erection even though they are unable to (physically) feel anything themselves. When the policy was introduced, most of
these ‘relationships’ ended as staff-partners then had to spend their own time, money and energy to see their client-partners out of working hours.

Mia explained that, besides his new love, Alex’s daily focus is on preparing himself to live as ‘normal’ a life as possible:

> With the help of our Independence Training Programme, Alex is learning about becoming independent and setting up his own apartment with twenty-four hour nursing and domestic care near his parents and two sisters. He’s driven; he is always up in his wheelchair working on the computer researching various pieces of information for himself and his family while other clients are fast asleep or watching television in bed all day. They don’t do anything with their time. I’m always telling them [that] they should at least get into a routine of getting up and into their wheelchairs every day.

I had already noticed that many clients tend to stay in bed all day. The only other client I saw dressed and in a wheelchair in Alex’s house was his room-mate, Len. The two men got on very well and, unlike most clients, enjoyed sharing a room and appreciated the companionship it brought.

**Alex about himself**

Alex talked about his renewed hope for the future since leaving the nursing home. He explained how he misjudged the suitability of the home for someone with C-SCI, and questioned whether some clients would have been able to cope there:

> Being a quad, when I went to the nursing home... I looked at it, talked to the staff, looked at the facility, and the medical staff all said they could deal with me. But when I got there, they were not qualified in terms of familiarity [with C-SCI]. [However,] it being familiar enough with your own [health] care that you can direct somebody who is qualified, but not familiar, is empowering. But not everybody is willing to learn how to do this.

> Some clients have the point of view... that, because of their condition, they need to be taken care of. There are people that don’t direct their care. They allow their care-givers to make all the choices and do all the decision-making. And since the person isn’t familiar with their own care and directing their own care, health’s going to depend completely on who’s with them. Achieving the state of being familiar with your own care that you can direct it puts you in a state where you can take responsibility for the situation rather lying back and waiting for some one else to mishandle it.
Thus with his knowledge and previous experience at the nursing home, Alex evinced no fear of ever going into a non-specialist unit at any hospital anywhere in the world.

Alex in public

Ironically, despite being one of the most highly-motivated clients with regard to gaining independence, Alex rarely goes out. If ever he ventures out, he experiences very little negativity towards him, although he admits that ‘[this] could be largely due to where I go…. I have been limited to environments where people are very familiar with people with this condition. This neighbourhood, there are clients in this area, and the people here are accustomed to seeing us’.

Nevertheless, he would be prepared to venture further afield, yet only:

> If it were a given that I could get around - the doorways were wide enough, the sidewalks were accessible as I’ve gotten to a point where I don’t really have concerns with regards to the public. For the first few years, it was a definite concern because ... people would stare or people would be uncomfortable looking at me. But now I’ve got to the point where I have no problem dealing with that.... If I feel, like, someone is uncomfortable, I just say, ‘Are you ok? Do you have a question? Is there something...?’ You know, I just let them know it’s alright to be curious, it’s alright to ask questions; it’s alright to look, and that generally makes most [people] relax. It takes away whatever inhibitions or problems they have..., and they stop having those problems.

Holidays

Although Alex has never taken a holiday since becoming a wheelchair-user, he talked at length about his holiday experience before injury:

> Vacations were varied depending on my financial situation at the time or whether or not I’d seen my family.... The best was the one I took to the Caribbean. It was wonderful! It was very different from where I lived and what I was doing. Got to meet people from other countries.... The thing is, I didn’t know what to expect, but when I got there, all my experiences were a surprise. To me, that was part of the experience – and exciting.... [Afterwards] I felt rejuvenated.... I was interested in getting back to work, but at the same time I was taking with me the experiences I’d had on the vacation. I was relaxed...was carrying great memories from the experience. I brought back clothes .... so when I wore them, I would think of where I got them from. I had never been scuba diving, so when I learned .... it was like walking on the moon, so I could reminisce about it and tell people about it.
Chapter 5: Narratives of non-travellers

When he was asked if a holiday would appeal to him now, Alex replied unhesitatingly: ‘Yes, if I had the resources and it was available, sure!’ He thought that taking a trip during hospital rehabilitation would encourage clients to be ‘more adventurous’, but that it would be too expensive even though he felt clients still had the desire to ‘enjoy a recreational activity or enjoy “times” [as] those things haven’t changed’ since injury. His dream holiday destination would be Europe, for all its cultural delights. Other than access issues, he would not be worried about being abroad any more than an able-bodied person would because: ‘I wouldn’t choose to go to a place if I didn’t have somebody with me who could speak the language or [if] it was dangerous. I wouldn’t choose to go to the Middle East’.

Alex suspected that there might be as many access barriers to holidaying in the USA, although:

*The first [barrier] would be financial. If I was able to save the money to go on vacation, then the next barrier would be how to get from place to place. Although I think it’s possible, I don’t think it is easy to book ... and take a flight when you’re in a wheelchair. If it’s a manual wheelchair, then it’s probably not very complicated, but if it is electric and has a ventilator, then that’s very involved. Other concerns would be getting to a location, and having the same resources that I need here. In other words, healthcare.... I know somebody would have to be with me and I would need the equipment to get in and out of the wheelchair. The bed that I sleep in is a hospital bed and the ventilator I have is rented from a vendor and I don’t know what their policies are on me taking them out of the State. And so, I would think of how... I choose the location and what’s going to be there at the other end, because the travelling part is just transitory, and when you get there, you have to deal with being there and there is a whole set of problems that go with that.*

He felt that a big part of the above, and other access issues, stemmed from being a ventilator-dependent power wheelchair-user because:

*If you had a manual wheelchair, first of all you could push yourself around; you can use your arms, feed yourself. If you’re on a ventilator, you have to depend on your machine to breathe, and that machine has its limitations and malfunctions. And if there are people around you that have no familiarity with the machine, then you’re in trouble, so you always need somebody with you all the time who knows what your equipment is for and how to handle it in case it stops working.*
As for accompanying attendants, Alex guessed that the number required for a trip away would depend on their knowledge of life support equipment. He estimated that clients would need only one attendant if that 'one...was familiar with your equipment and care. Depending on the individual, if you had someone who was there for your care, but not familiar with your equipment, then you would need two. It's going to vary...'.

The future

As long as problems encountered were not life-threatening, Alex thought that the benefits of getting away from home and enjoying different experiences on holiday would far outweigh any negatives or barriers he might encounter. Although he would be interested in going on holiday, he did not think it realistic. If, however, a genuine opportunity arose, this most ‘independent’ client with an urge to integrate further into society would nevertheless:

...probably tend toward a more segregated vacation with other wheelchair-users because that would automatically include a familiarised environment. In other words, you would be with other people that were also in wheelchairs. There would be qualified care-givers around and, as a group, you would tend to feel like there would be less likelihood that you would be discriminated against. Now, had I done that, gone on five or six vacations like that, I may say I want to go some place on my own. I don’t know. But my first choice would be to go in a group. I suppose the closest really I get to going on vacation, though, is going shopping or the movies once in a while... [as] immobility is very limiting to travel. The electronic mail or flyers and stuff I see for vacations, it’s all geared towards people who aren’t limited in mobility. Basically, the tourism market is for people who are working and walking, and that’s not me.
5.6 Len (African-American male; 36; car accident at 18; C2/3, ventilator used at night)

The first time I set eyes on this tall, elegant man dressed in a pale pink v-neck jumper, he was sitting in his wheelchair, framed in the doorway of his bedroom, fast asleep with mouth wide-open. I had just arrived for our appointment, but did not have the heart to wake him. Without startling him, I could not have woken him anyway, since he would not have felt my touch on his arm. I guessed that the time and effort involved in getting him ready for our morning appointment had quite exhausted him. I waited a while chatting with others willing to speak to me, and finally told an attendant that I would return the next morning to see Len.

When I arrived the following morning, Len was half-dressed in a white vest. Again, sitting in his wheelchair, he was this time in the middle of a large, highly-equipped bathroom being shaved by Natasha, the African-American nurse on duty. Despite my protestations, she insisted that I conduct my interview there and then while she continued getting Len ready for the day. Apparently, her boss had telephoned to say that two members of staff were coming over to talk to me later. She therefore suggested I start right away as she did not want Len to miss out again. It seemed that Len had been disappointed to have missed me on awaking the previous day.

Len could see that I was reluctant to enter the bathroom, but quickly reassured me that he was completely comfortable with the situation and had no problem speaking in front of Natasha either. He seemed to be one of the most easy-going and laid-back individuals I had ever met anywhere, and he talked and laughed as if he and I were the only ones in the bathroom. Nothing seemed to distract him. Even when Natasha ran water, smothered his face and head with thick shaving foam, wet-shaved his face, then his head twice, and took an age to clean his tracheotomy hole with countless cotton buds, he kept on talking through it all.
As for Natasha, I had the distinct feeling that she was in no hurry to finish. She appeared to be enjoying listening to our conversation and, at times, just could not resist joining in with an occasional comment or question. Mostly though, she expressed surprise or interest whenever she learned something new about Len, exclaiming with a smile: ‘Really? I had no idea. I never heard that before!’ or ‘Hey, Len, wow! I didn’t know that about you!’

Background

At eighteen, Len was involved in a car accident which left him with a C2/3. Unusually for someone injured at this level, he often goes out alone - to visit friends, to window-shop and, just last week, to the cinema with a friend - as he also has some C4 features. He is therefore able to breathe unassisted for part of the day, so uses his ventilator just at night and only very occasionally during the day. As a result, he rarely needs an attendant to accompany him when he goes out locally.

Len was brought up by his grandparents in Mississippi. Mia explained that:

_They still live there, so the only regular contact he has with people outside [NS] is with the local friends he met in the two and a half years he’s been at NS. Before that, he lived with a girlfriend... a care attendant, but, as usual, the relationship didn’t last.... Before that, he lived in a community hospital in northern California where he also enrolled as a ‘freshman’ [first year student] at a local college._

Len about himself / clients

With aunts, uncles and cousins in almost every State in the USA, all Len’s holidays pre-injury were spent visiting relatives all over the country which he enjoyed very much. When he was asked about what he looked forward to on an annual basis, he laughed and said, ‘...completing my New Year’s resolution’. He then added on a more serious note, ‘and being more independent’.
Len is, in fact, one of the most independent and sociable clients at NS. Yet he feels that if this is to continue, it is best that he avoids being in the company of most other clients as:

They could bring your morale down - they're depressing. And, you know, it's like: 'Why you coming [out], if you don't want to have fun?' They don't know how to act... in public cos some of them don't really go out that much cos they're scared of how people will treat them. They're depressed, but I think that most of the bad attitude that the [disabled] people have, they already had it before they got disabled. And their personalities haven't changed that much.... [When you're out] in public, sometimes you get people that is mean, don't want to help. Even 'Access' transportation, they have rude people working for them. Even when [you're] alone in 'Access' cabs, a lot of the time you have to initiate the conversation with the drivers... cos they don't know what to say. [It's] cos a lot of disabled people is rude, rude and angry, both, and if 'Access' is dealing with a lot of rude people, then I wouldn't want to talk to clients either,... and you don't know how that [disabled] person's gonna be, if he's rude and angry, so you don't talk.

**Local places**

Yet Len learned from bitter experience that no matter how sociable and independent he tried to be, there were always obstacles that prevented him from doing what he wanted to do independently. For instance, he enrolled at a local college to do an evening computer course on 'spreadsheets', but explained that he left the course due to access issues and bad advice:

> They advised me to get out of the [spreadsheets] course cos I was to take the class that you have to have before you can do the spreadsheet class. But [when I started that one], I already knew how to do it all, so I got bad advice. And the advice came from the disability office, not [from] the teacher. They didn't even ask me if I could [already] do it nor not!

Len expressed how disappointed he was when he also encountered access problems at this college which he had been assured was wheelchair-accessible:

> I can't push buttons, so when I go out by myself ... that's when I usually find a problem. At the college, I asked this lady to push the elevator button, and when I got on the elevator and turned around to tell her to push floor number two, she'd walked off and the door had closed.... Usually some elevators, when the door closes, it moves. It doesn't just sit there waiting for you to push which floor. That's what I thought would happen, but it didn't move.
No one came to use the lift. Len guessed that people must have thought it was out of order. He described how frightening it was to be stuck in a confined space unable to get out or even to call for help: 'It felt like I was in there three days, but it was twenty minutes.' Much to Len's relief, his tutor saved the day when he got into the lift on his way to class and found Len sitting there.

Len attended another college but, once again, it was not fully accessible. He explained: 'I didn't like that college [as]... it has buttons you have to push to get into doors and I don't want to go through that again. I used to [have to] ride around with a table, [a] flat table, on my wheelchair, and I [would] have to swing my chair towards the door and try [to] hit the button with the edge of the table. But now I don't ride with my table no more'.

After problems of accessing the second college, Len decided that he would not try a third college or consider the costly option of having an attendant accompany him to every class. Instead, he opted for online education and left behind all the access issues but, with them, the social world of the student too. Len concluded: 'It's a pity that. I know there's a lot of money out there, but I don't know what devices they have...to solve these types of [access] problems. If they show me what they have, I can give an opinion about what works'.

**Len in public**

Although Len could no longer tolerate the access issues at the colleges he attended, he generally remains philosophical about going out in public: 'I go around and find places that are accessible... or [accessible] parts to the place I'm trying to get into. People are really helpful; you just have to ask them. Some people are not bold enough to ask for help. But you have to make the public... aware of you'.
On other occasions, however, when he least wanted it, Len remarked how acutely aware people seemed to be of him. When crossing the road he would sometimes hear car horns being blown at him and ‘Get off the street!’ yelled at him. ‘They almost run you over with the car, [and] they look at you like: “What in the world are you doing out here? Why are you out?” But some of them, you know, wait. You know, ... [they] actually stop traffic almost to let you by, and I’m then thinking: “Oh man, why am I blocking traffic – go faster chair, go, go, go!”’

Len recounted a similar act of kindness from a complete stranger when he and the wheelchair specialist were on the road trying out his new wheelchair in order:

...to see how it would go over bumps, and this man stopped [his car] on the other side of the street, an older guy, and came across the street and said: ‘you all need any help? You sure, you’re fine?’ You see, in this area they’re used to seeing disabled people, but [in] other places I have encountered bad things.... Here, mostly, it’s just little kids, just curious, and they’re staring at you, and their parents is like: ‘Oh, my son is staring at this guy and I know this guy, like, is going to freak out cos my kid is staring at him. But I tell the parents, if they want to know anything, they just ask.... One time, this kid said: ‘Look, mom, he’s drinking’. ‘It’s not’, I say, ‘it’s the [mouth-]control’, and I show him how I move the wheelchair and he’s like: ‘Cool! I want one of those chairs’.

Recently, when Len was waiting to cross the road at the same spot as a lady and her little son, he noticed that: ‘The lady was trying to ignore... the situation, like she was thinking: “Hurry up, turn this light green so we can cross the street”, when the kid shouted out: “How fast does that chair go?” “Pretty fast”, I said. “No, how fast?” “About seven or eight miles an hour”. And the little kid said: “That’s NOT fast!”’ Len, Nadine and I simultaneously burst out laughing.

After we had composed ourselves, Len explained that interaction was always easier with children as they were much more relaxed with him than adults were because: ‘Adults is just different. It depends what mood I’m in, then I initiate the conversation. They never do. Suppose it depends on how you approach them. I talk to them normal, just striking up conversation’.
Holidays

Although Len once visited his grandparents when he was first injured, he has not taken a day trip or ‘a regular vacation’ post-injury. He had once intended to go on a cruise with friends, a respirator therapist and a nurse, but everything fell through when he moved away and they lost touch. In an attempt to make light of never having taken a holiday since his injury, he added: ‘Well, I’m always on vacation cos I’m not doing anything. But I want sight-seeing, the experience of leaving the country, but money is the only restriction’.

Len felt that the issue with holiday-taking was that it was inextricably linked with being in employment. Being on State benefits, in the form of ‘Medi-cal’ insurance, was for him and other clients problematic because: ‘If we worked, we’d have to make enough to pay for our [medical] care, but after $2000, Medi-cal would cut us off. So that’s the situation with working... having to find a job that would pay for the care and then have enough money left over to pay for the vacation.’ Len added that the number of accompanying attendants further increased the cost ‘unless you got friends that’s in the medical profession that’s willing to go on vacation with you.’

As for his choice of holiday destination, Len declared that his would be the ‘Bahamas, or a trip somewhere! Bahamas is just a destination that springs to mind. I heard a lot of countries aren’t equipped for wheelchairs,... so a cruise to the Bahamas, or anywhere, is good. Well, that’s what I hear, a cruise is good as you don’t have to get off the ship.’ As Len said that, Natasha was washing her hands at the sink. She looked back over her right shoulder at Len, smiled and said: ‘I’ll go with you’ and quickly turned back again to the sink.

Visit home

As he had once flown, Len was more aware than virtually all NS clients and staff that it was possible for an individual with high-level C-SCI to take a flight. Although this flight was long
before he came to NS, news of it spread quickly and he became quite a hero at NS. In fact, staff and clients alike constantly enquired, almost in disbelief, whether I had met ‘the quad who’s flown’. Len roared with laughter when he heard this. He then quickly pointed out that his experience of flying had been quite by chance. Like everyone else he knew, he had not thought it possible for ‘someone like [him]’ to take a flight when he had wanted to visit his grandparents at home in Mississippi nearly eighteen years ago: ‘I was misinformed by my grandparents. I was letting them take care of all my affairs; I was a new injury, so I didn’t know how to get the information on my own. It was easier for them to do it, I thought’.

As a result, Len, his grandparents and his great-uncle travelled by road in convoy all the way from California to Mississippi. He and his grandmother were in one truck. She drove and took care of him as they had no attendants with them. His grandfather and his great-uncle followed behind in another truck. Len described the journey as ‘awful because we just drove, drove, drove! We was travelling in my grandfather’s messed-up truck that kept on breaking down, so it took us almost three days. I was in agony. I sat in the wheelchair the whole time’. After the ordeal of a journey, Len could not bear the thought of the same agonising journey back to California. This therefore forced him to take over the travel arrangements:

Flying back was my taking charge, getting the information from social workers.... Well, I learned it was possible to take a flight, but I had to have a nurse... fly with me. They have agencies that just go around flying with disabled people on airlines. I never knew that.... Rehab told me nothing, [but] we need to know or people will make the same mistakes.

The flight

Len described how he was wheeled on and off the aircraft in a manual wheelchair and then ‘transferred onto a little biddy [wheel]chair that fits down the aisle, and then they lift you up and put you in the [airline] seat and put on the seat belt.... It’s okay as I wasn’t slouched over or anything. I just sat’. Unfortunately, after a good flight, Len arrived in California only to discover that his wheelchair leg-rests had been damaged in the luggage-hold:
I guess they kicked the chair into the compartment, but the damage was minor compared to the story I heard from my friend. I was looking for something worse than just the foot-rests. They broke one of the motors on his wheelchair. Next time, I’d take the leg-rests off the chair; you basically don’t know how they’re going to handle your equipment - you know, equipment you depend on, can’t be without.

Despite the damage, Len felt that his first flight was generally a positive experience – and certainly a great learning curve for him and those around him. Nevertheless, he has never flown since due to his financial situation.

The future

As we continued to talk about travel, Len was still thinking about his agonising journey to Mississippi. Thus he added: ‘I’d like to travel in the future, but if I would go on vacation, I’d go sight-seeing in the States. I would... take my time and enjoy it - not like when I never left the truck for three days even “to smell the roses”’. Nevertheless, he feared that if he were ever afforded the opportunity to go on holiday, he would be concerned that he would be constantly wondering afterward:

Where’s the next place I’m going to cos when I go places, local ones, coming back is the hardest, especially if you’re enjoying it. Even when you’re out for the day, you don’t want to come back.... You see, we’re on a time-schedule being in a place like this... early care, late care, being back by midnight, visiting hours and things like that.... And the thing about vacations, or any amusement parks..., the thing is, I can’t do what I’d like to do [there], so that’s some reasons why [disabled] people don’t want to go to amusement parks, Disneyland, Magic Mountain, places like that. They feel they can’t get on the rides. I didn’t want to go to Disneyland when I was walking, so it doesn’t interest me now either. I want other places.

Although Len mentioned he would like a cruise around the Bahamas, he later revealed that his dream holiday was, and had always been even pre-injury, Brazil - and Rio de Janeiro:

I seen a movie. Me and my aunt was watching it, [nineteen] eighty-five, somewhere around there, and there was this scene, it had nothing to do with Carnival or anything like that. Just the beauty of the place. I wanted to go before, and I want to go now. Nothing has changed - just my situation.
5.7 Maria (Caucasian female; 37; muscular dystrophy as a child; C2 no ventilator)

Fresh-faced, pony-tailed and diminutive, Maria looks years younger than she really is. Her spinal cord has been progressively damaged through muscular dystrophy, and in order to protect and elevate her tiny frame, she sits in a customised moulded-foam seat in her power wheelchair. Unlike the other clients at NS, she is able to operate her wheelchair by hand using a small lever, yet the same hand is unable to wash, dress or feed herself or, in the art class where we first met, move her paint brush more than a centimetre at a time. There will come a time though in the near future, when her progressive disease will strip her of any movement in that tiny hand. It will also cause her breathing to deteriorate and will produce other side-effects which will threaten her with premature death.

Background

Mia explained that when Maria was fourteen, her mother was knocked down by a hit and run driver which left her incapable of caring for herself or Maria. She had been Maria’s sole carer, so mother and daughter had to be separated. Her mother went to live in an Assisted Living apartment, and Maria into a children’s nursing home in a different town where she lived for ten years until she came to NS. However, Mia added that:

*In the twelve years she’s been here, she’s received no visits.... Well, her father has never been seen at NS, and her mother’s health has prevented her from making the long journey from Las Vegas to visit her.*

Maria about herself

My encounter with Maria was quite different from those with other NS clients, past and present. It was different in that she also asked me questions. She listened to my questions carefully and answered thoughtfully, and then would slip in her own question, usually about the UK. The British educational system particularly interested her. She listened with great interest as I talked about it and then spoke about her own educational experience:
I left my home town at fourteen and went to live in a nursing home. I had to go to a new high school. I was the first disabled student in my new school. It was a snooty but integrated school ... and one of the top schools in the area.

Despite the reputation of the school, Maria confided that she still has recurring nightmares of the years of bullying and intimidation she endured at the hands of a teacher there:

My life was made hell by the special education teacher assigned to assist me [physically] for at least an hour each day...so that I could do my homework for the next day in school before I left. This teacher was near retirement and had only ever assisted pupils with learning disabilities and just didn’t want to work [physically] with me. She was so unhelpful. She told lies about me, and put me down in public... to make me feel so inferior and uncomfortable in the school that I’d abandon my education. I still have nightmares about her.

Maria endured this intimidation alone and in silence. She had no one to protect her or fight her corner against this adult professional. Yet, despite this ‘horrible bully’, she was determined to finish her education and ‘graduated from school in the top ten percent of [her] class’ and went on to obtain a ‘B.A. in Criminal Justice’.

For a long time after graduation, Maria contemplated continuing her studies in law, but the opportunity never arose. She talked about wanting to make enquiries about an online law school she had recently discovered. After our appointment, as with all clients I interviewed, I left my email address with her should she wish to contact me about anything. Her first email came less than a month after I had returned to the UK. In it, she told me that she had successfully enrolled in the online law school, and had already started her online Doctorate in family law.

Interaction

Mia had advised me to attend the art class as it would be a good place to chat to those few clients who were ‘interested in something’. The class was held every Wednesday from 11am to late afternoon at NS head-office. Out of a possible forty-one clients, Maria was the only one who had made the effort to attend this week’s free art class. She was also early for class.
Chapter 5: Narratives of non-travellers

Apparently, it took time, effort and forward planning for clients to organise transport to class by ‘Access’, the only State-subsidised taxi company accessible for power wheelchair-users. Taxis needed to be booked at least twenty-four hours in advance, yet it could, and usually did, arrive an hour or so early, or late, without any warning. If clients were not ready, they missed their pre-booked transport altogether and had no other prospect of finding suitable alternative transport that day. Spontaneity was never possible. If clients wanted to go anywhere, they had to be both very organised and motivated to want to spend on taxis any of the little amount of their State benefit left after paying their living and medical expenses.

Maria looked quite the artist in her stripy, blue and white top with her long, dark hair swept back in a ponytail. Her tiny, turned-out feet did not reach the bottom of the special seat fitted in her wheelchair and were clad only in white socks. As the only student there, Maria had the full attention of both art instructors, although this seemed far from what this composed, softly-spoken individual would have wanted. She focussed entirely on her painting and the instructions she needed to give in order to receive assistance. One of the instructors had outlined in pencil Maria’s description of a tall, thin vase containing flowers with large blossoms. The other had carefully placed a paint brush between Maria’s thumb and the side of her index finger with the exact shade of green her student had selected for the base colour.

So that she could reach, the instructor held the canvas on Maria’s lap having first reclined her wheelchair to make enough room. The section of the vase being painted then needed to be positioned right next to Maria’s paint brush because her paint strokes barely extended a centimetre up or down. It was thus a slow, laborious task. While the instructors chatted happily away, Maria was silent. Her concentration was total. She had a clear vision of what she wanted as she slowly extended or softened the instructor’s rough outlines with her paint strokes. Her silence was only ever broken briefly to give the odd instruction for assistance, quietly conducted in a most calm, clear and precise manner. For instance, she would ask for the canvas to be
lowered or moved an inch to the right or left, or for less paint on the brush or for her brush or colour to be changed for another.

Later, lunch was provided in the art room for just $1 and, as such, attracted a number of NS office staff into the room. This time, Maria gave very precise instructions to the person feeding her. She clearly stated ‘only pasta please’ or ‘just cucumber this time’ or that there was too much on the fork or she needed a drink before she ate any more food. Every ‘task’ seemed intense for her. While staff were eating and chatting away in such an easy, relaxed and sociable manner, her ‘conversation’ could only be eating instructions. As a result, our conversation took place after she had finished eating and before she began painting again.

Human contact

The only time I heard Maria’s voice lose its calm, quiet tone was just after her meal. She had asked to have one of the instructors’ little dogs placed on her shoulder and laughed and squealed with sheer delight as the tiny dog excitedly licked her neck and face over and over again. Both dogs were just about eight inches long and were brought to class every week and kept in a play-pen in the corner of the room. I asked art instructors Janet and Carol why they had brought in their dogs. It seemed that, quite by accident, Janet had discovered clients’ love of small animals when a member of staff had brought in her tiny bunny rabbit to show a colleague. Janet explained how astonished she was to find that, on seeing the little animal:

*All the clients... male and female... their eyes just lit up, their voices softened, and we’d never seen them so excited about anything before. They asked for the little bunny to be placed near their face so that they could feel its soft, warm fur against their skin. Oh, they loved it.... We couldn’t believe their reaction. They all wanted a turn with it.... That little thing gave them such pleasure. It was so fun to see. You know, it’s hard getting them interested in most things. We found that whatever we suggest, first we know it’s got to be free, or nearly free, as they can’t afford much. And if a meal isn’t provided, they don’t come either or if it is only for one or two hours.... Well, it wouldn’t be worth all their transportation and attendant arrangements and costs if they had to return after an hour or so for lunch. But, you know, if animals are involved, they are always interested and... still talk about that time one of the managers’ friends*
got some of them into the horse races. They loved the horses... [but] that person has quit working there so we haven't been back.

Later on that day I discussed with another member of staff, Tara, the effect the little dog had on Maria. She felt sure that it was because most clients felt ignored or rejected and starved of close human contact. She also revealed that she regularly took her little white dog on visits to private clients, and explained why she thought these little creatures were such a ‘tonic’ for clients:

I’ve never seen regular visitors to the houses greet clients with smiles and hugs as they do me or the other staff or others in the same room as the client. When someone comes in, clients are often not even acknowledged... and they always miss out on the hugs... so they’re aching for attention, affection and someone to embrace them. That’s why they love the antics of a small dog sitting on their shoulder licking their cheek. But... when they are shown attention from someone, they can also read more into it.

Holidays

Although Maria had never been on holiday as an adult, she appeared to enjoy reminiscing about those she had taken as a child. Her favourite was to Disneyworld, Florida, with her parents when she described herself as ‘less disabled’. All the other holidays were taken while she was at the children’s home. Every year for five years she would go with a disabled children’s group to Lake Tahoe for a week. She commented how much she always looked forward to these holidays despite the burden of ‘having to pack and look after three big cases and four to six boxes of essential equipment - and the uncomfortable flight... [and] the huge airline seat’.

On several occasions Maria’s wheelchair was damaged in the airline luggage-hold, but fortunately she was still able to use it at the other end. Although these holidays were segregated for disabled children, the accommodation was not particularly accessible as the beds were bunks. Even so, she felt that segregated holidays were, and still are, preferable and ‘easier as disabled people need to be certain that everything is accessible’.
Despite the flight and accommodation being far from wheelchair-friendly, Maria explained how much she adored getting away from her usual environment and enjoyed the change of scene: ‘During the week, there would be swimming sessions, art classes and ‘dances’. But fun things like checking out the guys, I mean, the volunteer councillors who were fire-fighters was the best, and the best memories I have – and my favourite part of the vacation! After the week at Lake Tahoe I always came back happy and excited and just couldn’t wait to go again next year’.

**Travel today**

Bad memories of past experiences of transporting so much equipment and enduring such uncomfortable travel conditions prevented Maria from ever wanting to travel as an adult. Since her disability had increased with age, she felt that she could no longer cope with these and other barriers. However, she thought holiday-taking might be more manageable ‘if doors were automatic and wide enough for big, power wheelchairs. If hotels had equipment ready there, and aeroplanes somewhere to lie down and also to strap down your wheelchair as they do in “Access” cabs’. Only then might she consider going on a cruise around Hawaii or the Caribbean as ‘this type of vacation would be fun, easy and lots to do and see ... as long as they didn’t just have a “general” doctor on board’. Maria insisted that she would never take any risks with her health, so the doctor on board would have to be conversant with her condition.

**Day trips**

The only experience of a ‘change of scene’ Maria has had as an adult has been the occasional local day trip which she described as ‘fine, though kids always stare, but people are usually ok. Most leave us alone, but you can see they are uncomfortable looking at us and that makes us uncomfortable’.

One day trip to Venice beach was particularly memorable for all the wrong reasons though. Having finally overcome her fear of ‘unleashed dogs and teenage skaters bumping into [her] on
the path by the beach’, Maria managed to spend a pleasant time out of doors near the ocean. However, her pre-booked ‘Access’ taxi for the return journey arrived over three hours late forcing her to stay out much longer in the hot sun. Despite sun screen on her skin, she got sun burnt and became very ill. As a result, she became extremely fearful about venturing out anywhere again in case she was left stranded again by ‘Access’ and her health suffered as a consequence.

After this incident, staff noticed that whenever there was any talk of leaving the house, Maria’s first words would be: ‘How far is it?’ as her prime concern was how she would return if she could not ‘wheel’ herself back. Recently, she even decided to travel only by ‘Access’ taxis designed for one wheelchair-user. This is the most common type, although the company also has vans that can take two or even three power wheelchair-users. Her explanation for rejecting these larger vans was that: ‘The ride is more bumpy and uncomfortable with three of us, and also it takes so much longer to get home as you have to drop off others on the way’. Maria’s other concerns with regard to days out were about the cost and attitude of accompanying attendants as: ‘They have to be hard-working and willing to fall in with me as it is my day out and I’m paying for it. At the same time, they should not expect me to pay for their lunch or their movie tickets which sometimes happen’.

The future

After our talk I left the art class to go and interview a former client. On my return, Maria was already waiting at the front door for her ‘Access’ taxi home. We chatted about her painting and then I returned to speak with the instructors. They told me that, during the afternoon session, Maria had asked them if they knew of, or could find any information for her on, a short, three-day cruise off the Californian/Mexican border. Neither instructor had ever been on holiday with a client before, but told me with much excitement that they had offered to help gather information and even to go with her as they would ‘all have a fun time together’.
As we continued talking, I heard the familiar, dull whirring of a power wheelchair approaching. I looked up and saw Maria wheeling towards us. She came right up beside me and said quietly: ‘Angie, I want to thank you for talking to me because now I’ve decided I want to take a cruise, and I’m planning it already’.
5.8 Summary

This chapter presented the narratives of six non-travellers with C-SCI. The narratives were able to set their experiences of non-participation in context of their lives which allowed the reader a more complete picture of the person and C-SCI. This, in turn, offered further insight into their personal journey, assumptions and responses to disability, impairment and the mix of intrinsic, interactive and environmental constraints and barriers that affect holiday-participation. The next chapter will present the narratives of six travellers with C-SCI and their individual and collective experience of holiday-taking as a severely disabled person.
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NARRATIVES OF TRAVELLERS

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CHAPTER SIX
NARRATIVES OF TRAVELLERS

6.1 Overview of chapter

This chapter presents the narratives of six travellers with C-SCI constructed from data gathered via interviews, discussions and non-participant observation. Although they were former clients of NS, all now live independently, with varying degrees of daily assistance, in their own homes in different parts of California. These narratives will offer insight into the individual and collective experience and impact and issues associated with the lived experience of holiday-taking and severe disability. As in the previous chapter, background information will assist the reader’s understanding of each traveller’s approach to holiday-participation and the negotiation of barriers. The narratives will be presented in the order of the most disabled traveller, Daniel (C1), and conclude with the traveller with the lowest level of C-SCI, Lynette (C6/7). Again, for immediate clarity relating to each traveller, a brief overview of the individual’s personal history is provided at the outset of each narrative next to the person’s name. It includes: ethnicity; gender; age at the time of interview; the cause of C-SCI; age at which C-SCI was developed/sustained; and level of C-SCI (C7-C1).
6.2 Daniel (Caucasian male; 41; motorbike accident at 17, C1 ventilator-dependent)

Distressed and upset, seventeen-year old Daniel ran out of the house one night following some major family conflict and jumped onto his motor bike. In his confusion, he drove up a one-way street and head on into on-coming traffic. Had the accident not occurred outside a fire station, where he received immediate medical attention, he would not have survived the journey to hospital. His C1 was so high up the spinal cord that he sustained brain-stem injury which meant that, if it had been a fraction higher, he would have been brain damaged. It was practically a miracle he was still alive. However, he was unable to breathe unassisted, to move anything other than the corners of his mouth and chin, to swallow, to eat other than via a tube in his stomach at night, or even to speak.

A year later, when Daniel was about to leave the rehabilitation hospital for NS, hospital specialists did not approve. They warned that someone like Daniel would not survive more than six to nine months outside a specialist hospital. Twenty-four years later, however, Daniel has not only survived outside hospital care, but has also made the transition from NS to his own apartment in the community with twenty-four hour assistance. Since Daniel is still unable to speak audibly enough for anyone other than his regular nurses to understand just the basics, his story is told through separate interviews with Mia and nurse Liv. His permission was first sought and witnessed by his own nurses, Mia and by me.

Background

NS opened in 1985 with just two clients, both C1. The first client, thirty-three year-old John, who had suffered a motor bike accident, had previously spent seven years in a hospital open-ward where he was the only conscious patient. When Daniel joined him, he was unable to communicate with John except by blinking. Both were desperately unhappy and depressed and constantly begged staff to help them commit suicide by unplugging their ventilators. By
mouthing, Daniel made them understand that, like John, he could no longer see the point of living since he could not do anything at all. He could not even commit suicide without assistance - but for Mia, it was neither legally nor ethically possible to help him. The only way was a long, legal route with eventual court permission to disconnect the ventilator. In the meantime, Mia thought of another way.

A challenge
Mia gathered Daniel and John together and told them: 'Instead of thinking about what you can't do, start thinking about what you'd like to do. If you can think of something... something you'd enjoy, I promise I will help you do it if it's within reason.' It was left completely open for them to come up with something that they, themselves, would like to do. Mia was thinking of a trip to the mall or a restaurant, perhaps. After a week-long, serious discussion, John, their spokesman, said: 'We've decided and our proposal is, well, we want to go to Las Vegas for three days and two nights and we think it's “doable”.' Mia swallowed hard because, as she explained:

There were these two C1, fragile quads sitting in front of me and this was completely unexpected! There was a smirk on Daniel's face, just the corners of his mouth, and a gleam in his eye for the first time - and John was beaming! Here were two people with a goal - a vacation goal which left me speechless.

She was loath to shoot down a proposal they had taken seven days to formulate. So, taking a deep breath, she repeated: 'Las Vegas?' all the while thinking, 'Two C1 quads going to Las Vegas, out of State. Is this possible?' As she could not immediately come up with any reason to turn down the proposal, she agreed that it could be achievable if they all worked together and if they, themselves, played the major part in the planning. Much of the fun of a trip would be in its planning, she told them, but ended saying:

It'll take a lot of effort, but if you're up for it, I am, too, but you will do as much work to make it happen as we will.... Staff can help you make a list of all the equipment you will need. Make a check-list and I'll check it. We can't afford to miss anything.
Planning

The planning took five months and was too slow for Daniel and John. 'You’re never going to take us', they complained, yet Mia insisted: 'You will go when everything’s in place.' Although she and her staff had worked with people with C-SCI for many years previously, they had never accompanied anyone on holiday - or ever expected to. During their training, they had learned to attend patients medically and for everyday, practical tasks such as dressing and feeding, but had never been trained to take them away on holiday, and never thought it even possible. Nevertheless, she knew that the secret of success was understanding the clients’ needs and planning for every occasion and so:

All the ‘what ifs’ must be answered before going. Daniel’s parents came good after his accident. His alcoholic father sobered up and they decided they wanted to be involved, so they bought and fitted an RV (motor-home) to accommodate two wheelchairs which they drove. Next, John and Daniel had to find nurses to accompany them as those coming had to want to because it would be work, not just pleasure. No one should be under duress. We needed day and night shifts with three nurses to one client, plus me, so someone could always be off duty.

The necessity for such a high ratio was illustrated years later when it saved the life of a ventilator-dependent client. Mia had taken two clients to Sacramento to see a law being passed that would have a positive effect on their lives. To celebrate that evening, one client requested that he dine in the hotel’s panoramic view restaurant on the sixteenth floor. Mia and two nurses accompanied the first client to the restaurant. Just as they were about to eat, a fire broke out in the hotel. As all lifts were out of use, the client’s wheelchair with ventilator had to be abandoned. Mia and a nurse carried him in an ‘Australian hold’ with their hands and arms locked together, bench-like, under him, as he leant back against them, while the other nurse walked backwards down the narrow, spiral emergency staircase manually pumping air into his lungs with his emergency, portable ‘Amubag’. Sixteen floors later, their arms and legs were like jelly, but the client had survived. Had he been thrown over a fire-fighter’s shoulder, he would not have. Hence Mia explained how difficult it was to find nurses willing to accompany
clients with high-level C-SCI on trips because, if something serious happened and the client died, they would lose their nursing licenses.

Mia calculated that eleven people had accompanied Daniel and John to Las Vegas: Daniel’s parents and sister, seven staff and Mia’s husband who drove another accessible van as a back-up vehicle. There was also a car that could go for help quickly if needed. As there were only two clients in NS then, the company paid for the nurses as a one-off gesture. All medical notes and files were taken along and all the twenty-four hour hospitals and emergency rooms along the route were located and mapped out. A named doctor in each was made aware of the clients’ trip and a named doctor in Las Vegas could be contacted if necessary. Their NS doctor was on stand-by for consultation night or day. Also on the check-list was the medication they needed to take with them, plus extra should there be a delay returning home.

John and Daniel ‘signed’ a witnessed consent form by making their mark with a pen in their mouths that this was what they wanted to do, and they knew the risks and would not hold others responsible should something happen. Mia then submitted a plan of what the clients wanted to do, with all the precautions outlined, to the State insurance and no objection was raised. However, when the insurance company later realised they had gone out of State uninsured, it registered its disapproval and stopped payment of Daniel and John’s living and medical expenses to NS, so the company received no money at all that month.

**The journey**

The journey to Las Vegas was through a desert, so they travelled in the cool of night taking from 11pm to 6.30am with stops. The clients were prepared for the night journey by sleeping a little longer each day so that they would be able to travel at night. It was impossible to drive fast with two wheelchairs secured with straps bouncing around in the back, even though such a long journey would be hard on their fragile C1 bodies.
The chosen hotel was notified and Daniel and John were allowed to check in at 7am instead of the usual 3pm. All their needs were explained in detail beforehand, so there was, for example, enough space under the beds for the hoya lift. Extra hotel staff were sent to help carry the equipment, and the hotel provided extra blankets or anything else they needed. There were, as requested, extra plug sockets as the two clients were in the same room, both needing sockets for ventilators, suction machines and battery-chargers. One nurse was always on duty in their room, and the other nurses had rooms either side. The hotel was most accommodating and, just as Daniel and John were settled in, and about to be put to bed, even the hotel manager called to see if there was anything else needed as he had never had such hotel guests before.

The holiday

Late afternoon, Daniel and John were up and ready to ‘hit the casinos’. As usual, people stared at them and always talked to the nurses first because, as Mia explained:

They weren’t comfortable addressing disabled people, especially those with tubes sticking out of their necks. They were scared and didn’t know whether a quad could talk, but all the nurses were so comfortable with the quads that they’d give others the low-down first, and then people were so pleased to meet them and would always wish them a great time there.

Daniel loved the slot machines and nurses put the money into whichever machine he wanted. One casino employee told Daniel: ‘Use that slot machine’ - and he won $300! Mia guessed she had known that ‘it hadn’t given out for a while, and so Daniel’s eyes were like saucers’. He returned from the trip with an extra $400!

Liv laughed when she recalled her first time in a casino - and in Las Vegas:

John liked playing on the tables. Normally you’re not allowed to hold anyone else’s cards, so I explained that John was playing, and in command, even though he couldn’t hold his own cards.
However, officials were called and questioned whether this was a real situation, but after talking to John and securing the consent of the other players at the table, they finally agreed and welcomed him. Liv held his cards but could not talk:

He’d yell out, ‘hit me! ’ ‘I say, hit me!’ But I just stood there like a dummy. He couldn’t bend his neck to look at me, so he rolled his eyes up to the heavens and explained: ‘That means get a card or turn over a card’. He loved playing and being in the thick of things. He and Daniel were so happy. They both had a ball. Neither wanted to go to bed that night!

In fact, they later decided they wanted to go to a show, a musical, so seats were procured near the front, and the company on stage paid them a lot of attention and gave them hats to wear. They were thrilled and stayed up until 2.30am as Daniel returned to the slot machines once again. Although Liv was equally delighted to see the joy on their faces, she remembered that:

It was a lot harder work, and much more responsibility, being away with a quad. You always have to be ‘the mom’, always the care-giver, having to think ahead: ‘Is this safe?’... Drinking alcohol was always an issue. A beer within certain times of their medication meant that there was always a point when I had to say ‘no more’. The clash was between allowing them to have a good time versus their safety. For example, they wanted to stay up even later than they did, but it wasn’t good for their skin, so they just couldn’t.

The return/ the change

Daniel and John were tired but elated when they got back to NS. They stayed in bed for a few days to get over the journey, but they talked to so many people about their experience, and got as much out of saying, ‘We’ve been to Las Vegas!’ as the trip itself! In fact, Liv noted:

Both Daniel and John proved to themselves they could have a good time as a quad, and could do things they had not thought possible... just because they’d been stimulated to think. Vacations are very important for quads - something to look forward to, to reminisce about, ... to get away from the every day routine. Quads’ daily existence is very humdrum, seeing the same old things every day, so getting away is extremely important. It lifts them so much that it’s such a pity it’s so hard in so many ways, and especially financially hard, for them to do so. ... It should be part of rehab. It would make a huge difference.
Mia agreed that travel and tourism could be an important part of rehabilitation because it would be something they could look forward which would allow them to experience something a little further a field and meet new people. She suggested starting with a long weekend within the first two years of injury, then a week, but added:

*Anything is possible.... I knew a C1 quad who took lots of flights around the States. But a seat for the ventilator must also be bought as attendants must be able to have immediate access to the controls.... and take long leather belts to go around the back of the seat and buckle them in front so the quad is more secure in the seat. I always take them as the airline can’t be expected to have so many. Even short vacations by road can lift quads’ spirits, boost their morale to say: ‘Look, you have been able to enjoy something’. The Vegas trip saw a big change in Daniel and John. This was really noticeable in Daniel. He never asked to have his life-support disconnected after the vacation nor reverted to saying he wanted to die....

As for John, before he was sickly and always complaining. After the trip, he started taking more interest in everything. For example, he helped with the decision-making for cooking in the house, setting up menus for the week, deciding what the house would eat and how it was to be prepared.... He was a chef before. It worked very well and he was in the kitchen with the staff giving instructions – what spices to put in and how to cook the fish or chicken. He was in control, and the staff were just his hands.*

**Long-term change**

Above all, Mia believed that, from the Las Vegas holiday, *'they learned that it is still possible to enjoy life, even as a C1 - and the change in Daniel has lasted until today'*. Daniel now lives independently in an apartment and has had three girlfriends, all nurses, although they have not lasted. In fact, there were many things that came out of the Las Vegas trip, not only for Daniel but for his family as a whole as he now has regular contact with them. His parents realised after the trip that they could also take him places, and his engineer father became fired up to make things adaptable. He took Daniel on day trips fishing and put a fishing rod on Daniel’s head, and Daniel would come back with a smile, mouthing: *'I caught a fish!’* When the family moved to Arizona, he went with his nurses and parents on a ten-day holiday there, stopping to rest and see lots of places on the way.
Liv’s voice trembled somewhat with emotion as she recalled the time when she accompanied John to a hospital appointment after the Las Vegas trip. On arrival, she said: ‘Oh dear, I should have gone to the bathroom before coming’ as John could never be left alone, even for a moment. However, without saying anything, he put his chin on his central-piece to move the wheelchair and went to the information desk and asked: ‘Can you tell me where the ladies’ restroom is please?’ He took control to help Liv, and got another nurse at the hospital to wait with him while she went to the bathroom. ‘So, after the trip’, Liv noted, ‘it was not always us nurses looking after them like little kids’.

Sadly, John died five years after the Las Vegas trip of an embolism (clot to the lungs). But before he did, Liv recalled that: ‘Daniel and John were still reminiscing about the trip on and off years later. Even on saying goodbye to me when I was leaving NS, John said: “Oh Liv, remember when you didn’t know about playing cards and what ‘hit me!’ meant”...and he laughed.’

The ripple effect

Mia was astounded at how the Las Vegas trip changed the atmosphere of the whole house. The clients had a different attitude when they returned, but the staff’s attitude changed too as: ‘It’s heavy going, day after day, coming into work hearing: “I don’t want to live; I don’t like this, that”. And it’s hard to keep staff working with people who’re really depressed’. Moreover, Liv noticed how:

Out of a work-setting we saw their individual personalities for the first time, rather than seeing them just as clients. Before, it was always: are they getting medication? Is their skin care done? The practicalities, routine of nurse-patient relationship. On vacation, there was more of a friendship, more of a relaxed atmosphere and... getting to know each other better. It was positive for both sides.

Future travel

Overall, Mia concluded that the trip to Las Vegas was:
A ton of work, but with the right planning, the right assistance, nothing went wrong and they stayed healthy. When we went, it was 1985, things weren't so accessible. Today, with the law and all the technology, it's not such a problem, as legally they must be able to accommodate disabled people....

And you know, Angie, you have been talking to a lot of my clients, and you don't know this, but I've been coming behind you talking to them about their experience of talking to you. And there was a gleam in their eyes, and they said it was so great to think about vacations, so I said: 'Why don't you think about planning one?' - and I went back over twenty years when I was doing the same thing with Daniel! I've been so involved in building this model of rehabilitation practice that I, myself, have even forgotten about vacations. But Daniel and John proved it was possible, and I'd like to see all quads have these experiences as they are so beneficial.
6.3 Andrew (Caucasian male; 29; car accident at 17; C2 ventilator-dependent)

Before moving to his marble mansion on the hill, Andrew was known as the Latin-looking ‘Romeo’ of NS. He bought the imposing property after he received a multi-million dollar insurance settlement following his car accident when he was hit and driven off the road by a big truck. Later he lured licensed nurses away from NS for huge salaries to work privately for him.

Before this settlement came through, he lived at NS as his mother refused to let him come home at the end of his hospital rehabilitation period. He received no visits from any family members while he was at NS, but as soon as he received his insurance settlement, his mother reappeared. She asked for a top of the range Mercedes car and offered to give up her job to come and live with him and his staff at his mansion. He bought her the Mercedes but refused her offer. He has virtually no contact with her now.

Former mechanic Andrew still has a passion for cars and is determined to own the fastest mini-van for drag-racing which, as he explained, is: ‘when two cars go in a straight line for quarter of a mile and the lowest time is the winner’. He has already bought the car he needs for it and knows, from his mechanic contacts, ‘who’s going to do the engine work for me and what I’m going to do.... One of my male nurses has volunteered to drive it.... I love cars. Hey, I just bought a limousine like you see at the airport all the time. All black and it has a lift. I’ll receive it in four months, so will probably drive it to NS and show it off’.

Andrew about himself

Although Andrew wanted NS clients to see him being driven around in his new limousine, he was unable to go anywhere at the time of interview because, unlike all the clients I had interviewed at NS, he was bed-ridden as he was suffering from skin sores. He made it very
clear, however, that he had no desire to have any social contact with his former NS housemates:

*I don’t stay in touch with any clients at NS as they’re all too unmotivated and their depression brought me down. They’re too depressed; they can’t cope with their injuries and decide to be depressed and blame the world. Most are either depressed or in denial. They think that they’re going to walk again. Even if they come up with a cure, if you’ve been injured ten years, your muscles are gone and you might get feeling back, but... you’re not going to walk.*

**Background**

Despite Andrew’s feelings towards NS clients, Mia spoke of the help he had once given a client in need: *‘Andrew was always very interested in money, but he had a heart and actually gave one thousand, two hundred dollars to help another client pay his rent one month when his money had not been paid by the State.’* Likewise, Tara, NS ventilator therapist and friend and private therapist to Andrew, mentioned that Andrew donates generously to the Lakers’ youth basketball foundation. She then added that:

*Andrew’s given Tiffany diamonds and designer clothes to one of his private nurses, a pretty blonde, who’s his girlfriend. He took her from NS when he moved out. She looks like a model.... When she was going through a bad time with her husband, he helped her and her little daughter to get out... by buying her a million dollar house. But the word is, she’s back with her husband now and he’s moved in with her... into the house Andrew bought! Andrew doesn’t know.... You know, they [Andrew and the nurse] both kind of exploit, are controlling, one another. He controls her with his money and she, well, she’s his ‘girlfriend’.*

Considering his generosity, Tara regretted that Andrew had never ‘thought to give back to NS’. She described how the company had helped him when he was ‘homeless’ before his settlement, and that he knew how NS sometimes struggled to keep afloat keeping clients when they were unable to pay their rent at times.

**Holidays**

Before injury, Andrew took two enjoyable holidays: a school trip to Taiwan when he was ten and a trip to Mexico in his teens to stay with friends – ‘to party, drink, beach, ride bikes. I like
Although holidays have always come second to basketball and car racing, he feels they are as important to his enjoyment of life today as they were pre-injury:

*Just to get away... out of California, to have good time, to have something different to do... I can't even count how many vacations I've taken [post-injury], at least once every three months except if I have a [skin] sore*. He finds holidays are now: 'less stressful because I don't have to do anything when I get back. Before [injury], I had a week's work of stuff I had to catch up on in the garage.

The only 'stress' now is that none of the holiday information Andrew sees is aimed at or includes people with disabilities because: *They want to cater to the mass majority.... I’d never go on segregated [vacations] with other quads because they’re too depressing, so most information I find is either from the Internet or my American Express Concierge as I'm a platinum member.... I can speak to someone and they handle all the set-ups.

Yet, even with this 'concierge' option, Andrew always organises his holidays himself. He stressed that a crucial consideration is the time of the year he goes on holiday because he does not:

*...like going on vacation during the [school] holidays .... It’s too crowded and there’s too many people and you get bumped into and so I end up running into people on purpose, by accident! Sometimes you’ve got to give somebody a nudge.... Well, I can’t tap them on the shoulder, so I nudge their leg with my wheelchair.... People are fine usually... but I always get stares - so I just stare back, give them a nod and keep driving my chair.*

Although he has taken various trips, Andrew explained that he now prefers to go to the same place, Las Vegas, and even the same hotel there, because: *You don’t have to do anything as you know there’s no access problems as you planned it before, so all the work is already done.* As such, he never has any feelings of anticipation before his holidays but feels:

*There’s a lot of recollection if I win! You know, I felt good in myself when I came back ten thousand dollars richer once.... Wanted to tell everybody: ‘Hey, guess what happened?’ The great feeling lasted about a month until everybody knew, or until my next vacation.... But I don’t want to go too often as I don’t want to burn it out. I want to keep it interesting.*
Travel experiences

There seems little likelihood, however, that Andrew would be able to take holidays any more frequently. In fact, due to the lack of availability of his nurses, he is at times prevented from both going on holiday and from taking longer holidays. Nevertheless, he insisted: ‘I'd be willing to take a road trip from here [California] to New York... just go from hotel to hotel, sight-seeing good places if I had nurses willing to come with me’. He explained why, lately, he is confident that his vehicle could undertake such a long journey. After his van broke down on the way to Las Vegas in 120°F, and he was unable to get into the inaccessible tow truck, he decided to buy ‘a new van every three or four years, so it won’t break down with major problems that can’t easily be fixed. I have a new one out there right now’. However, he realises that the biggest problem with a long road-trip lies not so much with the van but the fact that:

All my nurses are independent contractors on twelve-hour shifts, both men and women. I pretty much have to work around their schedules or sometimes I have to pre-schedule [a vacation] ahead of time with them. Most of my vacations are three, may be four, days at the most... because my nurses have families, they have kids, so they’re not going to want to be away from their kids.... When they come through, we’ll catch a show in Vegas because I know some nurses don’t like gambling, or if someone wants to go shopping, I’ll just hang out with them. It’s a compromise: I’m going shopping with you, but then you’re going to gamble tonight. I play on open tables where the cards are facing up and basically tell the nurses how much to bet and put on the circle.... Except for that, I expect nothing out of the ordinary of my nurses on vacation compared with home and it’s always been fine. It’s the same routine: always two transferring me from bed to chair. Being two hundred pounds plus, it’s not easy for one [nurse].

Flying; wheelchairs

Apart from Las Vegas, most of Andrew’s holidays have been in California, although he had travelled to Utah and New Mexico. All trips were by van as he insists: ‘I don’t fly.... Last time I checked, I’d have to be transferred to an aisle-chair, but I’d rather not leave my power chair because I’m a big guy, and for someone to transfer me to a little, thin aisle chair, oh no!’ He remarked that he would only feel safe sitting in his wheelchair so: ‘they should find a way for a person to stay in the wheelchair at airports and on flights ... like in my van. I drive my
wheelchair in and it locks in. They push a button and I come out.... Even long flights would be ok as long as I'm in my wheelchair'.

Besides flying, concerns about 'curb cut-outs, cobble stones, steps' would deter Andrew from holidaying overseas. However, language barriers or having to go into a general hospital would not bother him:

Unless it was to do with my injury, like dysreflexia, but I would have my nurses because whenever I go to the hospital now, I still take my nurses with me, and they're with me twenty-four hours. They’d basically stay in the hospital with me.... [Before a vacation] I never find out about hospitals on the way there or at the destination because I haven’t gone far enough yet! Usually the problems on vacation have been things with the wheelchair.... At Yosemite, on the way to Lake Tahoe, something [in my van] got caught on the front underneath of the wheelchair.... [It] pulled a wire loose and broke it, so I couldn’t drive my wheelchair and my nurses had to push me. But they couldn’t push me very far. I wanted to go home because my wheelchair is my freedom. I can’t be without it. But when we got to Lake Tahoe, we got Yellow Pages and found a wheelchair repairer and he fixed it in twenty minutes.... Oh yeah, one time too my seat air-cushion got a hole, so we found a place that sold patch-kits.... So now I take a spare cushion and a pump to pump it up and I try to keep my chair in good condition.... In fact, I’ve had a new one; cost me around thirty thousand dollars.

Accommodation

Andrew recounted the problems he had with so-called ‘accessible’ hotels during his favourite holiday, a road trip to the south-side of the Grand Canyon where four States meet:

Arizona, Utah, Nevada and New Mexico - and I had one wheel in each State! The only concern I had beforehand was looking on the map and finding towns to stop in and seeing if hotels would be accessible. But I ... experienced turning up to a hotel in a small town outside New Mexico that said it was accessible, but it wasn’t, so we ended up sleeping in the car that night. I reclined my chair and all three of us just slept in the van. There was one step going into the room, so now I always take a ramp, but it wouldn’t have helped [then] as it was too tight a squeeze as well to manoeuvre.... Quads take up more space than paraplegics, but they experience similar problems... particularly small elevators and small rooms.... For Vegas, I don’t take a Hoya lift in the van any more [as] a lot of the time the hotel beds are blocked underneath and the lift needs to roll underneath the bed. The lift needs ten inches clearance.
Even when problems have arisen on holiday, Andrew has never allowed them to spoil his overall enjoyment. If something can not be 'fixed', he suggests that it is best to ‘Just laugh it off. Bad things happen, but that would not deter me from going again. You’ve just got to be understanding: be patient, eventually they’ll work it out, come to some arrangement [with you]. If they say “too bad” to these things, they open themselves up to litigation’.

Future travel

Andrew would very much like to visit Costa Rica one day because, as he explains:

I’ve heard it’s nice and there’s alternative medicine there, a lot of different herbs. Not a miracle drug to make me walk, but herbs in the rain forest that cut down on spasms so I don’t have to take eighty milligrams of Baclofen.. I’ve got my spasms under control with all the medication I take, but ... I’m destroying my liver at the same time.

Travel and tourism played no part in Andrew’s rehabilitation programme. Although he personally feels the need to get away from his environment every few months, he does not believe that travel should be included on rehabilitation programmes today:

...because it’s a perk, and rehab must get your life straight and get you out of hospital. It’s got to make sure you’re self-sufficient before you concentrate on taking a vacation which is a bonus, a pleasure, and you’ve got to take care of business before pleasure. If your number one goal is to live independent, and be out on your own [in the community], get that done first and then you can play’.

Andrew’s wealth may afford him the privilege to ‘play’ and acquire the confidence required, post-rehabilitation, to take trips away from his usual routine and environment, yet he insists:

I’ve done all my work to become self-sufficient, so I feel I deserve a little play-time.... I’d be miserable without, first, my money, [and] second, my wheelchair [which] is the main thing, a big part of my freedom and independence. It allows me to go to Lakers’ games, go out to a nice restaurant for dinner, [to] a movie, go out with friends - and then on vacations.... Vacations eliminate the redundancy of doing, day after day, the same thing. If I couldn’t go on vacation, I would be very angry because that’s my pleasure, that’s my play-time.
6.4 Ralf (Caucasian male; 48; sporting injury at 21; C2 ventilator-dependant)

Ralf describes himself as 'the first ventilator quad in the world to go sky-diving.' Before injury, he was a professional gymnast. He sustained a C2 at just twenty-one when he jumped off a trampoline and landed on his head which stuck in a defective landing-mat. He received a multi-million-dollar pay-out in compensation from the mat company.

Ralf is generally very positive about his adventures and the people he has met both pre and post-injury. He does not let the blunt personal questions from children and the 'constant stares of shock, horror' from people bother him, although he admits that, once, he wanted:

_To go and take someone down [with my wheelchair].... I was out... going for a 'walk'; and there was a guy who didn't want to spend the night on the street as it was Christmas Eve. And he was shouting, so I tried to go near him [and help].... And the homeless man said that, as I was ... on a ventilator, I was already dead.... I wanted to take him down and I told him what I thought of him. It's important to speak your mind if someone is being rude or unhelpful and tell them that they need to get re-educated._

Background

Apparently, only the incident above and a family issue have ever really disturbed Ralf post-injury. Mia explained that, following his insurance settlement:

_Ralf has little contact with his family as some [members] tried to get a lot of money out of him. But he's fine. With his good looks and confidence, he has always had lots of girlfriends and married a former care attendant who he's now divorced from. The big pay-out from the mat-company enabled him to buy several houses - one in Hawaii and [also] to afford his own nursing staff for his home in [southern California]. He's been able to get away on vacation more than any other quad, and he's still crazy about sports. He's even gone sky-diving!_

Ralf about himself

Ralf talked about how he managed to go sky-diving. He needed to design his own breathing apparatus, similar to scuba equipment, as his ventilator was far too bulky and heavy to use
twelve thousand, five hundred feet up in the air. Furthermore, in order to participate, he explained:

I had to sign my life away. I was strapped to a professional's front. It was outrageous! One thing I worried about was the apparatus failing because I tested it on the ground, but couldn't test it in elevation.... I took a chance as I had thirteen minutes of air and about an eight minute jump, so if we'd got blown off course, it would have run out of air. Dangerous, death. Wasn't really my favourite thing I've done.... I didn't really care for the ride up either.... It took half an hour to get to elevation and I couldn't see out of the plane [as] I wasn't in my wheelchair because I was in a tiny plane.... Had a lot of worry for half an hour about what could go wrong.

Free from such worry, Ralf prefers other sporting activities such as coaching 'power soccer' for wheelchair-users. It has been for this and other sporting events that he has done much of his travelling. He has travelled around the States as a coach and gym instructor, lectured at the Paralympics in Atlanta, given talks in schools and taken five holidays with other wheelchair-users connected with sport. One was to Canada for eight days to attend a two-day 'power soccer' tournament. Apart from combining a holiday with a sporting event for wheelchair-users, he is, however, not interested in specialist holidays for wheelchair-users.

Holidays

As Ralf was injured so young, holidays did not mean much to him then, but he still: 'liked going skiing, water-skiing, camping, and ... was hoping to do more travelling abroad. His favourite holiday pre-injury was to Europe and he recalled: 'That was a hell of a great trip, skiing, and I met lots of people, saw a lot of sights.... The memories are still pretty fond today!' After injury, however, holidays became far more important as 'they lift [his] mood.' He has therefore taken over thirty around North America. They have ranged in length from a week to a month and included camping and his favourite - house-boating which he described as: 'a blast... on a house-boat eighteen to twenty foot wide with sixteen to eighteen [able-bodied] people I knew'. He regrets, though, that post-injury he has never been able to holiday overseas again due to the long flights as: 'They beat me up too much.... My back, I can feel it.... We are all different. We
all have different kinds of feelings, sensations. Some quads don’t have any; some have tactile sensations’. 

Ralf recalled that his very first holiday post-injury was suggested by his pre-injury girlfriend because she wanted to get away. They went to Santa Barbara for a week, yet Ralf suspected that:

If she hadn’t suggested it, it would probably have taken me a couple more years to think about vacations; probably [until my] third or fourth year because a lot of us have worries about putting out care-givers and a lot of it is also monetary. Some of it is the unknown, worrying about things breaking down and getting used to things.... You’re adjusting, but twenty-six years ago quads on ventilators took a lot longer to get healthier than it seems... [it does] today.

After the relationship with his girlfriend broke down, Ralf was accompanied by attendants on further holidays. Generally, they worked out as Ralf considered the attendants’ feelings and wishes too. However, once, when his attendant asked to bring his wife, a complete stranger to Ralf, he was apprehensive. The holiday was not a success as the wife shouted at Ralf, accusing him of spoiling her holiday as her husband had been so preoccupied with Ralf’s care.

Ralf’s rehabilitation programme offered him no information about or experience of holiday-taking. He believes it should be included, yet fears that it would be ‘cost prohibitive’. But it would be a good idea for a short jaunt, a weekend, to get quads used to knowing what they can do. If they don’t know what to do, it’s all too difficult; it’s all an experiment. My life has been pretty much an experiment.’

Now a veteran traveller, Ralf talked with confidence about his latest holidays with his new fiancée, a former attendant, and how he learned to overcome obstacles:

We go to see relatives and friends that don’t live in California. I like going to Hawaii; lived there for a little bit. [I] have to pick and choose with the weather situation as too cold is an issue for my health.... Also I like to have fun, see sights, enjoy myself, get away from the usual routine, like I went to Florida Disneyland with my fiancée for a week.... Went all over south and mid Florida.
which is pretty accessible, but what isn’t, I make accessible. [Before] my trip to Alabama, I was told: ‘Oh, things are not going to be accessible’. People tell me that all the time, but it’s pretty easy to make things accessible where you go and rent a vehicle, rent or bring a ramp, persuade someone to take you upstairs in the wheelchair.... People are usually willing to help, but you have to be willing to go on that adventure. Any vacation is pretty much an adventure.

Being ‘fearful and uninformed’, Ralf believes, prevents individuals with C-SCI from even trying to go on that ‘adventure’:

Car rentals, hotels, airlines are aiming at mainstream America, not disabled people. But that’s not a big issue, as if I need information, it’s real easy to get it...online. But it’s also lack of education [as] most quads don’t think they can fly, especially people on vents.... Fear is a big factor too - and the comfort factor. Being in a situation where you’re dependent on a mechanical device, fear is fairly constant. Being dependent on equipment, you get used to your own environment and staying in another environment, you wonder if you are going to be able to move round, get in and out and whether things are going to be accessible.

Travel experiences

Ralf’s choice of holiday destinations is curtailed only by airline policy which does not permit wheelchair-users to sit in their wheelchairs on the aircraft. As a result, he explained:

My longest [flight] was six and a half hours to Hawaii. Don’t know if I could do much more than that. To go to China, Australia, Europe, it wouldn’t be practical to travel that far. A fourteen-hour flight would beat me up too much. You’d almost need a private cabin... with certain things. Fully reclining seats are nice...[but] you can only get those in first class on certain airlines. It would be nice if they could put a couple of sleepers in the front of the other part of the plane too.... Usually, bulk-head is the best place to sit if you’re travelling economy because there’s almost always about four feet of space in front of the seat. On some airlines, sometimes I get transferred from my wheelchair to a narrow one, and sometimes I get carried onto [the aircraft].... The seat belt around me is secure enough except that the issue is I have to recline while we’re taking off.... They usually let me,... they don’t usually bother me...and my nurses assist me too. But you need some privacy.... You know, there are a lot of people who have a catheter or that sort of thing. That’s hard to deal with on a plane.

Another problem with flying [is that] 75% of the time my wheelchair comes back to me damaged...even if I send a nurse down [with it] to the loading area, and she tells the baggage-handlers how they can grab it and load the chair.... I don’t ever let it go down alone now. If I put a sticker on it with handling instructions, I don’t think they would read it as they’re in such a rush, wouldn’t pay any attention. Once on a trip with five wheelchair-users,... all the wheelchairs were damaged.
As we talked about wheel-chair damage, I recalled an earlier conversation with private nurse Eva with nearly thirty years’ experience of travelling all over the world with her ‘inspirational speaker’ client with a C4-SCI. Eva had noticed that on the occasions a male friend had accompanied her to the baggage-handling area, his far less well-informed handling-instructions were taken seriously by male airport staff, whereas when she spoke ‘they’d look at [her] as if to say, “What do you know, lady, about this.” Apart from this constant niggle, and subsequent consequences, she felt that other holiday barriers just had to be overcome by her and her client as mainstream tourism providers’ responsibility has to be to the majority. Thus, ‘barriers, well, that’s life. ...Quads can’t go out expecting the world owes them anything. They’re in a wheelchair, so it’s going to be hard, but don’t complain and get bitter. ...You just make do.’

Planning

Ralf stressed that an essential part of each holiday was an ‘overwhelming’ amount of research to determine the accessibility of both the journey and the destination:

The biggest part of the vacation is the homework; you definitely have to do your homework. Be organised even though you’re not always going to remember everything, but doing your homework is essential. You always have to find out on the Internet, and call ahead, before you go [to know] where to find places to rent ramps, and where the wheelchair repair places are, where all the supply-houses are and so on.

As a result of all the planning beforehand, which could take up to a couple of months, Ralf’s holiday mood was generally rather negative to start because: ‘Anticipation is often worry and planning is stressful. But once I’m on the plane or the road, the weight is lifted and [I'm] feeling everything is good now and we’re going to have fun’. Yet he admits that when trips have adversely affected his health, for instance, when he developed skin sores during flights, the reverse was true as: ‘These [vacations] leave a bad taste in my mouth when I get back in poor health, so I’m left with eighty-five percent negative recollection’.
Health

Apart from the amount of planning and long flights, Ralf has few other worries about taking holidays. He never considers travel insurance or healthcare although there ‘definitely has to be a hospital in the vicinity. I usually call them up before I go about what kind of facilities they have and [I] get a contact there at the hospital’. He would have no issue about going into a general hospital because: ‘my nurses take care of me when I’m in ... hospital, but I suppose if it were anything neurological or serious, and they didn’t specialise in it, I would have reservations’.

The real key to holiday success, Ralf believes, is: ‘You must keep a positive attitude and strive to overcome problems.... You have to be out-going. You have to take the rough with the smooth and you have to take “can’t” out of your vocabulary’. The only time Ralf can remember ever accepting defeat was when he was refused entry onto a helicopter for a flight over the Grand Canyon: ‘The pilot was willing, but the owner said“no”.... He didn’t want the liability. I was disappointed; well, actually, I was pissed off and angry at the owner, but kind of understood as they didn’t have a proper seat for me. But I’ve been on roller-coasters and their seats aren’t proper for someone on a vent to go on’. He therefore sent one of his nurses to try to persuade the owner to change his mind, but to no avail. With hindsight, he wonders if it might have been more effective to have tried another tack, suggesting: ‘I ... could have gone in and talked to him - and signed my life away if he would have had the papers’.

Yet only ‘education’ about his condition and needs of travellers with a high-level C-SCI can, in Ralf’s opinion, ever really lead to improved tourism opportunities for him and others in his situation: ‘For example, airlines should try to educate their people more and the people in the hotels and attractions could use some more education too regarding our type of disability. I think education is a big part of it, and that’s the same thing with society’. 
Future travel

Despite his considerable holiday experience, Ralf’s enthusiasm for travel appears to have waned lately because, as he explains: ‘it’s become arduous, just all the things that I have to plan and take, like the vents. If I go on a plane, having the wheelchair put on, and ... the damage!’ At the time of interview, Ralf was suffering from a bad skin sore and had to leave early for hospital treatment. He concluded on a semi-positive note though by saying: ‘There are still things I want to do’, but stressed that there were two major factors which prevent him from being able to plan holidays at present:

_I used to definitely look forward to vacations... up till six years ago. My health was much better then and I had much better nursing staff - and it was more of a sense of adventure.... But it's my health now that stops me and I can't get carers to go. You see, anything a week and under, I could just about do it with two. A week or over, I would need more. One time...after two weeks, I flew one carer home and brought in a fresh person._

Still, Ralf hopes his situation will improve in the future because after a good holiday he says he always feels:

...happier. It lifts my mood totally – makes my day – and [it] could last a long time, this feeling. I still have fond memories of trips from ten ..., fifteen years ago. I still talk about [the vacation] and bring it up, and if I think about it, I go: ‘Wow, that was fun! I had a good time’. It’s about exhilaration and telling everybody we went here, there, and did this, that, and made friends etc, remembering all the good things that happened... with eighty-five percent positive memories outweighing the negatives. As I said, vacations lift me out of any negative feelings. I come back much happier and de-stressed.
6.5 Jake (Caucasian male; 52; slipped in Jacuzzi at 39; C4/5)

Jake was a busy journalist in his late thirties and happily married with two teenage children when his life changed overnight. He slipped getting into his open-air Jacuzzi and sustained a C-SCI. Twelve years on, he no longer requires a ventilator to breathe, but he is also no longer working or married. Instead, he lives with his partner of four years, Amy, a former NS nurse, with just four hours of bought-in assistance a day.

Background

Mia explained how Jake came to live at NS:

Jake is a good-looking and real smart man who needed a relationship because he had always been in one up to his injury. So he had one [relationship] after the other with his care attendants. His first was with... a single mother. He moved in with her and paid her rent. But, as often happens, it turned into an abusive relationship.... A huge bruise was found on his hip when he was thrown out of his chair. He left her house, and within a month, he got himself an apartment and hired nurses. One of them moved in with him as his partner.... It was another abusive relationship, but this time he couldn’t get her to move out.

The only option Jake had was to move out himself and, in desperation, he turned to NS. Mia recalled that ‘Jake had big bruises on his body when he arrived here.... But once he had settled in, he established a real relationship with a nurse, Amy.’ For the first time since his injury, Jake was happy in a relationship. His outlook changed and he offered to use his writing skills and work for NS voluntarily. He came into head-office every day with his duty-dog, a golden Labrador, and used the computer to write. His old journalistic talents returned when he secretly wrote to the Government in praise of NS’s rehabilitation work. As a result, Mia won national recognition and NS was set up as a States-wide C-SCI rehabilitation model.

Later, Jake moved with Amy to the warmer climes of southern California. Mia keeps in occasional contact with him by telephone but senses that he may be rather lonely and depressed now that he is no longer working or writing: ‘I know he’s found a true partner in Amy, but
whenever I ask: "Well, Jake, what are you doing down there...?", he always gives the same
down-beat reply: "Oh, just watching the sun set". The only thing which occasionally occupies
Jake is planning of his and Amy's holidays. They are always mainstream and thus a long time
in the planning.

Jake about himself & holidays

Before injury, holidays hardly featured in Jake's life:

I had no time; I was working hard and was broke with raising children....
Vacations are more important now since becoming disabled; it's a struggle...
day to day, and it's important to have something to look forward to. So having
a vacation planned or on the horizon is a lot more fun. It's very important for
me to know there's one on the horizon.... [My favourite was to] Florida...for
its uniqueness. We saw a couple of alligators by the road and took boat trips,
went to a small part of Disneyworld that we were interested in.... Everything
was accessible, but [I] didn't do any of the rides. Not interested in them.

Jake explained that he likes to take at least one holiday a year, usually for a week. That said, he
has taken only eight in the twelve years since injury as he did not take holidays straight away
mainly because his rehabilitation programme did not prepare him for travel. He insists,
however, that holiday-taking 'definitely has a place in rehab, especially providing information
which is the first and vital part.... It would have been nice to take a short trip during rehab,
towards the end maybe, just to be certain I could do it.'

It was due to this gap in his knowledge and practical experience beforehand that Jake described
his first holidays post-injury as: 'much more difficult because I didn't have the strength or
experience I do now. Anxiety beforehand took away from the overall pleasure [of the
vacations] as I was too nervous'. Although Jake feels holiday anticipation and recollection are
'critically important to the overall vacation experience', he still finds anticipation unnerving:

I look forward to [the vacation], but it's tinged with fear and nerves of whether
I might get hurt or sick, or forget medicines that aren't available [elsewhere].
But [afterwards] always, I was very, very glad I went.... I just enjoyed it. I felt
good like everyone else, emotionally and psychologically.... Since I've been
with Amy, I've just gone with her, no travel assistant. Before [her] , I went with
either a paid aid or a trained friend [which was] more successful because we were there for the same reason [and] it's more like 'palling around' than having someone there who's your paid employee. It helps psychologically.

Even with attendants, Jake always considered what they wanted to do on holiday too. As a result, his expectations of them were always met because: 'The paid aid would take care of my needs and be friendly and also enjoy it him or herself.... One time even, for a conference at Salt Lake, I planned ahead and contacted the Home Health Agency which sent an attendant in the morning to get me up, and it worked well'.

Both Jake and Amy stressed that the success of any trip is down to good national medical insurance cover and thorough planning which Jake always does with the help of a travel website for wheelchair-users called 'Life rolls on':

> Depending on how far you're going, planning is at least a month, sometimes more [if looking] for accessible hotels with accessible bathrooms.... If it's in California, we're usually in our car, so we just book hotels. It's easier by road.... We don't plan access of attractions as we just assume they are [accessible] in the U.S. But there's a whole lot more preparation for overseas, but people are starting to look at it, "Accessible Europe", especially Spain as it's supposed to be accessible. Next Winter Olympics is in Vancouver and hopefully it'll be real accessible as the Mayor is a quad.

Jake talked about a wheelchair-user friend of his who was currently visiting Lisbon. He was eagerly awaiting her return to hear how she managed to get around there. As I heard this, I offered to look at the accessibility of some other European cities for him and he responded enthusiastically. Although he had misgivings about international travel, he admitted that his dream holiday would be to revisit all the places in Europe he had seen in his youth whilst inter-railing from London to Greece. He had thought about returning a few times but had always concluded 'that can't be done' due to inaccessible Europe. Jake would, however, not worry about being in Europe as far as the language was concerned:

> as so many people speak English in the tourism industry. But it would worry me if there were no English-speaking doctors or people in the hospital if I had to go in, so I'd make sure I knew a medical person in each city.... I'd go via the
tourism office to find [that] out.... I would not go to a small city abroad as I must have specialists, so only big cities like London, Paris with a major hospital'.

Long-haul flights were the big stumbling-block to Jake's revisiting Europe: 'I wish airlines would make travel more comfortable'. He and Amy guessed it might only be possible to fly long-haul if they broke up their transatlantic flight by first flying from California to New York. They could stay in a New York airport hotel for a couple of nights to rest and then fly on to Europe. This would be highly unusual as they normally preferred to find direct flights to avoid additional hotel costs and problems with missed connections. Both flight delays and the fact that wheelchair-users were always last off the plane, and even further delayed when their wheelchairs were often returned damaged or broken, meant that Jake had missed many flight connections or pre-booked accessible taxis at the airport. When another taxi eventually arrived, it was invariably not power wheelchair-accessible and so he was left stranded for some considerable time.

Nurse Eva also talked about long-haul with her private client, Ann, a sponsored 'inspirational speaker', and how they always insist on flying first class for comfort as 'most quads have a time limit for sitting up, and then they need to lie down'. Furthermore, their long-haul flights were always broken up into a number of shorter flights with several days between, resting in airport hotels. However, 'water is the biggest problem abroad' because:

> In a couple of places I bought bottled mineral water for Ann's chair ...for her drinking container on it, but they'd been filled with other water and the seals glued back. That was stressful for me, the thought of giving Ann contaminated water and her ending up in hospital. ...I always inform the American Embassy of the country we're in case she gets sick and has to leave in an emergency. That's why it takes so long ..., three months, to plan the trip. Biggest problems are attendants – there must be three - and planning. Here there is stress too. When we go on vacation here and hire an accessible van, they usually turn up with one that's okay for a small manual chair, so we send it back. After waiting a long time for another, a bigger one arrives, but it has no windows in the back for Ann!
Travel experiences

Even around the USA, Jake was not comfortable with flying: 'The only thing that scares me is the airlines. They're unpredictable; they have a 'make it up as they go along' attitude in dealing with passengers with disabilities. He sensed that most airline employees were poorly trained, as they did not know what the straps on the narrow aisle-wheelchair were for or where they went or even how to transfer passengers onto their airline seat. Often, even when Jake had given the airline prior warning, the pilot would have to be called from the cock-pit to assist the male attendant transfer him onto the seat. Cabin crew would almost always only speak to Amy about him or, on occasions he was addressed directly, he would hear: 'Can you stand up now and move over there?' or 'Just hold on!' Further frustration and embarrassment was created by the inaccessible W.C. on board as Jake’s urine bag had to be emptied in full view of other passengers.

Since his power wheelchair had come back broken so many times from the luggage-hold, Jake decided to take only a manual one on future flights. This was no solution as attendants were then left with extra, heavier physical work throughout the holiday with Jake unable to wheel himself or do his own weight-shifts every hour or so. Yet whatever type of wheelchair Jake flew with, airline policy did not permit him to use it during a flight. Attendants therefore had the difficult task of assisting with weight-shifts in the tight space between rows of seats unless they had managed, on some occasions, to secure bulk-head seating.

Although bulk-head seating allowed for more room in front, when Jake’s seat needed to be reclined to relieve pressure, it was often not allowed during take-off or landing, or impossible when people were using their table-trays behind. Furthermore, Jake needed to sit on top of a special pressure relief cushion placed on the seat. This meant he was lifted so high up that, although a six-footer, his feet were dangling and so his skin could get knocked and damaged. Finally, with just a lap belt on, Jake’s whole body could be thrust forward, or to the sides, when
the plane landed, took off or during turbulence. Attendants therefore needed to hold onto his upper body because, if he were thrown forwards, with his head to his knees, his breathing could be affected.

Road trips

As a result of these problems on flights, Jake’s holidays now tend to be by van. He regrets that this greatly limits his choice of destination, but feels that peace of mind is more important for him. To help with road trips, he bought a mobile-home, but sold it soon afterwards as it turned out to be ‘a bad thing as the non-disabled person has to do all the work – loading, driving, filling with gas, cleaning the windows, cooking, preparing for bed - and she was exhausted’.

Jake and Amy therefore stay in hotels whenever they travel now. Amy explained that, although they always take along items such as an egg-crate mattress:

We try to keep equipment to the minimum as the packing and unpacking was like moving home.... So trips must be two nights minimum to give me a chance to load and unload stuff and settle in.... We’d be too tired if we were constantly moving.

They agreed that most problems on road trips were ‘self-inflicted when transfer boards, dog food for Jake’s duty-dog and even medicines have been forgotten’. As a result, they now always make lists and try not to be in a rush before starting off so that they arrive at the hotel with everything they need for Jake.

Accommodation

Most problems at hotels were due to the lack of understanding of accessibility on the part of hotel employees. Even though Jake always telephones ahead and asks, for instance, for a bathroom with a ‘roll-in shower’ for his plastic shower-wheelchair to be wheeled straight in, he might be given a bath and a transfer bench or he might not be able to fit his wheelchair under
the sink. Other times, Jake has not been able to get his wheelchair into the bathroom because of the narrow doorframe. According to Amy, these problems occurred so frequently because:

They [hotellers] don’t understand really what you want and they definitely don’t get the difference between power and manual chairs. They often just say ‘yes’ to everything just to get the business. But Jake has a sixth sense, and after talking and explaining to someone, we put the phone down and he says: ‘They have no clue what I’m talking about, even if they gave the impression they do’. So he calls back several times to talk to someone who does know before we go.

As telephoning ahead does not guarantee accessible accommodation on arrival, Jake now always stays at the same hotel chains he knows have accessible bathrooms and helpful staff. He has rarely had problems apart from staff ignorance in relation to his duty-dog. On this, he has wasted a lot of time and energy at hotels, bars and restaurants having to fight his corner to be allowed in with his dog. Yet he remains quite philosophical about this and all other travel issues, saying:

You know that things are going to go wrong; you just have to be of the mindset to deal with it. You have to be willing to stand up for yourself and not accept “no”; to explain how things work or how they can help.

In addition, being friendly gets you more than being difficult’ as does, he contends, being creative and flexible when problems arise. Yet Jake insists that travel will only become easier if the tourism industry has ‘experts on hand, that is, disabled people. Have disabled people on the staff so there’s real awareness’.

Future travel

Jake happily reminisced about a three-day cruise he had taken to Mexico when, unusually, he had ‘no problems and the staff were very helpful.... You know, there are cruises just for the disabled too’. However, he feels that, compared with other wheelchair-users, travellers with C-SCI have more issues to contend with even on accessible cruises as:

Paraplegics with upper body strength might be able to get out of spots, but quads can’t transfer themselves, go to the bathroom by themselves or do other things themselves. In fact, many vacations involve having a physical good time
- for example, water-skiing, and diving, hiking, fishing. Most vacations have a secondary purpose that's not possible for a quad to participate in. On a beach vacation, people swim the whole time, [but] I can only eat, drink and be merry. I wouldn't go swimming even if the pool were accessible.... Oh, quads that sky-dive are idiots! I would only go on vacation where the people are the most important.

As I thanked Jake for his time and contribution to the discussion on travel, he replied: 'Sure, it's been fun'. I took his words at face value and enquired whether he had ever considered writing a 'practical guide' to holiday-taking for individuals with C-SCI. I wondered aloud whether he, given his professional writing skills, varied travel experiences and sensible approach, might be the ideal person to write one. Yet, he showed no enthusiasm for sharing his practical knowledge now or in the future. His next holiday - a cruise around the Caribbean - had, however, already been meticulously planned to avoid all the pitfalls of travelling with a C-SCI that only a skilled and seasoned traveller with C SCI could do.
6.6 Don (Caucasian male; 43; car accident at 24; C4, now ventilator-free)

Softly-spoken and quick to blush, Don describes himself as a shy man, although he was NS’s first ever client to move into an apartment on his own in the community. Don became injured when his truck turned over driving home from a wedding celebration. Experts believed that, had he been wearing a seat belt, he would not have sustained a C-SCI. He now has the unique position of being a former client and, currently, a NS full-time employee inputting computer data and creating the company’s first website. Typing with a mouth-stick all day is physically exhausting, so it is not uncommon for him to have the odd nap in front of the computer screen. When I observed this, I noticed colleagues lifting their eyes to the ceiling in the open-plan office and heard mutterings of ‘wish we could sleep at work!’ I noted also, however, that he was always the last to leave the office each day by at least an hour.

Background

Before Don moved from NS into a rented apartment, he learned how to use a sip and puff emergency telephone as he would be alone sixteen hours a day. Nurse Liv recalled how he responded when asked to consider the consequences of a possible earthquake occurring when he was alone in the apartment:

He decided that he would be prepared to take the risk if it meant he could live back in the community and... taste independence again.... But not long after Don moved in, a big earthquake struck in the middle of the night. All he could do was lie there with everything crashing down round him, listening to neighbours screaming and scurrying around hysterically.

Eventually, neighbours rescued him. After the devastation, no-one would buy the badly-damaged apartments, even at rock-bottom prices. Yet, Don seized this opportunity to get onto the property ladder and bought two — with a down-payment on his credit card. He eventually sold one to buy an accessible van and to pay for a course to train as ... ‘a Private Eye!’ Once qualified, he did most of the detective work on the computer. However, he was hardly
inconspicuous in his bulky wheelchair, with a tiny camera strapped on and connected to his mouthpiece, to snap cheating spouses, so he had to call it a day six months later.

As for Don’s private life, Mia mentioned that she had recently spoken to him about his forthcoming marriage and his decision to adopt his fiancée’s child. She advised him to protect himself legally because, if the marriage failed, he could lose everything he had striven for over the last fifteen years without any contact or support from his family:

Don’s had plenty of girlfriends - all care attendants except for his last one, a divorced mother of one.... They met here when she was working as a cleaner. She moved in with Don as she had no home of her own. He seems happy, but...he’s not long recovered from a broken leg which happened when he and his fiancée were ‘dancing’ with the sides of his wheelchair pulled down, and he fell out.

Don about himself

Don enjoys everything about living and working in the community - even using public transport to get to work in warmer weather. On the chilly March morning of our appointment, however, Don’s ‘Access’ taxi was delayed and he was over an hour late. He thus talked about how, although he preferred travelling by bus:

Only one out of twenty buses has a ramp, so mainly it’s lifts – and they’re kind of scary to get on. People have to wait...for me to get on. You kind of think they'll be throwing spit-balls or something, but nobody ever says anything, at least I haven’t noticed, but I don’t pay attention. I avoid eye-contact...I’m pretty shy.... One time though, I was waiting for a bus... at the bus stop and it kind of pulled ahead of me, and the others ran in front of me and got on, and it kind of tried to make a run for it [without me]. But the driver hit a light, he got a red light, and I kind of got ahead of him right in the street and wasn’t going to move, so he had to let me on. So I was kind of assertive there.

The only other times Don recalled having to deal with unhelpful people was when he had: ‘a companion dog ... and one or two places didn’t want me in.... Most cases they were foreign [hotel and restaurant] owners and didn’t know the law, and I just left as I didn’t want to file a law suit’. Similarly, Don had to leave a cinema when he was accused of being a fire-hazard
when he was sitting in the aisle, the only ‘accessible’ area. He finds the general public to be divided into those who are ‘friendly and helpful’ and those who ‘don’t want to be helpful.…

Like, [when] I’ve been waiting for a door and they will just jump in real quick so they don’t have to hold it for me. But there’s always someone else coming along, so it’s not a big deal.

Despite these occasional incidents, Don remarked how dramatically different his life is today compared with when he first became disabled, particularly during rehabilitation as:

I didn’t go more than two blocks from the hospital, but once I got to NS, I did get transported to social security and the bank in an accessible van…. But during my rehab experience, they just didn’t prepare you for the real world as best as they should. They just prepare you to go home and stay there. They don’t really give you confidence or, like, real useful tools for getting anywhere. Travel really needs to be part of rehab as that’s part of life…. Just getting across town, how to find accessible transport…. [which is] less problematic than a vacation, but if you can find an accessible vehicle across town, you can take it across the States…. I’ve never seen an airline or a cruise commercial that has someone in a power [wheel] chair… so people expect that they will be excluded just because they don’t see anybody doing it. I’ve travelled enough that I know I can do it. Most people in my situation… don’t think it is very practical or possible, so travel should absolutely be part of rehab.

If travel had featured on Don’s rehabilitation programme, he is sure his earlier holidays would have benefited from understanding the importance of:

Planning ahead, asking: ‘How in the world will I do it?’ They [tourism providers] don’t volunteer information. You have to find out for yourself. Call the airline, the hotel and do a lot of checking ahead to see if it’s going to be accessible and what their definition of accessible is…. Check the website for a picture and, if not, you just call and ask specifically. You have to be assertive, but that’s not my personality at all, but they’re not going to volunteer stuff. Explain your past experience and problems so that they will see what barriers [there] could be that they didn’t think were barriers. For example, if I know there are steps…. I bring a portable ramp…. Once, the [accessible] motel I checked into, [the width of] the door-way was fine, but when getting out into the corridor, I had to go back and forth so many times to get out that it made me not want to come back all day once I left the room, or once I got in there, not want to go out again to eat. They considered it ‘accessible’ as there were no steps, but the turn was just too tight….
In other hotels, either the lift was too small for Don to use or the bathroom too tight, so attendants ‘managed’ his urine bag and ‘bed baths and other [bowel] programmes on the bed which was no big deal’. However, he felt a real solution might be:

A set of standards for what is truly accessible and what is not.... A motel room, for example, or a door without any steps going in needs a user-rating system. For example, level one to six; six being totally accessible for power wheelchairs... including things you can do when you get to your destination, [as] a paraplegic will transfer into some of the [amusement park] rides, but there are very few [accessible ones] for me - one or two maybe. I can squeeze on the tram-ride, barely, to see Jaws and the Earthquake, but most are not accessible.

Holidays
Don had little experience of or interest in holidays pre-injury, but explained that travel had since become important because ‘as you get older, you want to see the world... get away from home,... [take] time off work. He has taken on a number of holidays post-injury and all were independent with attendants as he feels ‘travelling with a bunch of disabled people sounds kind of depressing’. The holidays gave him ‘good memories... for months after[wards] thinking about and talking to people about them. And I felt slightly less disabled knowing I could travel’.

Recollection is, in Don’s opinion, always sweeter than anticipation because of the: ‘Planning for all the things that could go wrong and affect your health, like not taking certain medical things I absolutely need. I start making a list and I’m always adding to it, checking it off’. That said, on Don’s last road trip to Arizona with his fiancée, he left some essential equipment behind, and had to improvise. Travelling is a constant learning-curve and he has now learned ‘to make sure everything gets into the vehicle... [by having] a double-checking system .... But if forgetting stuff is something you’re going to worry about, you’re going to have to stay home.... The positives outweigh the negatives unless it’s a really catastrophic problem’.
Travel experiences

Although Don’s first holiday could not be termed ‘catastrophic’, it made him reluctant to attempt another for over a year and a half afterwards. Prior to the holiday, Don had wanted to go to Las Vegas and had already bought an expensive accessible van to get him there. He explained that he had ‘got a package deal. Paid ahead for the room, got a discount in advance, but had to wait six months to go - a promotional thing’. In the meantime, Don’s ‘care attendant, who was going to Vegas and didn’t want to miss time [or money] at work, said: “Why don’t you come along?”’ Don was thus able to take his holiday to Las Vegas sooner. The attendant was equally happy as he was paid by Don to accompany him and they travelled together in Don’s van. However, it was the van which caused all the problems:

My van blew the engine about half way there.... If you break down, they’re not going to tow you sitting in the back of your vehicle, but this guy bent the rules and I was hiding in the back [of my van] with a blanket thrown over me.... Couldn’t do anything else. No cab is going to come and pick up on the highway,... and a person in a wheelchair trying to rent a car - nothing around! Found out the bus [to Vegas] was leaving in a couple of hours - and that was three miles away and the only way to get there was to start wheeling... at three o’clock in the afternoon and 110°F! Got there just in time..., but the bus wasn’t accessible. So the six-hour trip to Vegas took eighteen hours.... Now I’ve better towing coverage in case the vehicle breaks down. Tow coverage for a hundred miles.

Flying, wheelchairs

Bad luck struck again on Don’s second trip to Las Vegas when he decided to fly there and his wheelchair got broken in the luggage-hold:

The wheelchair was just dead. The airline loaned me a manual one which was no substitute.... I had to be pushed around and couldn’t lay back and do [my] weight shifts. It was horrible. Just stayed in my room and didn’t get up much as it was so inconvenient not having the power chair.... Ended having to leave early. It was completely unenjoyable; zero out of ten.... I felt so glad to be home, never wanting to leave home again. Kind of put me off [vacations] for a while.... Even in the most accessible city like Vegas, there’s no guarantee your vacation’s going to be hassle-free - especially if your wheelchair gets broken.
Don admitted that he would have left Las Vegas immediately had he not been accompanied by two attendants. Without his power wheelchair, which the airline eventually got repaired after the holiday, there was so much more physical work, pushing and lifting with weight-shifts, that one or even two assistants could not have managed easily. Although Don no longer requires a ventilator to breathe, he still needs to fly with one assistants because: 'I need help with weight-shifts and I have no upper body strength, so the person next to me has to hold on to me to keep me from falling. Got a lap belt on that's only going to keep me off the floor, but [I] wouldn't want to fly without a care attendant'.

The next time Don flew, five different parts of his wheelchair got damaged which the airline ignored until he asked for it to be repaired. To prevent this from happening again, Don had: 'labelled all the connections, given instructions for people to dismantle it, requested to talk to the actual person who's loading it', but found 'nothing is fool-proof against wheelchair damage'. Ironically, some airlines had sometimes charged extra for carrying his wheelchair, while others had waved the extra charge. Similar airline inconsistencies occurred when, on a few occasions, there were sling-hoists to transfer him from the aisle-wheelchair onto his airline seat and, on others, a male flight-attendant and the airline pilot had to lift him onto the seat.

Getting onto the aircraft could also be problematic at Don's local airport with no gang-ways onto aircrafts. As a result, he has to be lifted up alone to the aeroplane 'in a glorified forklift which is kind of scary'. Once when it rained, he got soaked and had to sit in wet clothes throughout the flight. Likewise, flight delays could be a health-hazard. When Don took a short day-return flight to attend a seminar for work, he booked an accessible taxi to meet him. Although the flight was delayed by just ten minutes, the taxi left without him. He was then forced to wait over one and a half hours for another and thus missed the seminar. Don warned
of the knock-on effects of delayed flights and insufficient numbers of power-wheelchair-accessible vehicles as: ‘You can get stranded somewhere if you can’t get back to the airport and miss the flight. It’s serious for your health if you get stranded somewhere over night with no equipment’.

**Holidaying abroad**

Don’s first ever experience of flying, pre or post-injury, was to Mexico when his Mexican attendant invited him to accompany her on a trip home to visit her family. Despite earlier misgivings about holidaying in an apparently far less wheelchair-friendly country, Don singled out Mexico as his most enjoyable holiday ever. Even so, the holiday started badly when American Airlines refused to let him fly as ‘they did not know how to deal with [him]’ although they had knowingly sold him a ticket months earlier. Eventually, a Mexican airline agreed to take him, and the only time his wheelchair has not been damaged during a flight was on this airline.

On arrival in Mexico, Don was met by his attendant’s family in a hired ‘regular truck’. Yet they transferred him onto a seat and placed the wheelchair in the back. He described with great admiration his Mexican hosts’ determination and effort to make the holiday work despite countless access issues:

> I knew they weren’t going to find an accessible van, but ... everything worked out.... Their house, where we were staying, was up a bunch of stairs, so they carried me up - and then... the wheelchair.... In Mexico everything is stairs, but there's ways around it though - round the block, or they picked the accessible restaurants and everyone was friendly. There was a lot of lifting; a lot of family and friends and locals were willing to lift a big, heavy wheelchair up a flight of stairs or two. Every day they carried me down,... into the truck and [we] went to a different place. Even on the streets, they had to lift me up a step here or there. I saw only one curb cut-out and got a picture of it as it's so rare....

> I did get a bit of a urinary tract infection there, but they had prescriptions over the counter, so I took my best guess and had antibiotics. Her mother suggested something too. [Not speaking] the language didn't bother me because I had a carer with me. And I never use travel insurance - never think
about that. Don’t think about healthcare too much in planning vacations even though I should really.... But even in the local specialist hospital here [USA], I have to let them know what to do - keep on at them. Specialist or general hospital, you have to be in control, manage your own situation. I wouldn’t be surprised if other countries have better [health] care than here. There’s no guarantee that travel will be hassle-free even in the USA and even with the law.

Future travel
Don dreams about taking a cruise around the Mediterranean or a trip to Europe, but he fears some door-ways might be too narrow on a Mediterranean cruise. He feels it would also be too expensive with the additional cost of attendants and perhaps too physically challenging as ‘Europe is so old [with]... a lot of inaccessible places. Hundreds of years-old cities, like London, I would think that there’s a lot of stairs there and things that are inaccessible’.

Yet travel closer to home is definitely part of Don’s future plans as he intends to go to Hawaii for his Honeymoon. He fears though it might be somewhat bitter-sweet because he and his fiancée would love to experience: ‘one of those helicopter tours of the island, but I just don’t think it’s going to be possible.... A paraplegic... they probably would be able to transfer in, but I don’t think I would be allowed unless they were extremely accommodating’.

Nevertheless, Don is still very much looking forward to starting his new life as a married man with a holiday on a beautiful, sun-kissed island.
6.7 Lynette  (Caucasian female; 44; car accident at 31; C6/7)

‘There should be a movie made about Lynette’s life!’ exclaimed nurse Liv when she heard I had met the Londoner. Decades ago, in a desire to see the world, Lynette arrived in California because, as she explained, ‘it was Freddy Laker days and it was cheaper to come here [USA] than to go to Europe’. She never returned home as she met and married a Californian and together they enjoyed countless wild ‘road trips’ around the States before they came to an abrupt end. Lynette sustained a C6/7 in a car accident and, due to her husband’s increasing drink and drugs lifestyle, she and their four-year-old daughter found themselves with no one to take care of them.

Lynette about herself

Lynette described how, lying in hospital after the accident, her sole concern was for her daughter:

I wanted to get independent and raise my daughter; that was the prime motivation. My husband was alcoholic. He used to bring her into the hospital. He’d been drinking. She hadn’t been taken care of, [so] they told me when I was still in rehabilitation, [that] ... Social Services might have to be called. So I’m thinking: ‘Look, on paper: mother quadriplegic, father alcoholic. She’d get in the foster care system, [and] I’d have to fight to get her back’. I’d have to prove stuff, so I needed to be independent.

Yet, her ‘couple of [trial] weekend visits home from hospital were so appalling’ that she had to readmit herself after just one night because her husband was drunk and had left her and their daughter completely alone unable to fend for themselves. As a result, she then made the decision ‘to go it alone’ because she thought:

I can’t live with him. I can’t rely on him. [But] I didn’t really know what I was going to do either! And then two, three weeks before my discharge day, this lady walked into my room with a ventilator quad, said her name was Mia... and would I be interested in her [NS independence] programme. And it was like God [had] sent me an angel.... It was amazing... and the independence programme worked for me.
But you know, when I was first in NS, I saw people that had twenty-four hour care or people who had compensation insurance that could have people with them all the time. I thought: ‘Oh, that would be so nice, wouldn’t it? Wouldn’t have to struggle to do this and that’. [But] I found that [these] people weren’t happy. They had turned into disgruntled people ... because you don’t learn any independence, any feeling of self-worth. Even high-level quads who can’t do many things, can still plan their day and can make it ... work. It’s empowering.

Background

Mia continued the story of Lynette’s journey from dependence to independence:

From the hospital, she moved into NS...and within six months moved into an apartment on her own. I remember how scared she was the very first night alone in the apartment. But she knew that if she was to prove that she could make it alone, she could not call for assistance during the night.... She succeeded and was reunited with her daughter.... Soon afterwards, Lynette managed to put a down-payment on a little house from the small settlement her lawyer got her due to some defect in her car which contributed to the accident. She raised her daughter on her own with just four hours of bought-in assistance a day to help... with washing, dressing, bowel programme, urine leg-bag and exercises for the joints.

Life today

Lynette’s zest for life shines through. The vivacious red-head has a large circle of disabled and able-bodied friends and many interests. She talked about how she has adapted to being a wheelchair-user and learned to accept a different kind of life. Recently, she learned to swim with a collar around her neck at the pool in the local hospital which had installed three different methods of transferring wheelchair-users into the water: ‘It’s easy to get in. I can swim backstroke up and down ... the pool. And I cried because I was propelling myself for the first time in years’.

At first though, Lynette found it difficult to adjust to her new life and her old friends’ change in attitude towards her. Yet with hindsight, she admitted: ‘I alienated people at first as I was so needy and...it was tough. A lot of people my own age stayed away a bit. The older people
kept me going and were less intimidated and uncomfortable [with my disability]. So you have to make people feel comfortable, I found'.

As Lynette made progress in reclaiming her life and hope for the future, a remark her mother made whilst visiting from London has stayed with her until this day. She recalled that they had just had a little tiff and 'my mother blurted out: “Well, I know your life is miserable, but there's no need to take it out on me”. And I was just floored that she thought my life was miserable because I didn’t think that was the picture I was painting'. Even though she was clearly striving to live as full and 'normal' a life as possible, the remark confirmed for Lynette that her mother still equated disability only with misery.

Two years ago, Lynette embarked on a sociology degree, but she has been unable to complete it as she needed to have undertaken a period of work-experience before entering her final year. She explained how she had contacted one of NS’s managers to see if she could do the required unpaid placement at NS, but was refused. With Lynette’s permission, I later raised the matter with Mia who, incredulous, immediately tried to remedy the situation. However, it was already March and too late in the academic year for Lynette to join the final year. Currently, Lynette spends much of her free time volunteering to counsel and visit in hospital those who have recently sustained a C-SCI. She tries to pass on more workable, practical tips she has picked up post-rehabilitation. She then demonstrated a couple for me – how to type with an ordinary pencil that has a rubber at the top and to eat with the spoon placed under the middle finger. Equally, she stresses the importance of understanding patients’ emotional response: 'There’s a lady... right now who’s been crying for about three months.... I know how she feels as she’s got two young kids, and what help she needs to get her life back that she won’t find at the hospital.
Local places

Before receiving her ‘assisted car’ for local driving, Lynette recalled the time ‘... when I started to use the bus ...[and] my life started to open up a bit’. She would return from the supermarket by bus with ten bags of shopping hanging from the handles at the back of her wheelchair. She also remembers the dreadful episode the first time she got stuck on a bus lift:

I’d taken my daughter to the doctor and was half way in and half way out of the bus when it [the lift] stuck. It was cold and I was like in a wind tunnel... and I heard someone behind me say: ‘People like that shouldn’t be allowed to use the bus in rush hour. I’ve got to get to work’. And that was the first time I really felt like I’m ‘people like that’.... But now my thought is: ‘You step off that curb and you could be people like that’. But I ... got that same feeling from some of the people who were on the bus just the other day.... You can hear the murmurings and mutterings... on their cell phones going: ‘Well there’s a wheelchair, you know’.... Sometimes it’s hard [to speak up] because when my daughter was younger, she didn’t want me to make a scene or be a bother.

Many of Lynette’s wheelchair-user friends are far more outspoken about being treated differently or presented with a less dignified option. She, however, does not mind entering a restaurant through:

...a side door or the kitchen.... It depends, I mean, if I’m just turning up somewhere and that’s the only way in right now, but I have a real problem with anything that’s new and improved and they haven’t made it accessible. [In the local cinema] they have stadium-seating...which is atrocious because if it’s below, I think, four hundred seats, it only has to have one wheelchair area, and a lot of the time it’s way at the front ... for a huge screen.... At the bank, everything takes longer for me as they have one counter that’s down low,... but there’s not a tiller there most of the time. If they see you, they say: ‘Go over there to the low counter, but the till’s not open there, so you’re giving them stuff here, and they’re running over there to their computer!

Whenever Lynette is out with other wheelchair-users, she notices how public reaction is generally more negative towards those with higher levels of C-SCI, particularly ‘if you’ve got a ventilator or you’ve got a bigger wheelchair or... if the “speaking thing” is really hard’.

Yet one of her most uncomfortable experiences happened when she had gone alone to the cinema to watch ‘Million Dollar Baby’, a film about a female boxer who sustains a C-SCI and
manages to persuade someone to assist her to commit suicide. On leaving the cinema, Lynette was shocked at the general reaction to the film and confronted the people behind her whom she overheard saying loudly:

'That [suicide] was the best thing for her. The best decision because who could imagine wanting to live like that...'. Did they think I couldn't hear them? You know, people think everyone in a wheelchair has a brain injury.... But one of the things that happens a lot is, if we went out to a restaurant, ... servers would talk to you saying: 'What does she want? Can she sit here?'. Also,... waiting in line, people just walk by me and get in front of me, and I'm like: 'I'm in line here too' or 'what do you think I am - an ornament? What do you think I'm sitting at the bagel counter for if I don't want a bagel...?'

**Holidays**

It was entirely for her daughter's sake that Lynette first embraced new challenges such as travel because, as she explained: 'I had this huge thing about being a mother and not having my disability spoil her life and development.... You know, we've got to do stuff and my husband wasn't able to... drive her and take her camping and stuff, so I felt I really needed to make an extra push'. Lynette thus pushed herself to go to San Diego on holiday. She used a company called 'Accessible San Diego' to arrange morning and evening attendants: 'We just went for a weekend and we did "Sea World". We went to the children's museum. The next day we went down to, like, this harbour place and you can do the harbour cruise too.... We didn't have time to do it, but I did check it out'.

The feeling of accomplishment after her first short holiday was immense and gave Lynette the confidence to take further and longer holidays in the USA. All were independent travel because she insists: 'I want to go where other people can go'. There were always obstacles to be overcome, but the holidays were still very worthwhile as she regularly feels the need of a change of scene for some relief from her daily life which is a constant physical challenge for her. She therefore believes that it would be very beneficial to learn how to travel before leaving rehabilitation as, afterwards, people tend 'to become more fearful and depressed the
longer they "stagnate" and never dare to travel for fear of: 'access issues, things breaking down or being broken ... being away from their comfort zone, and [due to] a general lack of knowledge'. She admits though that she never has any knowledge of hospitals at her destination because:

It's all the same, any hospital, I'm telling you... it doesn't matter. I can go to the hospital here which has a fabulous spinal cord rehab unit, but if you go to the emergency room, they say, they told me [that] I'm not quadriplegic! I'm moving my arms, so I must be paraplegic.... They haven't even heard of certain terms to do with my disability! So you just have to speak up and say: 'This is what's happening to me, this is what I need'. You have to know your needs. You have to talk about the mattress you need... [and] say: 'You cannot leave me; I'm going to need to be turned. I'm going to need people to check on my catheter, my urine out-put. I'm going to have to have a bowel programme'. If they are incompetent or refuse to do it, that's when it's really hard. You have to have some person you can call or... you can, um, threaten them [with a law suit].

Travel experiences

Two years ago Lynette flew home to London for the first time since injury to see her family for a three-week holiday with her daughter and an attendant. Beforehand, however, she admitted: 'I was so worried about having her [the attendant] with me twenty-four hours a day... because I wasn't used to having one with me all the time... and sharing my bedroom.... And the cost...well, I'm still paying for it now'.

As for access problems in London, Lynette 'expected it because it's so much older'. She therefore travelled with a manual wheelchair, but even with this smaller, folding wheelchair she and her attendant stayed at a hotel as none of her relatives' houses were wheelchair-friendly. Lynette's hotel room was not entirely accessible either as she 'wasn't able to take a shower, but... worked something out... like bed baths. Her brother moved her to a 'better' hotel, but she was forced to return to the first one because:

Where they'd knocked out the bathroom to make it have a shower, the bedroom was so tiny that we couldn't get round the beds as easy as in the other one.... But even here [USA], you run into a lot of problems like, I couldn't get in the bathroom of one hotel. The door was too narrow and I
Chapter 6: Narratives of travellers

said to the manager: ‘Well, what were you thinking?’ And he goes: ‘Well, this [room] is the nearest to the elevator’. And that was a Hilton!

Getting around London proved very difficult, particularly pushing Lynette up the incredibly steep ramps, even with four people lifting up the front wheels of her wheelchair. She found the experience very frightening and knew that the gradient would have been impossible in her power wheelchair. Furthermore, she noticed that:

[Bus] drivers hadn’t that much experience [of bus ramps]. One of them didn’t even pull up at the curb.... He was in the street opening the ramp! It felt pretty unusual for London transport workers to be dealing with wheelchairs.... And the underground stations! You can leave from a station and it’s accessible on one side, and you can come home in the evening, but on the other side, there are stairs! I was surprised just how many pubs had steps too.... One time, I needed to use the Ladies’ bathroom in this pub but couldn’t because there were steps, and the guy behind the bar is like: ‘No, all you gotta do is you gotta go in the Men’s... I’ll go in first; see if it’s empty’. You know, like, no big deal! That was their accessible plan!

What astounded Lynette was how badly ‘improvements’ to London’s accessibility had been made. For instance, ‘...the accommodation had not been researched very well. And there were curb cut-outs done, but they were done really poorly and they were broken up already and ... dangerous’. Yet, despite all these issues, Lynette still remembered this, and every other holiday, as overall far more pleasurable than problematic as:

Even when stuff has been horrible and gruelling, it’s still been good to get away and feel renewed. It’s to do with expectations.... I was realistic about what it [London] would be like, and sometimes it was pleasantly better. [Yet] it would be easier if more hotels or establishments had a little training in asking what exactly people [with C-SCI] need because I know there’s no point in calling up and saying: ‘Do you have a wheelchair-accessible room?’ because that can mean all different things. And staff need to ask: ‘What special needs do you have?’ One of the things that gets me down is that I don’t get away as much now and it’s not so easy as before [injury].... Travelling is going to be on my list of things to do more of. I want to be able to go and stay where Emma’s [my daughter’s] going to be [at university].... Hopefully San Diego, just three hours away, because I know the trains. I can get the train down there and I already have [attendant] contact down there.
Future travel

Later, as we discussed travel to less developed countries, Lynette mentioned that she knew: ‘A Nigerian guy [with C-SCI] who travels a lot, and when he goes back to his village, they treat him like a king. They all come running and carry him, and he’s ... six foot three and he’s a big guy - a wonderful guy... I don’t think he thought twice about going back to his country and how hard it would be..., but the people were just great.’

I remarked how positive interaction with others can often have a great impact on holiday enjoyment, yet for fear of physical access issues, most NS clients tend never even to contemplate holidaying outside the USA. To this Lynette replied:

*I'm a little like that – but, actually, as I even just verbalised that about the Nigerian guy, I realised may be I am limiting myself, and if I let go a little bit, then may be ...there's more out there. But, you know, it takes what it takes, because you've got to realise these things first.*

Finally, Lynette spoke about her excitement at the prospect of returning to the UK after the 2012 Paralympics in London there and finding her home town far more wheelchair-friendly. Then, after hearing about my trip to Barcelona, post Paralympics there, Lynette reconsidered saying:

*I'm pretty interested in looking at Barcelona now from what you said. I mean, that's just how we do things. Word of mouth is way better..... I think information is the key.... That's why I like to do peer-counselling to talk to people, but I also like reading magazines, and I'm on the Internet. Once you start looking, you read things, and you talk to people, then you feel that you might be able to do it too. ... Travel then becomes part of your story, and things that you can share with other people.*
6.8 Summary

This chapter has presented the narratives of six travellers with C-SCI. Their collective narratives explored the perceived positive impact of holiday-participation on the lives of usually socially-excluded individuals with C-SCI. In addition, they detailed the complex and inter-related nature of the individual, social and societal barriers to holiday-participation encountered and negotiated.

The following chapter will present the main findings that emerged from the analysis of the fieldwork data presented in the narratives of this and the previous chapter.
### CHAPTER SEVEN (PART 1)

**THEMES, ISSUES & PRACTICAL SUGGESTIONS**

7.1 Overview of chapter

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CHAPTER SEVEN (Part 1)

THEMES, ISSUES & PRACTICAL SUGGESTIONS

7.1 Overview of chapter

This chapter presents the emergent themes and issues from the data collected from in-depth interviews, discussions and non-participant observations during fieldwork in the USA. It is divided into two parts. Part 1 explores the near absence of holiday-taking followed by the perceived impacts of holiday (non)participation for individuals with C-SCI. Part 2 focuses on the issues which inhibit and exclude them from participation, although both barriers and potential solutions to counter barriers to participation are highlighted throughout the chapter. Where appropriate, these are also discussed in relation to the literature reviewed on disability and tourism and social holidays.

In contrast with most existent literature, however, the barriers will not be presented in terms of numbers and statistics or labels or categories. Rather, the chapter will explore, in-depth, the complex interweaving of individual, social and societal barriers which constrain, inhibit and/or exclude individuals with C-SCI. The purpose is to analyse how they inter-relate and - with ripple-like effect - what their root causes and consequences may be so that practical suggestions can be offered in the hope of providing potential solutions. Finally, although each section heading responds to one or more of the study’s five research questions outlined on page 18 of chapter one, to avoid unnecessary repetition, attention will only be drawn to them early on in the chapter.

7.2 Rarity of holiday-participation amongst those with C-SCI

Earlier chapters of the study have revealed that very few severely-disabled individuals are ever seen on holiday, in public spaces, in the media’s representation of tourism or in tourism
research. Thus, as Lonsdale (1992) noted of public preconceived attitudes to disabled people generally, the widespread assumption that such individuals have neither the desire nor the capability to take a holiday was found to be equally present at NS and thus influenced both client and staff attitudes and non-actions regarding holiday-taking and C-SCI. Holiday-participation was therefore virtually non-existent as only seven individuals were ever known to have taken a holiday from the many thousands of people with C-SCI with whom NS director had come into contact over a period of forty years.

Even talk of holidays was rare at NS. Some clients had still not come to terms with their condition (Yau et al., 2004), and so anger, depression and/or putting life on hold until a cure could be found inspired contemplation of nothing other than a scientific cure that would enable them to walk again. Most, however, had never even considered holiday-taking because, unstimulated and uninformed in their cocooned and increasingly-isolated worlds, they passively accepted their ‘lot’ as a severely-disabled person to remain outside mainstream society and, consequentially, tourism. Both responses illustrate the power of the metanarratives of disability circulating in society that represent a disabled person either as a hero overcoming disability to walking again or, without thus cure, as a victim doomed to a wretched life (Smith & Sparkes, 2005, 2008b).

7.2.1 Undisclosed desire for holidays

Although virtually no client had ever openly articulated a desire to take a holiday, this was often not due to lack of interest. Apart from the practical issues of resources and accessibility, a lack of belief and confidence prevented them from acting on their instincts. Again, this reflected the notion of the dominant narrative of disability which inferred that life with a disability was practically over, ruined and even useless (Smith & Sparkes, 2005, 2008ba) and thus they had resigned themselves to a joyless, uneventful life without holidays. In response to research
question 2b of this study, therefore, this dominant narrative is, in part, responsible for inhibiting clients’ participation as they bought into the notion that holidays could not be part of their world as Alex’s comment reveals: ‘the tourism market is for people who are working and walking, and that’s not me’.

Nevertheless, when stimulated through dialogue to think about holidays (Friere, 1972a), all six of the study’s non-travellers declared a desire, or at least a former desire, to take a holiday even if, ultimately, they considered it impossible or had been later discouraged by bad experiences on days out or during bygone holidays as a disabled child. In fact, some openly announced their desire, even if peppered by mention of what they considered to be insurmountable barriers: ‘I’d love, really love to go on vacation, but it’s impossible; I don’t have the money’ (Susan). Others, however, with the effects of the limitations of their impairment instilled in them by the dominant medical discourse of disability, believed that holidays were impossible for them. Thus they inferred that it was their impairment, rather than societal structures, which prevented them from participating, as Jose implied when he looked down at his body and ventilator tube, and sighed: ‘Like this, no… Tourism, I think it’s not for me’. Yet, there may also have been an element of ‘holding back’ due to embarrassment or fear of being mocked if they dared openly admit any desire contrary to the perceived ‘wisdom’ of the dominant medical discourse relating to ‘people like them’.

Despite this apparent acceptance of their non-participation, an unarticulated or suppressed desire for a holiday was still unwittingly revealed at times in their words or actions. This both highlighted the pervasiveness of tourism to infiltrate their segregated world and also reinforced the poignancy of their resignation and exclusion from tourism. For instance, the ‘Travel Channel’ was a television favourite; details and pictures of Cardiff’s tourist attractions were searched on the Internet as soon as the city was mentioned in conversation; and, although a client insisted that holidays were not for ‘the likes of him’, his subsequent comment revealed an
indirect, yet subtle, desire for holiday-taking when he added: ‘[vacations are] just thoughts in my dreams ... when I’m on a beach in Cancun’ (Jose).

7.2.2 Cycle of ignorance regarding holidays

Clients generally suppressed their desire for holidays because they lacked confidence and were uninformed to be able to challenge the dominant narrative of disability. Reinforcing this narrative, holiday information had never been disseminated nor holiday-taking ever discussed or practised during or post their hospital rehabilitation programmes across the USA. Thus no client had any practical experience of even a day trip before being discharged from hospital and had returned to society as a newly-disabled person wholly unprepared to be able to function in a world, and a tourism industry, designed by and built for able-bodied people. Throughout rehabilitation the entire focus had been on the management of their injury and, apart from the recent introduction of art classes, NS had employed a similarly medical approach. Thus, while clients’ physical and medical requirements were well met, their psycho-social, including their tourism information needs, were not. This severely inhibited both their holiday-participation and re-integration into mainstream society as traveller Don’s remark reveals:

_I didn’t go more than two blocks from the hospital... during my rehab experience; they just didn’t prepare you for the real word as best as they should. They just prepare you to go home and stay there. They don’t really give you confidence or, like, real useful tools for getting anywhere. Travel really needs to be part of rehab as that’s part of life.... Just getting across town, how to find accessible transport....[which is] less problematic than a vacation, but if you can find an accessible vehicle across town, you can take it across the States._

Attendants inadvertently contributed to the cycle of ignorance as they too had been influenced by the dominant narrative and so were equally uninformed about the possibilities of travel and C-SCI. Furthermore, apart from the director, none of the current staff had any client-holiday experience. Neither had staff learned during training about accompanying a client on holiday
which, again, precluded them from lifting the veil of ignorance. Their training, like the clients’ hospital rehabilitation, had been influenced by the medical model of disability and had thus exclusively focused on the physical. Consequently, they too had never associated holidays with clients.

### 7.2.3 Paucity of role models or sharing of holiday stories

This cycle of ignorance was further maintained as the media and mainstream tourism marketing provided scant holiday information, stories or photographs related even to manual wheelchair-users. With no power wheelchair-users ever featured in any of the holiday literature or advertisements participants saw, both the media and the tourism industry perpetuated the dominant narrative and left clients bereft of role models to inspire them or challenge their mindset. This and the above section ‘cycle of ignorance’ therefore respond to research question 4 of the study relating to how stakeholders affect holiday-taking. Similar to the stakeholders of the media and tourism providers, others, such as hospital social workers, rehabilitation professionals and attendants, were equally unable to inspire or enlighten clients about the possibility of holiday-taking, or offer them any practical information or experience.

The only possible role models clients were likely to encounter were those few, rare travellers with C-SCI who were ex-clients of NS. However, the travellers seldom, if ever, had any contact with clients because, as Andrew explained: ‘I don’t stay in touch with any clients at NS as they’re all too unmotivated and their depression brought me down’. Consequently, no opportunity arose for travellers to be able to share their holiday stories and practical travel tips with non-travellers - or staff - or even to enlighten them that holiday-taking was possible. Thus, with reference to research question 5 of the study regarding practical suggestions to facilitate holiday-taking, virtually all participants proposed that ‘[holiday-taking] definitely has a place in rehab, especially providing information which is the first and vital part... ’ (Jake).
Expanding on this popular and practical suggestion, it would also be effective if any local travellers with C-SCI were invited to talk to patients, and staff, during hospital rehabilitation about their experiences of holiday-taking. Additionally, and on an even more practical level given the paucity of travellers with C-SCI and the potential impact of counter-narratives, travellers' narratives should be available, in an accessible format, as a resource during rehabilitation. Yet, rather than attach labels to the types of available narratives, which could be limiting especially as narratives are fluid and may merge or change over time (Smith & Sparkes, 2005, 2008b), the purpose of this resource would be to expand the current small repertoire of disability narratives. Newly-disabled individuals with C-SCI would then be able to draw upon different or alternative notions of severe disability. They and their families could therefore choose to be informed, at their convenience, about the practicalities of holiday-taking and of other possibilities of living life with C-SCI, and may be inspired later to take a holiday or to do other things they hitherto believed impossible. Additionally, alongside this resource needs to be an accessible web-based and paper version of a 'practical guide to holiday-taking for individuals with C-SCI' offering practical holiday advice and tips, check lists, recommendations and negotiation strategies.

7.2.4 No contact or communication-channel to stimulate action

Along with most of the travellers, the more out-going non-travellers avoided being in the company of the vast majority of clients because they felt that the latter's depression, apathy and/or anger post-C-SCI could also 'bring your morale down' (Len). In stark contrast with the studies on the positive by-products of generally lower level SCI (eg Affleck & Tennen 1996; McMillen, 1999), their mood had largely developed from the devastation of finding themselves alienated from almost every activity and everyone they had known before injury. They thus appeared to have 'given up' and, as if to avoid further rejection or thoughts of how life once was, had closed themselves off from the world that had discarded them. Consequently, they had
no goals (Yau et al., 2004) or enthusiasm for holiday-taking (Hunter-Jones, 2003) or anything else.

Their self-imposed isolation also from clients in NS usually resulted in their spending each day alone lying in bed watching television, their horizons barely above windowsill level. Some explained why they chose to have such little contact with others with comments like: 'I don't mix with other clients. I'm a loner; I've always been like that' (Jose). However, Jose's assertion that he had always being 'a loner' did not correspond with the overtly sociable way he conducted himself with staff and even during interviews. It clashed also with various accounts of his pre-injury self when, even at the time of injury, he was socialising with a group of friends on the way home from a party. It would appear, therefore, that the experience of living long-term with C-SCI without a distraction even altered the natural social tendencies of the most relaxed, non-angry and non-despairing clients like Jose.

The fact that Jose and other clients preferred isolation to the mutual support and companionship of those who were in the same position, exposes the inadequacies of the professional rehabilitation response to the psychological impact of living with C-SCI. Moreover, no contact meant no communication-channel was open that could give clients the opportunity to learn from one another that most shared the same undisclosed desire for - and concerns about - holiday-taking. They might have gained strength and formed a common bond from this knowledge and, through further dialogue, managed to engage in 'consciousness-raising' followed by possible contemplation of holiday-taking and action (Freire, 1972a).

'Consciousness-raising' had naturally occurred during the interviews with several non-travellers and, as such, responds to research question 2a of the study relating to factors which facilitate holiday-taking for individuals with C-SCI. Having first been first stimulated by general discussions of holidays, a number of non-travellers, unprompted and unexpectedly, declared an
interest in or intent to travel. Moreover, just months after his interview, the only severely-disabled participant of the pilot study took his first ever flight and holiday abroad. Equally, inadvertent ‘consciousness-raising’ had taken place for staff on the occasions they had been present during non-travellers’ interviews, and had listened, for the first time, to clients talking about their lives, struggles, desires and travel goals. Unprompted, staff felt moved to offer there and then to accompany them on holiday. A number of experienced travellers also began to reconsider their common fears of accessibility barriers abroad after having listened to and discussed various travel stories. By the end of their interviews, some also wished to investigate, for the first time, the possibility of travelling overseas.

For virtually all other clients, however, both an acute lack of holiday information and the absence of stimulation and consciousness-raising from dialogue with others, meant that the cycle of ignorance which fuelled fear of holiday-taking, remained unchanged and unchallenged. Furthermore, with their only resource being themselves and their experience of non-holiday-taking, clients held many misinformed views. For instance, Ralf explained that: ‘most quads don’t think they can fly, especially people on vents’. Such misinformation was echoed by family, friends and staff alike, and even a former senior nurse who had once accompanied a client on a road trip. Summing up the full cycle of ignorance with regard to air travel, traveller Don explained:

*I’ve never seen an airline or a cruise commercial that has someone in a power [wheel]chair...so people expect they will be excluded just because they don’t see anybody doing it. I’ve travelled enough that I know I can do it but most people in my situation... don’t think it is very practical or possible.*

With nothing to break this cycle of ignorance, holiday-taking remained part of clients’ distant dreams; something that only other people did. Thus, with nothing to look forward to, clients were unable to contemplate their future existence as anything other than joyless, played out in the shadows of mainstream society.
7.3 Impact of non holiday-taking

The following responds to research question 3a of the study dealing with the impact of non holiday-taking on the lives of individuals with C-SCI. With no holiday experience or information to inform them about travel, or even how to manage back in the local community, the possibility of taking a holiday appeared to become more remote with each passing year following discharge from hospital. A vicious circle ensued when, according to Lynette and others, clients would tend to 'become more fearful and depressed the longer they stagnate' alone in their rooms because, without any practical skills, they never dared leave the one square mile around them to experience anything interesting and acquire new skills. Consequently, like Smith and Sparkes' (2005, 2008b) individual with high-level C-SC, many clients reported their lives post-rehabilitation to be 'a living Hell' (Chris). Thus, with nothing on the horizon to look forward to, a downward spiral of depression was often set in motion which sometimes rendered them too disenchanted to connect with others or to want to continue living.

7.3.1 Calls for assisted suicide & the impacts

With the absence of a distraction or a goal of a holiday following injury that could take their minds off their situation, clients became more insular, focussing solely on themselves and, in particular, on their injury and limitations. As a result, they became more anxious and depressed about the 'hopelessness' of their situation, developing overly negative, with-drawn, fearful and depressed ways, often culminating in daily pleas for assisted suicide. Some also became more demanding and self-centred, showing little regard for attendants. A combination of their anti-social behaviour and constant demands for assistance with suicide eventually took a heavy toll on staff's morale and on the director's ability to retain staff. Attendants who did not resign nevertheless protected themselves from clients' constant demand for suicide by carrying out their practical duties with as little social interaction with clients as possible. Consequently, clients' social re-adjustment was further affected as attendants were often their only contact
with the outside world and also, in the absence of friends and families, their only potential travel companions.

7.3.2 Increasing fear of ‘the unfamiliar’

As traveller Ralf explained:

*Being in a situation where you’re dependent on a mechanical device, fear is fairly constant. Being dependent on equipment, you get used to your own environment and staying in another environment, you wonder if you are going to be able to move round, get in and out and whether things are going to be accessible.*

With no knowledge of the skills required to manage in the world outside, clients’ physical dependency had, as Hunter-Jones (2003, 2004) revealed with cancer patients, developed over time into a deep psychological dependency on both the familiar person (attendant) and place (NS) which tended to deepen the longer they remained non travel-active. They feared distancing themselves from the local specialist hospital, their familiar attendants and local ventilator specialists no matter how accessible or skilled ‘the unfamiliar’ equivalents elsewhere might be in reality. With nothing other than their impairment to occupy their minds, and on which others around them had exclusively focused since their injury, the fear of ill-health was so great that whenever health was, or nearly was, affected on day trips, non-travellers were put off further outings for a long time afterwards, or even stopped going out altogether.

In an attempt to alert patients to, and perhaps combat, this potential decline into total social isolation, non-travellers’ stories also need to be included as a resource and made available during hospital rehabilitation alongside the travellers’ stories discussed earlier. By detailing their stories, patients and staff, and friends and family, could discover the unspoken yet common desire for, as well as fear of, holiday-taking many individuals with C-SCI have. This must at least be explored and, hopefully, resolved before the end of rehabilitation because, as outlined earlier, if clients leave hospital without discussion of this or the practical skills needed,
they continue to believe that holiday-taking can never be for them and often become too frightened to venture out anywhere. Consequently, they can not see how they might improve their lives or enjoy themselves, even momentarily, ever again. For many, therefore, existing like this becomes pointless.

The practical experience of both planning and taking, with support, a short, local, one-off holiday by road would help resolve these issues. Thus a holiday break needs to be government-funded and incorporated into the latter stages of hospital rehabilitation programmes - ‘[just] a short jaunt... to get quads used to knowing what they can do. If they don’t know what to do, it’s all too difficult’ (Ralf). Likewise, on reflection, Jake commented: ‘It would have been nice to take a short trip during rehab, towards the end maybe, just to be certain I could do it.’

7.4 Impact of holiday-taking

Although only a total of six individuals with C-SCI had any holiday experience, they nevertheless demonstrated that holiday-taking was possible, if problematic, even for those with the very highest level of C-SCI. Furthermore, experienced travellers relied on holidays to provide them with a means of temporary escape (Shaw & Coles, 2003) from the limitations, monotony and difficulty of the daily grind of life with a severe disability, and emphasised that: ‘Vacations are more important now since becoming disabled as it’s a struggle... day to day, and it’s important to have something to look forward to’ (Jake). Holidays thus also brought release from the boredom of their often empty social worlds by giving them something on the horizon to look forward to in an existence that consisted of little more than sitting around all day and ‘just watching the sun set’ (Jake) and, quite possibly, setting on their lives too. Holidays therefore provided a goal to work towards, something to occupy their time as they became engaged in choosing and planning their next trip. Above all, however, holidays allowed them to escape the prison of their four walls and to reconnect with the world outside, to feel ‘alive’
again and part of mainstream society how ever barrier-riddled it might be. Later, they also provided them with precious, ‘feel-good’ memories and stories to share with others (Long et al, 2007; McCabe, 2009) for years afterwards.

Yet, given the cycle of ignorance surrounding holidays, most travellers’ first holiday experiences were initiated by family members (Yau et al., 2004) or by former or new partners. Exceptionally, the travellers with the highest injury, C1, Daniel and John, came up with the idea of taking a holiday themselves. Admittedly, they needed to be first challenged to discuss with one another something that could lift their spirits and take away their every waking-thought from suicide. Nevertheless, the choice of a holiday to enhance their mood was not influenced by anyone else because, as illustrated earlier, staff had never associated holiday-taking with them. Once again, this demonstrates the power of consciousness-raising through dialogue (Friere, 1972a) and how holidays were regarded by severely-disabled and non-disabled people alike in the same light - as a vehicle for pleasure, escape and relief (McCabe, 2009). Importantly, holiday-taking was also perceived by both these clients to be a possible life-line, a glimmer of hope, during their darkest days of despair post-injury.

Finally, as evidenced in previous work with cancer patients (Hunter-Jones, 2004) and low-income families (Long et al., 2006; Quinn et al., 2006; McCabe, 2009; Minnaert et al., 2009), holidays were perceived to have had a positive effect on the psycho-social well-being of the two travellers which benefited both them and those around them. In fact, holiday-taking proved to be a catalyst for positive change on many levels for all the travellers. Thus, in response to research question 3a of the study about the impact of holiday-taking for individuals with C-SCI, details of the changes and impacts are presented next.
7.4.1 Interaction improvement between staff and clients

On holiday, away from the usual nurse-patient environment, both clients and attendants got to know the other as a person rather than just as someone who gave or received assistance. Stimulated and distracted by everything around them, and no longer preoccupied with their predicament but with enjoying themselves, clients finally relaxed. For the first time since injury they were able to feel content and ‘normal’ again and thoughts of suicide began to fade. As they became happier, and witnessed how staff did everything within their power to give them a good time on holiday, a more considerate, thoughtful and communicative side to their personalities emerged. With their attention no longer centred on their impairment, they became less self-concerned and self-centred and, for the first time, more open to external things and sensitive to other people’s feelings and needs. Consequently, they became more thoughtful towards staff as nurse Liv discovered, post-holiday, on a hospital visit with John. Apparently, she had not had time to visit the Ladies before leaving for the hospital. However, on arrival at the hospital she found that:

[John] took control, was helping me, and got another nurse at the hospital to wait with him while I went to the bathroom. So it was not always us nurses looking after them like little kids.

Equally, holidays acted as a vehicle for changing staff’s attitude, and their largely medical approach, towards clients as they had witnessed, first-hand, the many barriers clients faced outside their accessible, medical world of NS. An appreciation of the social model of disability thus developed and was evident by comments such as: ‘...getting away... lifts them so much that it’s such a pity it’s so hard, in so many ways, and especially financially hard, for them to do so’ (nurse Liv). Holidays thus promoted genuine mutual empathy and respect and resulted in better working-relationships so that the atmosphere of living and working at NS dramatically improved. With the overall improvement in the environment, the director also found it easier to retain staff.
7.4.2 Motivation to (re)discover other interests

Following the success of the holiday, better relationships were also forged with those few parents remaining in clients' lives as they then felt more confident to take their relative out for the day. Moreover, for the first time since injury, clients were motivated to take an interest in a range of activities in and outside NS. Thus, as they became occupied in various pursuits, their social worlds expanded.

Even meal-times improved post-holiday at NS as John, a former chef and one of the travellers with C1, volunteered to take responsibility for managing the catering with assistance from the housekeepers. The other, Daniel, took up fishing with a rod attached to his cap and later moved to his own apartment in the community with twenty-four hour assistance. There he developed a number of romantic liaisons with his attendants and took further holidays despite warnings from his hospital rehabilitation medical experts that he would survive less than a year outside a specialist hospital. Had he never dared risk leaving the hospital, their medical model approach would have condemned him to 'living' the rest of his life in a hospital ward or, perhaps, as many clients had done before coming to NS, in a nursing home where most of the elderly residents had dementia.

7.4.3 Raison d'être

The most remarkable changes in attitude and life-style were, once again, with the two travellers with C1. After the holiday, a new-found raison d'être emerged for them as, finally, they had 'proved to themselves they could have a good time as a quad and could do something that they hadn't even thought possible (nurse Liv). A direct consequence of this realisation that it was actually possible to enjoy themselves as a disabled person was a desire to remain alive as neither traveller ever spoke of suicide again. For the first time since injury, the experience of
holiday-taking had thus given them hope for the future as a severely-disabled person simply because 'they [had] learned that it is still possible to enjoy life, even as a CI' (NS director).

Given the profound change in the travellers with CI, it is could be argued that, even within the category of severe disability, those with the most severe disabilities, who are also often the most socially-isolated and despairing of their situation, might stand to benefit most from holiday-participation. Within a disability context, this confirms what Hughes (1991) hypothesised generally, that the psycho-social benefits are likely to be more deeply-felt by those who face the greatest obstacles to holiday-taking. Finally, holiday-taking may not only represent a vehicle, however temporary, of transcending illness (Hunter-Jones, 2003, 2004), but also of the most severe disability as Don revealed post-trip when he concluded: 'I felt slightly less disabled knowing I could travel'.

7.4.4 Life-time benefits

Earlier research evidenced short to medium benefits of holiday-taking for those usually excluded from participation (Quinn et al., 2006; Minnaert et al., 2009). Some of the study's travellers experienced similar feelings of enhanced well-being for months afterwards, and many, also, for years afterwards. Once again, most remarkable were the long-term benefits experienced by those with the highest injury as Daniel and John permanently changed their approach to life. Post-holiday, they chose to start 'living' as a disabled person rather than merely continuing to 'exist' as one. The benefits of holidaying were therefore found to extend over decades, or a life-time, because, as NS director remarked over twenty years later about the one surviving traveller with CI: 'The change in Daniel has lasted until today'.
7.4.5 (Re)entering the mainstream

Like Daniel, but in contrast with most clients at NS, the other five travellers also returned to living in the community and, to a greater or lesser extent, all re-entered mainstream society. Demonstrating a positive outlook and ability to 're-engage' with life post-holiday, all travellers continued taking holidays whenever possible and, like the travellers with C1, developed new or adjusted former hobbies, from coaching disabled sport and going to the cinema, to taking an interest in cooking and car drag-racing. Five of the six travellers bought their own homes; the same number met several new partners; two became engaged to be married and one had re-married. Furthermore, two were occupied with voluntary work either with recently-injured individuals with C-SCI or with disabled sports people, and had one embarked on a degree at a local university.

Only one traveller, however, was in employment, although that was in NS, not mainstream employment. Thus, not even one of these exceptionally determined and pro-active travellers, who had succeeded against all odds in other mainstream areas, could find employment in the wider community. This confirmed that, even amongst the disabled population, the lack of access to paid employment was particularly acute for severely-disabled people which naturally affected clients' ability to afford holidays (Darcy, 2002). Thus, despite such dramatic, life-changing and life-affirming triumphs post-holiday, this is a poignant reminder that these travellers remain very rare exceptions to the rule because, with insufficient financial means and a lack of access to paid employment, most individuals with C-SCI are never able to participate in holidays. In response to research questions 2b and 2c of the study, an in-depth discussion of this and other issues which inhibit or exclude individuals with C-SCI from holiday-participation will follow in part 2 of this chapter.
CHAPTER SEVEN (Part 2)

THEMES, ISSUES & PRACTICAL SUGGESTIONS

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CHAPTER SEVEN (Part 2)

7.5 Limited resources

One of the most frequently-cited and significant holiday barriers reported by the study’s participants was limited financial means. Although earlier research reported holiday-taking to be financially prohibitive for many disabled people at an estimated extra cost of between 30% and 200% (Cameron, 2003) - and even higher for those with severe disabilities (Burnett & Bender, 2001; Darcy, 2002) - little detail or explanation of this phenomenon has been offered. The following hopes to redress this.

7.5.1 Medical insurance

Apart from the already high cost of a holiday for someone on insufficient state benefits, the two most insurmountable, yet essential expenses, were attendant costs (Darcy, 2002; Burnett & Bender, 2001) and travel/medical insurance (Hunter-Jones, 2003). With the state of clients’ health likely to deteriorate rapidly if, for example, skin became damaged during transit, most non-travellers were concerned about and not willing to risk needing, but not being able to afford, to go into hospital for treatment:

*I don’t have the money for national medical insurance.... Our biggest problem is medical insurance and we wouldn’t dare go anywhere without it.*

(Susan)

7.5.2 Higher levels of C-SCI, greater number of attendants required

Likewise, attendant costs affected clients’ ability to take holidays, or even day trips, as the attendants’ hourly or daily work rates needed to be paid by the client as did the attendant’s travel and other general expenses. While existing research (eg, Bender & Baker, 2001; Darcy, 2002) highlights the extra costs involved for those with severe disabilities who require extra equipment and ‘an’ attendant, a minimum of three attendants were needed to accompany a ventilator-dependent individual with C-SCI, which increased the cost three-fold. The necessity
of this three-to-one ratio was illustrated when a fire broke out at a hotel and the client’s wheelchair, with attached ventilator, had to be abandoned in order for staff to carry him down sixteen flights of stairs. Two carried him sitting on their locked-together forearms leaning against them, whilst the third walked backwards manually pumping air into his lungs. He would not have survived without the assistance of these three trained attendants as he could never have been carried over a fire-fighter’s shoulder.

Apart from the substantial cost of the daily work rates of three attendants, on top of their accommodation, meals, sight-seeing and entertainment, the cost of air travel was completely prohibitive. A total of five airline tickets needed to be purchased by one ventilator-dependent client: three for the three attendants; one for the client and another for the ventilator since staff needed immediate access to its controls in an emergency. Thus, the overall cost for individuals on state benefits rendered holiday-taking virtually impossible for those with the highest levels of C-SCI. Consequently, holiday-taking at this level had only been possible for the two millionaire travellers (both C2) and the C1 client who had been accompanied by a team of attendants, paid for by NS as a one-off gesture when the company first opened. All of the low-income travellers were, or had become, non ventilator-dependent before their first holiday, and thus incurred less expense by travelling with one attendant or a partner who paid for or shared the cost of the holiday.

7.5.3 Social tourism policies regarding attendants

It would appear that even the laudable practice of social tourism has failed to appreciate the extra costs incurred by very severely-disabled tourists. No doubt influenced by existent tourism research focused predominantly on tourists with mild to moderate disabilities, its reduced entrance fees to attractions appear to assume that all disabled tourists either arrive alone or are accompanied by only one attendant who pays for him/herself. Belgium’s otherwise excellent
social tourism policy offers a prime example of this oversight. According to Minnaert (2009), a ticket for Antwerp Zoo is available at a discount of 5 instead of 17 euros for a tourist from a low-income group - with the same discount for an accompanying attendant - making it a maximum of ten euros to be shared or paid by one person. However, an individual with high-level C-CI requiring three attendants pays a total of twenty euros to purchase four discounted tickets amounting to an extra three euros over the original, non-discounted price. Thus, the most severely-disabled tourists are financially disadvantaged even within the 'inclusive' remit of social tourism.

7.5.4 Extra teams of attendants

Whenever travellers wished to take a holiday of a week or longer, more complicated travel arrangements and greater travel costs were incurred on top of the costs outlined above. This was because holiday plans, dates and length of stays were largely dictated by the availability of attendants. As Andrew explained: ‘Most of my vacations are three, maybe four, days at the most...because my nurses have families,... so they’re not going to want to be away from their kids’. Spontaneity and choice were therefore virtually non-existent for travellers. To take a week or a fortnight’s holiday, a new team of nurses needed to be flown in at the end of the week or even every three to four days. This added substantially to the cost of the overall holiday, which only the millionaire traveller who travelled by air was able to afford.

However, extra teams of attendants brought this traveller extra stress and time spent planning and making additional travel arrangements for the different teams to be flown in and out. Although attendants could be hired from an agency at many city destinations, most travellers and non-travellers alike naturally felt more comfortable entrusting their specialist care to familiar, experienced attendants. Moreover, like most people, they would not choose to be on
holiday with complete strangers as, particularly for ventilator-dependent travellers, this would entail being in their company twenty-four hours a day.

7.5.5 Extra equipment and overnight stays

Whilst the responsibility for overseeing the packing and the transportation of usually three large cases - and six or more boxes of essential equipment - presented a major obstacle to participation for non-travellers, for travellers, it represented yet another extra cost and additional burden that did not apply to manual wheelchair-users. With such a large amount of essential equipment to organise, something, such as a portable ramp, transfer board, sling-hoist, suction machine, battery recharger, egg-crate mattress or even essential medicines, was often forgotten.

Despite a ‘double-checking system’ to ensure everything got packed, experience had taught travellers that the amount of luggage to load into the vehicle was so great that invariably something got accidentally left behind in the garage or house. Yet, unlike non-travellers, Don concluded that, if transporting and ‘forgetting stuff is something you’re going to worry about, you’re going to have to stay home’. Nevertheless, forgetting equipment added once again to the holiday cost and complication if a replacement could be located and hired at the destination. One simple solution, perhaps, would be to have a second person check the first person’s ‘double-checking system’ for not just the contents, but also for the actual placing of each item in the vehicle. Further costs again were incurred when some airlines charged extra for carrying travellers’ equipment and even wheelchairs which, ironically, were invariably damaged or broken in transit, leading to a host of subsequent barriers and problems discussed later. Additionally, with their wheelchairs in the luggage-hold, travellers were on occasions also charged for the loan of an airport wheelchair to get them onto the aeroplane.
Finally, any trip involving fewer than two nights away in the same accommodation was just not practical as both travellers and attendants would 'be too tired if ... constantly moving' (Jake) since the amount of packing, unpacking, sorting and repacking of equipment required was, each time, reminiscent of 'moving home' (nurse Amy). However, increasing the number of overnight stays to ease the burden on the way to and from the holiday destination added, once again, to the financial burden of the holiday which few clients could afford without financial assistance from partners or access to employment.

7.5.6 Lack of access to paid employment

Despite the many intellectual/sedentary jobs made possible by advances in computer technology, to which severely-disabled and renowned British university professor and physicist, Stephen Hawkins, is testament, the status quo which excluded clients from mainstream employment – and thus the ability to afford holidays - was unchallenged. No participant, including staff, referred to a lack of access to paid employment as a financial barrier (Darcy, 2002; Barnes et al., 2005) – or even a social barrier which denied them the opportunity to build a social network of contacts with whom to travel. Most appeared to believe that no other choice existed other than to 'make do' with insufficient (state) 'handouts' reminiscent of the old charity view of disability.

Moreover, by focusing solely on the problem of insufficient state benefits to fund a holiday, participants appeared to have absorbed the dominant discourse that implied employment was the sole domain of able-bodied people. Confirmation of this notion occurred when it was inferred by comments made by members of the public waiting for a traveller to enter the bus on a ramp: 'People like that shouldn't be allowed to use the bus in rush hour. I've got to get to work' (Lynette). Such personal prejudice was so deeply-rooted and even more difficult to combat than institutional prejudice (Daruwalla & Darcy, 2005) that it was prevalent even
amongst some individuals working in professional environments like NS, dedicated to disabled people.

Thus, although NS director had been proactive in employing a former client, Don, as a computer programmer and two manual wheelchair-users as receptionists, a number of her office staff voiced objections regarding the receptionists. With regard to Don also, staff were observed rolling their eyes and commenting: 'wish we could sleep at work!' if he had a few moments' shut-eye in front of his computer. They appeared, however, neither to appreciate that Don always stayed later to finish his work, nor the extra time and effort it took him both to be ready for and also to get to and from work, or even the strain placed on his neck and mouth as he typed all day with a mouth-stick.

Likewise, personal prejudice was displayed by a NS manager who refused an ex-client’s request to undertake an unpaid work-placement at NS, without which she was unable to finish her sociology degree. Equally, the outcome reflected a disregard for widening participation on the part of the local university in not providing an accessible curriculum. Tutors could have either provided (in-house) work-placements for marginalised students, and/or assisted in the face of work-placement discrimination, or even provided an alternative piece of work to the work-placement so that students could return to complete their degrees and, potentially, find employment. Above all, however, the incident confirms how powerful individual prejudice towards severely-disabled people is when, even those in senior positions working for a company whose principle goal is to assist severely-disabled people’s integration into the community, were not prepared to consider ex-clients even for unpaid work.

Such personal prejudice, which translates into ‘why would “people like that” want to work’ and ‘how can they work with such a severe disability?’ tended to reflect public attitude even to living with C-SCI as, after a film about a female who sustains a C-SCI, Lynette heard people
say: 'That [suicide] was the best thing for her. The best decision because who could imagine wanting to live like that...'. This attitude negatively influenced clients' views on everything, holiday-taking included and thus, arguably, public opinion on the need to increase state funds to enable those with C-SCI to finance a holiday. Given that negative personal attitudes towards disabled people are more difficult to change than societal ones (Daruwalla & Darcy, 2005), only when more individuals with C-SCI are seen in public spaces and interacting with the public, will such views, and the exclusion of disabled people from the workplace, ever decrease so that they are able to afford the very high costs of their holidays.

Moreover, government policies on social tourism and state benefits need to be revised so that every unemployed disabled person has the ability to afford an annual holiday, which for individuals with high-level C-SCI requires additional resources to cover: the cost of national and some overseas medical and travel insurance; the extra charge by some airlines for the loan of an airport wheelchair as well as transporting wheelchairs and essential equipment; the cost of larger hotel rooms to accommodate power wheelchairs; and the full costs of travelling with the number of attendants required in the absence of personal travel companions.

7.6 Travel companions

Good social interaction ranked highly in the overall enjoyment and success of travellers' holidays and their desire to take further holidays. The significance of this social aspect of holiday-taking for individuals with C-SCI, who generally experience social exclusion, cannot be underestimated. Thus, along with the initial motivation, financial assistance and confidence to take a holiday provided mostly by loved ones (Yau et al., 2004), being in the company of a genuine travel companion, particularly a friend (Hunter-Jones, 2004) or partner trained to assist, enhanced the overall atmosphere, fun and enjoyment of the holiday (Yau et al., 2004):
[When] I went with...a trained friend, [it was] more successful because we were there for the same reason; it’s more like ‘palling around’ than having someone there who’s your employee. It helps psychologically'.

(Jake)

Likewise, another traveller revealed that his favourite holiday was at the invitation of one of his attendants to accompany her on a trip home to visit family in Mexico. Even the greater number of accessibility issues there appeared to pale into insignificance because of the warm welcome, camaraderie and sheer determination to overcome accessibility barriers of his Mexican hosts. Equally important was the fact that he and the attendant had chosen to be in one another’s company on holiday. Having been prepared to take a risk with Mexico, he subsequently discovered that the feeling of being so genuinely welcomed and included by people in general there more than compensated for the increased accessibility issues encountered. Ironically, however, non-travellers were unlikely to discover such warm interaction with people as their fear of accessibility barriers prevented them from taking even relatively local trips away.

7.6.1 Lack of genuine travel companions

For most clients, ‘real’ travel companions were virtually non-existent whether initially to inspire them to travel or to accompany them, as around 95% of clients had little or no contact with family, partners or former friends. The loss of contact with family members appeared to be greater for clients from white and African-American backgrounds than from Oriental, Hispanic and Middle-Eastern cultures, however. Yet, even amongst the latter three groups, family contact gradually became reduced over the years. Thus, with fewer visits made to NS each year, relatives virtually never became travel companions of any. In fact, no close contacts remained in most clients’ lives, so if they wished to travel, they needed to rely solely on attendants for travel companions. However, attendants were often not their preferred choice; and attendants were not always ‘willing travel companions’ either.
7.6.2 Strained relationships with attendants

Finding attendants willing to accompany clients on holiday could be problematic, as tension and a general lack of social interaction between them often inspired neither to want to be in the company of the other outside NS. As outlined earlier, many client-attendant working-relationships were strained largely due to clients’ depression as a result of their fear and/or lack of acceptance of their highly-dependent condition, and subsequent rejection by loved ones, and also their pleas for assisted suicide. Many clients took out their frustrations on their attendants; some verbally abused them, others spat in their faces or became highly-controlling, and some completely ignored them. Yet, notwithstanding many clients’ uncompromising and negative behaviour to attendants, taking ‘pot luck’ with an unfamiliar attendant from an agency, who might not have the same skills or experience, was generally not an option for them or even most travellers.

7.6.3 Lack of social skills

Even on the rare, complimentary day trip arranged through contacts of attendants, clients often exhibited self-centred, uncompromising ways towards accompanying attendants. For instance, unlike travellers, they rarely took attendants’ feelings or wishes into consideration on any day out. Their attitude towards attendants was generally not like that of a travel companion but of an employer as: ‘[attendants] have to be hard-working and willing to fall in with me as it is my day out - and I’m paying for it’ (Maria).

One client cut off all contact with a member of staff on return from what she perceived to be an unsuccessful day trip because the staff member had refused to use the noisy saliva-suction machine on her in a crowded public restaurant. Arguably, following her C-SCI as a very young child, and thus her early exclusion from mainstream society and then from her family, a lack of opportunity to acquire appropriate social skills (Smith, 1987), and consideration for others,
resulted in her clashing with the attendant. Consequently, she declared that she would never go on a day trip again, and she has kept to it, confirming what Israeli (2002) suggested, that even one negative experience for disabled people could result in complete withdrawal from any further participation in holidays or day trips.

Yet this incident also arose as a result of other factors, not least a lack of resources. Had the client been able to afford to pay for her own attendants to accompany her on this day out, the situation might not have arisen. Even before the incident in the restaurant, the client had become disgruntled. She resented being treated like a child on a school-outing, forced to stay in a group of other clients all day as too few attendants were in attendance to accompany each of them individually. Additionally, she resented not being free to choose what she wanted to do and where and when she wanted eat on this very rare day out. Given also that most clients avoided being in one another's company at NS, she no doubt resented being forced to stay together and became increasingly sensitive to people's stares, as any individual, unwanted public attention she received only intensified when she was part of a group.

Another non-traveller who attempted to exercise some means of control in her otherwise powerless existence, would not go out if she could not choose the attendant to accompany her. It transpired that this attendant was the only one with whom she remained on 'speaking terms' but, despite having her request granted, the client showed little regard or consideration for the attendant. No social interaction or any rapport between the two was evident on return from a local shopping trip as the client ‘wheeled’ ahead while the attendant followed silently behind carrying the client’s bags and blankets. Thus, given the way some clients treated staff at NS and on local day trips, attendants were generally less inclined to accompany them on holidays.
7.6.4 Acknowledgment of attendants' wishes and needs

In contrast, all travellers made a conscious effort to accommodate their attendants' tastes and wishes on holiday. As Andrew explained: 'we'll catch a show in Vegas because I know some nurses don't like gambling; or if someone wants to go shopping, I'll just hang out with them - it's a compromise'. All travellers had, however, prior to injury - and some post-injury also - experienced family life and/or personal relationships, mainstream education and/or employment as well as a variety of leisure activities, including tourism. All the male travellers had also met new partners, and some had maintained contact with their families as well. Consequently, like the female traveller who lived with her teenage daughter, they possessed good interpersonal skills and an understanding that holiday success depended as much upon compromise and good interpersonal skills as on ramps or lifts to access the built environment.

Thus, besides displaying consideration and respect for attendants or anyone with whom they were in communication, travellers exhibited flexibility, compromise and sensitivity towards travel companions whether they were family members, friends or paid attendants. One traveller, for example, had bought an accessible mobile home for holidays in the hope of eliminating the countless barriers he had experienced with airlines and hotels. Although the mobile home was, from his perspective, by far the less stressful holiday option, he soon sold it when he realised that his partner had no holiday herself in it as she not only had to pack, sort and drive the vehicle, but also shop, cook, clean, prepare the beds and manage his care twenty-four hours a day, all in very a confined space. Thus, compromise and sensitivity towards travel companions and their needs were crucial so that they equally enjoyed the holiday which made for a good atmosphere and which, in turn, secured their company on future holidays.

7.6.5 Age at time of injury/disease affects social skills

The non-travellers who displayed the most inconsiderate and uncompromising attitudes towards attendants had either been injured as very young children or had developed the condition
through disease at or near birth. Contrary to Parker et al.'s (2007) findings relating to similar individuals with general disabilities whose longer experience of disability meant they were the most frequent travellers, these non-travellers were the most unlikely to take holidays of all clients. Unlike the travellers, these individuals could not recall being part of a family or mainstream society. Acquiring appropriate interpersonal skills to manage trips (Smith, 1987; Yau et al., 2004) thus proved more difficult for them as they had spent virtually all their lives in institutions. They therefore had never been exposed to the 'niceties' or subtleties of social interaction in order to be able to build any social networks or establish non-problematic relationships with attendants with whom to travel.

Moreover, being, or feeling, rejected because of their condition subtly reinforced the medical model and the notion that their impairment was the full sum of them as human beings. Thus, issues to do with familial abandonment appeared to continue to affect them and the realisation of their aspirations, holiday-taking included. For some, the feeling of not 'belonging' was so powerful that it appeared to affect their judgement in social situations and their ability to connect with attendants or other clients. As such, they were perceived by those around them as 'difficult' or too needy and, consequently, they were unable to develop a social support network without which, as Yau et al. (2004) suggested, holidays for disabled people were practically impossible. Seeking, yet not knowing how to nurture, friendship, these clients tended to frighten off staff and others with their demanding ways, 'unusual behaviour' or requests for close family ties with them. In reaction to other people's generally negative response to this, they withdrew into themselves, and socially isolated themselves further by rejecting most staff and clients around them.

To counter the development of such difficult relationships with attendants, psychological support needs be available during rehabilitation specifically to deal with potential family breakdown and abandonment; support should also extend, in the initial stages, to family
members so that they can learn how to cope with their relative’s new situation before family breakdown is irreconcilable. In addition, patients must be given support during rehabilitation to acquire, or hone, the social and communication skills needed to facilitate good working-relationships with attendants on whom they are dependent in daily life and on holiday in the absence of genuine travel companions.

7.6.6 New partners as travel companions

In contrast with the more senior men with SCI in Creek et al.’s (1989) study who were the most dissatisfied with their lives, clients in their ‘mid years’ seemed the most agitated by theirs. As such, many were eager to seek new partners to fill the post-injury void of having lost, at once, their spouses, families, careers, homes, social contacts and leisure activities. Since NS staff were frequently clients’ only social contacts, any relationships formed tended to be with staff who, in turn, became their travel companions. Although these relationships were often short-lived, NS’s strict code of conduct ensured clients suffered neither the emotional nor the physical abuse, or the general or financial deception, that some individuals had experienced in relationships with their private staff prior to or post their stay at NS. However, just as disabled academics (eg, Lonsdale, Oliver, Zola) noted of disabled people generally during and post rehabilitation, the relationships formed at NS were exclusively between female staff and male clients. This had repercussions for females and their ability to take holidays.

7.6.7 Fewer holiday opportunities for females

The claim that severely-disabled females are more likely to be single or divorced than their male counterparts (Burnett & Bender, 2001), was confirmed by the acute lack of partners as travel companions for female clients compared with male clients or the pilot study’s female manual wheelchair-user who was married. Although Susan and Maria’s narratives, and observations of and conversations with other female clients, all illustrated an interest in the opposite sex, no
female client had ever, in the forty years of NS director’s career, formed a relationship with a male member of staff or any man outside NS.

As indicated above, the reason why various male clients had found new partners was that they had formed a relationship with either an attendant, nurse or house-keeper, the majority of whom at NS were female. However, as there were also numerous male nurses and attendants, as well as others male employees at NS, the lack of relationships with female clients could signify that, culturally, many men do not see themselves as ‘carers’ in their personal relationships. Possibly, due to genes also, many men appear to place greater initial importance on the physical/sexual attributes of potential partners and so, according to Lonsdale (1992), disabled women are overlooked as they are generally perceived as asexual and thus, it would appear, the more physically-disabled they are, the more asexual and invisible they become. Whatever the case may be, ‘factors’ certainly conspired over a forty-year period to place female clients at a significant disadvantage in being able to find a partner with whom they might also take holidays and, importantly, whose presence would enhance the overall holiday experience.

7.6.8 Additional holiday costs and anxiety for females

Female clients generally faced a considerably greater number of barriers to holiday-participation than their male counterparts or less disabled females. With no partner, their inadequate state benefits and a lack of access to employment (Darcy, 2002) could not be compensated for by the financial contribution of a new partner as it had been for the low-income male travellers. Their partners made travel possible either by paying for or contributing to the cost of the holiday and also assisting with daily tasks to reduce the number of the three paid attendants required. The absence of partners thus excluded female clients from holiday-taking or had significant financial repercussions even for female travellers like Lynette with the lowest level of C-SCI. Fortunately, at C6/7, she had been able to travel with only one attendant. Yet, with no partner
to contribute to the overall cost of the holiday, she was still paying years later for an overseas holiday she had taken with a hired agency-attendant.

To keep the cost of the holiday down, Lynette had shared a hotel room with the attendant. The mere thought of sharing with a total stranger had, however, caused her considerable stress and anxiety long before the holiday, rather than, as Gilbert and Abdullah (2004) proposed, being able to enjoy the pre-holiday excitement and anticipation that can extend the overall pleasure of the trip and thus offer enhanced happiness (Nawijn, 2010). She had also been apprehensive about being in the company of an unfamiliar attendant twenty-four hours a day when, at home, she required only four hours of daily assistance. Despite her pre-injury passion for travel and need to get away regularly to feel ‘re-energised’ since becoming disabled, she has not been able to afford to take a holiday since.

Since culture and gender are generally considered to be socially-constructed, and thus constantly evolving as social conditions change (Henderson et al., 2005), the situation Lynette and other female clients found themselves in is considered likely to alter in due course. Yet, in relation to gender, if one accepts the nature versus nurture argument (Ridley, 2004) indicating that, largely as a the result of genes, women generally posses a far broader concept of sexual attraction than most men do, the disadvantage females with C-SCI face in finding a partner, who could then facilitate holiday-taking, would seem unlikely to change much over time. Furthermore, alongside the reduced pleasure and the extra cost and anxiety involved in holiday-taking without a partner, females would also have to cope alone with the stress and anxiety which all travellers felt during the planning stage.
7.7 Planning a holiday

As previously indicated, clients felt excluded from holiday-taking due to the lack of readily-available information suitable for power wheelchair-users in all sectors of the tourism industry (Darcy, 2002). Consequently, they found the planning of a holiday to be extremely stressful and ‘the biggest part of a vacation. You definitely have to do your homework and be organised’ (Ralf) in order to acquire as much relevant accessibility information as possible to prevent ‘all the things that could go wrong and affect your health’ (Don). Planning was thus a highly problematic and lengthy task.

In contrast to the findings related to the self-defined severely-disabled tourists of Burnett and Bender’s (2001) study, whose holidays were planned and booked by a third party, travellers always undertook these tasks themselves since they were so complicated and detailed in order to counter any risk to their delicate health, that it required specific knowledge or lived experience of C-SCI. In sharp contrast again with Burnett and Bender’s (2001) findings that the preferred holiday destination of their severely-disabled participants was the peace and quiet of the countryside, most travellers were eager to exchange their quiet, socially-isolated existence for being in ‘the thick of things’, stimulated and invigorated by as many distractions as possible around them. Moreover, given that they were such medically-vulnerable individuals and thus ever mindful of their health, they generally preferred to be near a hospital, and preferably a specialist unit, which meant staying in cities. This, in turn, increased the complexity of planning especially if they chose to locate a ‘named doctor’ in a hospital at their destination who could be given their medical history beforehand.

As power wheelchair-users, travellers were all too aware of the accessibility barriers associated with their wider wheelchairs. Consequently, they would never travel without prior knowledge of: steps or the width of door frames; dimensions of rooms, bathrooms and corridors; the height
of and clearance under beds to accommodate sling-hoists; and the number and location of
electricity sockets for life-support equipment and the charging of wheelchair batteries (Darcy,
2002). Yet, with such scant accessibility information available, and just as disabled tourists had
done in other studies (eg, Daniels et al., 2005; Eichhorn et al., 2008), travellers insisted that:
‘You always have to find out on the Internet, and call ahead before you go (Ralf) to confirm the
accuracy of the information found on the Internet. However, if individuals were not (fully)
computer-literate, or had no access to expensive, adaptive computer technology, or perhaps did
not have the aptitude to be able to conduct such detailed research on the Internet or over the
telephone, obtaining this information was highly problematic. However, without it, most would
not risk travelling anywhere.

7.7.1 Telephoning for information

Even when information was successfully obtained on the Internet, follow-up telephone calls
were essential to verify the ‘fully accessible’ claims since they usually only applied to manual
wheelchair-users. Mostly, however, calls were made to request further details not provided in
text or visible in photographs. As providers were often not familiar with the concept of ‘fully
accessible’ (Eichhorn et al., 2008), travellers needed the skills not only to query information,
but also to ask appropriate questions, recognise a lack of comprehension or detect omissions or
confusion in a service provider’s response. They also had to be able to explain their own needs
in very precise terms as, according to Don, tourism providers just:

... don’t volunteer information. You have to find out for yourself. Call the
airline, the hotel, and do a lot of checking ahead to see if it’s going to be
accessible and what their definition of accessible is.... You just call and ask
specifically. You have to be assertive; explain your past experience and
problems so that they will see what barriers there could be that they didn’t
think were barriers.

Apart from being perceptive, travellers also needed to be very persistent and determined as they
were frequently required to make countless repeat telephone calls to the same hotel or venue
because, as Amy, the partner of one traveller explained:
Jake has a sixth sense, and after talking and explaining to some one, we put the phone down and he says: 'They have no clue what I'm taking about, even if they give the impression they do'. So he calls back several times to talk to someone who does know before we go.

7.7.2 Delayed speech

Ventilator-dependent individuals' attempts to telephone for information were frequently thwarted. Just as they were drawing breath to speak, the other person would often put the telephone down believing the delay meant that there was no one on the line. Travellers persisted whenever this, or any other problem, arose with providers. They believed that when dealing with providers, 'You've just got to be understanding: be patient' (Andrew) because, in contrast with tourists with general disabilities (Bi et al., 2007; Packer et al., 2007), they viewed them as largely helpful though ignorant of C-SCI. However, non-travellers' frustration and lack of forbearance after just one or two failed attempts to telephone, generally resulted in their abandoning any further attempts to make essential telephone calls that would enable them to venture out without fear of accessibility barriers.

Notwithstanding that this communication barrier initially stemmed from clients' physical condition and was, at times, heightened also by a lack of emotional strength and determination, its emergence as an actual travel obstacle lay more, perhaps, with Tourist Information employees' lack of disability awareness. Arguably, their terminating the call early reflected an absence of effective disability training with regard to calls from customers with delayed or different speech patterns or sounds. Equally though, the incident reflects a lack of instruction and practice in making fact-finding, as well as emergency sip and puff, telephone calls during hospital rehabilitation. Thus, although this sub-section highlights delayed speech, which responds to research question 1 of the study relating to issues associated with C-SCI which affect participation, two environmental barriers ultimately eclipsed this intrinsic physical issue and prevented participation.
7.7.3 Tourism providers’ insufficient knowledge of disability

Despite travellers’ success in making telephone calls, experience had nevertheless taught them always to remain sceptical about any information they received before travel. Although this increased their stress levels, such scepticism was justified as travellers had frequently found themselves stranded at airports due inaccessible pre-booked taxis or outside pre-booked ‘accessible’ hotels that turned out to be inaccessible on arrival (Creek et al., 1989). Part of the problem was that hotel staff tended to say ‘yes’ to every accessibility query, either because they wanted to secure a hotel booking or, more often, because they and other providers genuinely could not distinguish between the needs of different wheelchair-users.

This lack of understanding of the needs of consumers with C-SCI was so widespread that it was present even amongst ‘experts’ (BASICS, 2005). For instance, hospital medics had not known how to deal with travellers and had even presumed one traveller had paraplegia and not tetraplegia. In addition, participants in both the main and pilot study had arrived at local and other destinations only to find various insurmountable physical barriers for power wheelchair-users when accessibility information had been provided by specialist agencies for disabled people. Thus, just as many experts were misguided, and had misguided others regarding C-SCI, it is perhaps not too surprising that tourism providers were unable to obtain the correct specialised knowledge needed to improve provision for severely-disabled tourists. Essentially, as disability legislation’s guidelines were, like most tourism research examining disability issues, rather general, and thus biased towards individuals with mild to moderate disabilities, little guidance was readily-available to implement change effectively.

Furthermore, since clients seldom ventured out because of the multitude of barriers they faced, providers rarely had any personal experience of consumers with C-SCI to enable them to observe, first-hand, the extent of their need or even the size and workings of their power
wheelchairs. However, even if service providers had been provided with C-SCI-relevant information, how thoroughly most would have implemented change to accommodate tourists with C-SCI remains debatable if, ultimately, individuals with C-SCI were not perceived to be high-spending consumers or ‘good for business’ given the largely negative reaction they generally received.

7.7.4 Lack of power wheelchair-specific information

Without the provision of specialised accessibility information relating specifically to severe disability, providers’ most common misconception was that all wheelchair-users belonged to one large homogenous group. Generally, they wrongly assumed, for example, that wheelchairs were all able to be tipped back to manage a step. Insurmountable accessibility barriers were thus often caused by providers simply failing to mention a small step into a room or bathroom. However, while a step might be a minor inconvenience for a manual wheelchair-user, but could be overcome, it was a complete barrier to access for a power wheelchair-user. Consequently, when a traveller arrived to find one step into his room at the pre-booked and only ‘accessible’ motel in the area, he and his attendants had nowhere else to go, so ‘all ended up sleeping in the van that night’ (Andrew). Yet, such an accessibility error was, as traveller Don explained, not just an inconvenience, but also ‘serious for your health if you get stranded somewhere overnight with no equipment’ and cannot recharge the wheelchair battery to drive the wheelchair or make weight-shifts to prevent skin sores. Accessibility issues could, therefore, have serious health implications.

7.7.5 Stress of lengthy planning process

Given the difficulty of acquiring accurate accessibility information and the impact misinformation could have on health, even experienced travellers needed between one and five months to plan a two to three day trip. Stress was therefore sustained over a considerable
period, from initial inquiries until arrival at the destination months later. Yet, heightened stress and anxiety - and even a feeling of dread - would always be felt just at the point of departure due to the risks travellers knew were involved on the journey and no guarantee of accessibility on arrival unless they had previous personal knowledge of the destination. Thus, on occasions, rather than holiday-anticipation extending the pleasure of the holiday (Gilbert & Abdullah, 2004) and thus enhancing happiness (Nawijn, 2010), 'Anxiety beforehand took away from the overall pleasure [of the vacation] as I was too nervous' (Jake).

Since travellers concurred that 'Anticipation is often worry and planning is stressful' (Jake), the two millionaire travellers, who had been able to afford to take the most holidays, had thus also planned the most holidays and, consequently, endured the most stress. However, these two travellers eventually found the difficulty and accumulative stress of planning each new holiday too much to bear. One had therefore restricted himself to the same accessible hotel in the same town, Las Vegas, for all his future holiday. The other had not planned a holiday in years. Thus, in contrast to studies of tourists with general disabilities (Yau et al., 2004), the stress and length of time involved in planning never eased with experience. This was because the planning stage of each new holiday destination was an entirely unknown entity in relation to accessibility barriers. It thus required the same lengthy, stressful process and exacting attention to detail as any previous holiday since the objective was always to counter barriers that might seriously affect health.

In contrast to taking habitual, as opposed to complex decision-making, holidays which are a common but under-reported aspect of tourist consumption, the wealthy traveller, who only ever holidayed in Las Vegas, had done so because he had become jaded by the relentless stream of accessibility barriers wherever he went. He was thus forced into involuntary habitual tourism consumer behaviour. Furthermore, in contrast with those who choose habitual holiday-taking,
there appeared to be little prospect of other holiday options available to him if he ever decided to change this pattern.

Statutory agencies of health and tourism thus need to liaise with a team of experienced individuals with C-SCI and professionals at specialist SCI units to provide the tourism industry with a more in-depth understanding of the travel needs of severely-disabled people and train service providers to respond appropriately. Furthermore, they would need to draw up a comprehensive yet easy-to-use ‘accessibility guide’ with a simple ‘one to six’ user-rating system to be applied across all sectors. Outlined within an attached key – which would have been useful, a rating of ‘six’, for example, would indicate that the establishment, facility or activities were fully accessible for power-chair-users such as those with high-level C-SCI and ventilator-dependent. These ratings would need to be included in mainstream tourism marketing and on providers’ websites to assist travel agents and disabled people with holiday-planning and booking. Finally, hospital rehabilitation units need to provide guidance and practice in using accessible computer technology and, in making telephone calls, particularly for ventilator-dependent patients. They would thus learn the skills necessary to be able acquire the correct accessibility information from service providers as well as essential information about medical facilities and a ‘named doctor’ from a hospital at their destination in case of ill health.

7.8 Ill health

Since fear of ill health away from home generally cancelled holiday-taking for non-travellers and inhibited and caused great stress during planning for travellers, distinction must be made between having a severe medical condition like C-SCI, yet still being ‘healthy’, and being in poor health due to largely avoidable common side-effects of C-SCI, such as skin sores and urinary tract infections. Of all the travellers and non-travellers at the time of interview, only the two millionaire travellers were in poor health. One was confined to bed due to a skin sore and
had been prevented from taking holidays in the past because of them. Likewise, the other had skin sores at the time of interview and, partly due to health problems, had not taken a holiday in six years. Thus, ill health prior to travel cancelled any form of holiday-taking for all travellers (Mckercher et al., 2003) because of the potentially fatal consequences of even a simple skin sore if not treated.

7.8.1 Responsibility for own healthcare management

Apart from the problems of planning and the availability of attendants, the two wealthy travellers' more frequent ill-health seriously affected their ability to take holidays. Arguably, their lack of adequate knowledge of their condition and/or their not taking responsibility for directing their own daily healthcare management contributed to such frequent health problems (Younis, 1998). All the low-income travellers warned against playing this form of 'Russian-roulette' with their health and lives. Even non-traveller Alex commented that, if 'the person isn't familiar with their own care and directing their own care, health's going to depend completely on who's with them' and that person may not be as competent as hoped. Although some travellers declared that they would never venture far from a hospital, or a specialist unit particularly on a foreign holiday, low-income travellers took a very different view. They believed the responsibility for managing health always rested with them wherever they were in the world because general medics' knowledge of C-SCI could never be guaranteed (Creek et al., 1989; BASICS, 2005). Thus, as Don explained:

*Even in the local specialist hospital here, I... have to let them know what to do - keep on at them. Specialist or general hospital, you have to be in control, manage your own situation.*

7.8.2 Knowledge of common complications

Unaware of the incompetence and thus, ironically, the potential danger to health of most general hospitals in relation to C-SCI, (Creek et al. 1989; BASIC, 2005), the predominant reason most
non-travellers chose not to travel to any country whose language they did not speak was, as Hunter-Jones (2003, 2004) suggested with cancer patients, fear of communication problems at hospitals. Yet, low income travellers ignored such language barriers since the art of persuasion and the power of their knowledge of their condition, even if articulated via an interpreter, was their true safety-net. One such traveller demonstrated his knowledge of a common complication on holiday in Mexico when he recognised that he had a urinary tract infection. As a result, he was able to instruct his non-medically trained Mexican attendant to acquire the correct antibiotics.

However, being in charge of their daily healthcare management reflected not only clients' own knowledge, capability and acceptance of personal responsibility, but also how effective their hospital rehabilitation programmes had been in developing patients' knowledge and competence to do this. Furthermore, it highlighted whether adequate time and effort had been spent in assisting patients to acquire the necessary communication skills to manage their healthcare. They needed to be able to instruct attendants clearly and precisely regarding their healthcare routine and also to explain to general hospital staff such essentials as manual evacuation of stools for which general staff had not been trained.

7.8.3 Effect of nurse-client interaction on health

Since most NS clients had never learned, nor had the desire, to take responsibility for their own healthcare management, yet generally maintained good health, other factors must explain why the two wealthy travellers tended to suffer from ill-health more frequently. Apparently, some wealthy travellers' private, unsupervised nurses, who no longer needed to retain their nursing licences for private work, tended to become less vigilant on occasions, and did not spot early signs to prevent health complications. Furthermore, some individuals with C-SCI were apt to use their multi-million dollar fortunes from insurance settlements as a subtle hold over their
private nurses. These former state nurses’ fear of losing such lucrative private employment, along with their other ‘financial perks’, often resulted in their feeling less able to insist that their boss take seriously their medical advice to prevent medical complications from occurring.

Yet, for state nurses, ‘playing mother’ could be equally problematic but, for the sake of their clients’ health, this had to be done. It was particularly difficult on holiday, however, when it could be met with even greater resistance, dampen high spirits and generally spoil the overall holiday atmosphere. Nevertheless, NS staff insisted that a client retire earlier to bed than desired during a holiday to relieve skin pressure or consume no more alcohol in case it affected medication. Such unpopular actions added to the stress and tension of accompanying a client on holiday. They also clearly conflicted with the ideology of freedom and the right to do whatever one likes on holiday away from the constraints of every day life and routine, which other disadvantaged groups had acknowledged as very important holiday benefits (McCabe, 2009).

7.8.4 High-level C-SCI, greater pressure on attendants

Being on holiday with a ventilator-dependent client brought significant personal risks to nurses’ livelihoods as nursing licences could be suspended if anything went seriously wrong and the client died. Consequently, apart from their already strained working-relationships with many clients, attendants were often reluctant to shoulder the extra responsibility of being away from their working-environment with such medically-vulnerable individuals. Finding travel companions was thus even more problematic for those with the highest levels of C-SCI.

The situation was further complicated by widespread ignorance of C-SCI and, as indicated earlier, a lack of sufficient knowledge of the condition amongst the general medical profession (Creek et al., 1989; BASICS, 2005) should a medical emergency arise. In fact, little appeared to have changed in hospitals from the time Creek et al. (1989) reported that further medical
complications often occurred during hospital stays due to general hospital staff’s ignorance of C-SCI. However, as Lynette reported, it could be just as precarious in a specialist hospital:

*It's all the same, any hospital... I can go to the hospital here which has a fabulous spinal cord rehab unit, but if you go to the emergency room, they haven’t even heard of certain terms to do with my disability! So you just have to speak up and say: ‘This is what’s happening to me, this is what I need’. You have to know your needs.*

### 7.8.5 Drinking water and general hospitals

Travellers were generally reluctant to embark on international travel. Most would not contemplate holidaying overseas because of the possible effects on their health of long-haul flights and greater accessibility problems. Europe, for example, was perceived to have much older, inaccessible buildings and uneven, cobbled streets which would be difficult and uncomfortable to wheel over and a potential risk to health by inducing spasms. However, apart from private nurse Eva, who had travelled internationally with her ‘inspirational speaker’ private client with C-SCI, no traveller or attendant had even considered the potential risks of purchasing drinking water overseas. Yet, on one international trip, bottles of what Eva believed to be mineral water were purchased for her client which had been filled with contaminated tap water and their seals glued back intact.

Individuals with C-SCI need to drink a large quantity of water throughout the day. They drink via a tube connected to the water container on their wheelchairs, and additional fresh water is required for their ventilators to keep the air moist for their lungs. The issue of safe drinking water therefore placed extra pressure and responsibility on the attendant and became Eva’s prime concern during most international holidays. If she failed to distinguish between safe and contaminated water on sale and the client became ill and hospitalised, there was then a risk of further medical complications occurring due to the lack of knowledge of C-SCI associated with
general hospitals (Creek et al., 1989; BASICS, 2005). Subsequent factors to be considered were the extra time away from home and preserving her nursing licence.

Thus, to facilitate any hospital visit or stay during a holiday, travellers need to carry, with consent, the contact details of their local C-SCI specialist and a ‘named specialist’ at a hospital at the destination who would be contacted and informed prior to departure. In addition, travellers should carry a copy of their medical notes and details of their care-routine as well as an extra supply of essential medicines in case delays occurred. This, in turn, would ease the pressure on accompanying attendants. First and foremost, however, hospital rehabilitation programmes need to equip patients with the knowledge and skills to be able to take responsibility for their healthcare management in any given situation (Younis, 1998). Yet to do that, many individuals need to acquire the confidence and communication skills during rehabilitation to enable them to give precise instructions and to explain their practical and healthcare requirements to hospital staff and their own, or unfamiliar, attendants.

7.9 Accessibility

Although travel generally involves an element of risk for most people, the majority of clients lacked the confidence even to risk venturing outside their immediate square-mile zone let alone, as participants feared in Yau et al.’s (2004) and Hunter-Jones’ (2003, 2004) studies, venturing into the complete unknown. While this reluctance stemmed largely from the cycle of ignorance outlined earlier, it was also inextricably linked, once again, to fear of serious, or possibly fatal, health complications caused by accessibility issues with public transportation or the built environment.
Chapter 7 (Part 2): Themes, issues & practical suggestions

7.9.1 The built environment & power wheelchairs

While problems with physical access deterred the majority of non-travellers from venturing virtually anywhere, they also presented travellers with their most frequent problems on holiday. The sheer size, extra width of up to 32 inches/81.3 cm, and functioning limitations of heavy power wheelchairs meant that access was denied whenever ramps or hills were too steep, terrain too rough and uneven, or door-frames too narrow as most were only 30 inches/cm 76 cm although 32 inches/81 cm should be the minimum. In addition, pavements with broken or no ‘cut-outs’ were impossible to negotiate, buildings impossible to enter alone without automatic doors as were lifts that did not automatically open or close on each floor. Moreover, as ‘Quads take up more space than paraplegics’ (Andrew), many lifts, rooms, bathrooms and corridors were impossible to enter and/or easily manoeuvre within which ruined the holiday as traveller Don explained:

*One motel I checked into ... when getting out into the corridor, I had to go back and forth so many times to get out that it made me not want to come back once I left the room or, once I got in there, not go out again to eat.*

As illustrated earlier, moving to more spacious accommodation, which would generally be at the more expensive end of the market, was not an option financially for Don or most others (Darcy, 2002). He therefore returned home early with the same intention of most non-travellers – never to leave his own relatively accessible environment to go on holiday again and face such difficulties.

7.9.2 Different locations and barriers, similar negotiation strategy

In reality, however, and in contrast to the suggestion that even one barrier might deter disabled people from ever taking a holiday again (Israeli, 2002), travellers always returned at some point to holiday-taking. It could take a year or more after a bad experience before they were ready again but, unlike non-travellers, travellers always returned to holiday-taking because it lifted their spirits. Furthermore, given the difficulty and routine of their daily lives, the general
feeling about holidays was: ‘Even when stuff has been horrible and gruelling, it’s still been good to get away and feel renewed (Lynette).

The additional accessibility barriers faced on a daily basis by power wheelchair-users compared with manual wheelchair-users, who ‘with upper body strength, might be able to get out of spots’ (Jake), resulted in two contrasting responses to travel from participants, although most considered a cruise to be the least problematic holiday. Nevertheless, non-travellers generally never dared attempt to go on holiday for fear of potentially encountering even greater physical barriers than they already faced locally. Travellers, however, largely went through the process of becoming ‘travel active’ described by Yau et al. (2004) and Packer et al. (2007) but, despite many obstacles, always continued taking holidays which, they insisted, were always mainstream. This was because experience had taught them that, whether at home or on holiday, power wheelchair-users always encountered increased barriers but, whatever and where ever they were, they needed to employ the same effort and set of skills to manage them.

Solving the problem of general access at grass-roots level, however, requires governments to ensure that trainee architects are informed of the requirements of different wheelchair-users so that all built areas can be designed with full inclusivity in mind. Service providers should also be better informed by governments about the whole realm of wheelchair access so that adjustments and additions can better accommodate power wheelchair-users. The process could be improved by involving disabled people (Bennett, 2002) or, preferably, by employing staff with C-SCI who could advise on all areas of access and also help counter prejudice towards severely-disabled people in the work place and in the tourism industry. In addition, medium and large-sized hotels should be required to have a number of bathrooms with ‘roll-in’ (ie, ‘wheel-in’) showers that can be used by any guest. In the adjoining bedrooms, a 10 inch/25.4 cm clearance under the beds is needed to accommodate a portable sling-hoist, a number of which be need to be available in the hotel store-room and provided on request.
7.9.3 Accessibility issues incur extra work for attendants

Greater effort was generally required by attendants on holiday as their work was far more physically-strenuous away from their well-equipped working environment. For instance, in hotels, there was more lifting with too few ‘roll-in’ showers and no hoists to lift clients from bed to chair. Consequently, attendants were far more physically exhausted doing on holiday the same tasks they did at NS.

Furthermore, unlike at the end of a shift at work, if attendants were with a ventilator-dependent client, they were unable to relax as they could never leave the client’s side in case the ventilator malfunctioned. In brief, ‘It was a lot harder work, and much more responsibility, being away with a quad’ (nurse Liv). Thus, apart from cost and working around attendants’ family commitments, arranging a holiday with attendants could be problematic as their job was far more physically and psychologically draining on holiday. On day trips too the pressure could be draining because, with little experience of the world outside, clients were either overly-demanding and needy or excessively passive and nervous. Their physical dependency had thus developed into psychological dependency (Smith, 1987; Hunter-Jones, 2003; 2004) on their familiar attendants who were expected to take sole responsibility for initiating everything and negotiating every barrier. This was just as problematic for attendants as they too had no previous holiday experience or training to be able to accompany a client outside their working environment.

7.9.4 Ground transportation & Power wheelchairs

As outlined earlier, when clients were unable to access public transport, they could develop serious health complications. This was particularly the case if they found themselves stranded outside in extreme temperatures as their bodies were not able to perspire in hot weather, or feel the cold in cold temperatures, below their level of injury, and many not above it either (NSEM,
2006). Consequently, they took on the temperature of the environment they were in and were thus in danger of hypothermia (abnormally low body temperature) or hyperthermia (overheating) which could lead to fatal complications. Those with the highest levels of C-SCI, who were not able to feel anything below the head, were therefore at greatest risk.

The health of a non-traveller with high-level C-SCI (C2) was badly affected after a day trip to the coast because her pre-booked 'Access' taxi home arrived over three hours late, forcing her to wait too long outside in the hot sun. Even with sunscreen applied, she became seriously ill as a result of sunburn which could have led to a common complication of C-SCI, autonomic dysreflexia, that can cause stroke, seizure and even death (NSEM, 2006). Consequently, she did not dare to venture out anywhere for a long time afterwards and, even today, still remains reluctant to go any distance from where she can not 'wheel' herself back in case of transportation problems. Despite the initial intrinsic nature of this barrier (Smith, 1987), her ill-health and subsequent fear of day-trips were, nevertheless, inextricably linked to and exacerbated by an external force, namely: an inadequate and inaccessible ground transportation system that left her stranded and at the mercy of extreme outside temperatures both of which were environmental barriers.

7.9.5 Additional travel costs & complications for power wheelchair-users

As Burnett & Bender's (2001) study indicated, the general lack of public ground transportation suitable for severely-disabled people added to the extra planning and cost of travellers' holidays. Additionally, it would have reinforced feelings of isolation from mainstream society as travellers had to hire private accessible vans to travel, alone, to, from and around their holiday destination. Arguably, this enforced separation from the general public further contributed to public's ignorance, negative attitude and even fear of individuals with C-SCI as they rarely encountered each other.
Hiring private transport also brought an additional set of problems. Despite warnings to the contrary, van hire companies mistakenly believed ‘wheelchair-friendly’ vans were accessible for all types of wheelchairs. Travellers were therefore often stranded, or they missed the event for which the van had been arranged, when pre-booked vans arrived entirely inaccessible for their power wheelchairs. Similarly, pre-booked vans to take travellers out for a day’s sight-seeing were often too small on arrival. When, or if, the company eventually returned with a larger van, it invariably had no windows in the back where the client had to sit and ‘sight-see’ in complete darkness.

Spontaneous, hassle-free travel with a choice of transport was equally impossible at home. In order to travel with ‘Access’, the only local taxi service which could accommodate power wheelchairs, each single journey had to be booked at least twenty-four hours in advance. In spite of the booking restrictions, the taxi invariably arrived an hour or more early, or late, without any warning. If clients were not ready to go the moment the taxi arrived, they missed their only means of transport that day. The return journey could be even more fraught and, as outlined earlier, lead to possible fatal health complications if clients were left waiting too long outside in the heat or cold. Worse still, if clients were not on time at the agreed return collection-point and missed the taxi, they could be stranded with no other means of getting home as there was no guarantee that passing buses would be accessible, or even stop. Bus drivers had, at times, deliberately driven past travellers at bus stops to save themselves the time of lowering the ramp/lift, and then getting up to secure the wheelchair on board with tie-ins.

7.9.6 Private transportation & inaccessible company policies

Given such frequent problems with public transport, taxis and hired vans, all six travellers had eventually purchased their own private vans. These offered far greater freedom of movement and reliability, but were far beyond the financial capabilities of clients on state benefits without
family or partners to help finance or drive them. Yet, once again, these vans produced their own set of travel barriers whenever they broke down.

Despite accepting travellers’ vehicle break-down membership and payment, the rules and regulations of vehicle recovery companies appeared to have been made with only able-bodied people in mind. Similarly, the ‘non-inclusive’ rules of casinos in Las Vegas at first precluded an attendant from just holding the cards of a traveller with C1 at a card table. However, when travellers’ vans broke down on their way to their holiday destination, and they could not be accommodated in their wheelchairs in the small recovery truck, they were stranded and left to ‘wheel’ to the nearest town in temperatures of up to 120F/49C. On the only occasion a recovery driver broke the rules, the traveller had to be hidden under a blanket in his broken-down van as it was towed away. Apart from the indignity of having a blanket thrown over him, in over 110F/43C heat, it further increased the risk of over-heating and incurring potentially fatal health complications.

7.9.7 Denial & delusion regarding health risks
Although travellers appreciated that, when considering holidays, they had to be mindful of outside weather conditions and other environmental barriers that might affect health, they displayed a more realistic and resilient approach than non-travellers did to these health risks. It was travellers’ ability to reflect on the overall holiday experience (Yau et al., 2004) and to appreciate the ‘bigger picture’ rather than focusing on one negative incident that ensured travel continued: ‘It’s about... remembering all the good things that happened... with positive memories outweighing the negatives’ (Ralf). Above all, however, they accepted that their severe medical condition invariably involved higher health risks than for most other wheelchair-users. Furthermore, they appreciated that it was invariably a combination of unexpected external factors that were out of their control which actually led to their health being affected.
For instance, when there was no gang-way onto an aeroplane at a local airport, one traveller had the frightening experience of being raised up alone in the pouring rain onto the aircraft in a fork lift truck. He had no option other than to sit in cold, damp clothes throughout the flight and risk hypothermia. Due, perhaps, to a more optimistic and/or realistic approach, this incident did not prevent him from flying or even using the same airport again, since next time the weather might be fine and/or there might be a gang-way onto another flight.

Yet, although travellers’ resilience and ability to accept such risks ensured they continued taking holidays, it would seem that an element of ‘denial and delusion’ also needed to exist with regard to the potentially fatal health consequences of such risks. However, since no form of risk-taking can really flourish in an atmosphere of psychological dependency common amongst clients (Kennedy, 1987; Packer et al., 2007), most non-travellers were unable to develop such an approach to facilitate travel.

However, for individuals with C-SCI to be able to travel easily and with minimum risk to their health, policy makers need to ensure that: all buses and trains are eventually fitted with a number of wheelchair tie-ins; airports provide gangways onto aeroplanes for wheelchair-users; a reliable, state-subsidised taxi service is provided for power wheelchair-users that requires a maximum of a few hours’ booking notice; van hire companies also have power wheelchair-user-friendly, temperature-controlled vans with windows in the back; and vehicle recovery companies have both the policy and procedure in place to fully accommodate power wheelchair-users as should all other providers.

7.10 Over-emphasis on the physical on holiday

Apart from fear of the unfamiliar and accessibility issues that might incur health risks, an over-emphasis on what could not be done physically on holiday deterred many non-travellers from
holiday-participation. Admittedly, certain physical activities for ventilator-dependent individuals with C-SCI were more problematic. They could not, for instance, be easily detached from their bulky ventilators, or risk the ventilator becoming detached, damaged or falling out on amusement rides or during other activities. So dangerous was this to health - and life - that before a traveller with C2 was able to sky-dive, attached to a professional, he had to sign that no one except him would be held responsible should his portable ventilator become detached and/or run out of air if they were blown off course.

Although greater risks were posed for those with high-level C-SCI during activities out of their wheelchairs, most non-travellers still appeared to lack the imagination to consider any holiday activities that did not ‘involve having a physical good time’ (Jake). They were usually associated with popular amusement park or beach holidays. Given society’s obsession with bodily perfection, and often further emphasised on such holidays, concerns about their physical limitations and being stared at were then raised. Jose thus concluded that holidays were not for him and that:

Some clients might say ‘no’ to the offer of a trip or vacation because people might be staring at them ...and they might feel depressed, like seeing everybody in the swimming pool or on the beach.

In contrast, travellers largely dismissed the idea of taking beach holidays or holidays at amusement parks like Disneyworld because of the difficult ‘physical element’ imposed by the built environment. Unlike the manual wheelchairs of those with paraplegia, their power wheelchairs were virtually an extension of themselves. They were vulnerable out of them as amusement park rides did not have up to seven belts to secure their whole body, head to foot, as their wheelchairs did. If they were to go on any ride, they therefore needed to be able to sit in their wheelchairs. Although one or two of the amusement rides could usually accommodate power wheelchairs, these were always designed and themed for very young children. Moreover, apart from the inappropriateness of the ride, a captive audience of curious little
children and additional stares from on-looking parents and siblings accompanied clients on the only ride available to them. Thus those with high-level C-SCI had the more problematic experience at amusement parks and in not being able to sit in a tourist helicopter seat for aerial views of natural attractions like the Grand Canyon.

Contrary to the medical discourse-influenced beliefs of most non-travellers, however, this was due more to the unaccommodating design of all adult amusement park rides and all tourist helicopter seats - and even the lack of sling-hoists to transfer them - than their physical limitations. Policy-makers need to ensure, therefore, that all designers are trained to design inclusively or, at least, to provide some inclusive designs within the range.

7.10.1 Influence of medical discourse

Much of the above preoccupation with the physical and physical limitations illustrates once again the power of the dominant medical discourse in conveying the idea that holiday-taking is problematic due to physical impairments rather than the non-inclusive design of the built environment, transportation and so on. Yet the power of this discourse was equally evident in the (re)actions and vocabulary of all participants, travellers and staff included. Just as all the staff used the word ‘quad’, all travellers and non-travellers referred to themselves and others with C-SCI as quads, thus subconsciously highlighting their physical limitations rather than human qualities. Shortened from the old medical term ‘quadriplegic’ and meaning paralysed in four limbs, the use of the word ‘quad’ subtly drip-fed the idea that all travel barriers encountered were not structural but the result of severe paralysis. Consequently, the underlying message was that it was not society’s responsibility, but those with the ‘deficits’ to overcome barriers, and whenever they could not, exclusion was a natural consequence.
This notion of responsibility was reflected in many participants’ responses to overcoming holiday barriers. In true medical metanarrative style, all staff, and even most travellers, felt it their responsibility to cope with the inaccessible designs of mainstream transportation, buildings and facilities. As such, Ralf stressed his role in being able to ‘keep a positive attitude and strive to overcome problems... [and] what isn’t [accessible], I make accessible’. Without complaint or compensation, travellers therefore heroically ‘made do’ with bed baths on holiday because bathrooms were inaccessible, or attendants unquestioningly held onto travellers during flights with only the usual single lap belts on to keep them from falling or being bent double and breathing affected. As participants generally did not expect airlines - or any service provider - to provide for non-mainstream consumers, even NS director had purchased and carried on flights a number of long, leather belts which, with permission from the person sitting behind, she placed around the back of the seat and secured in the front of the client. After over a hundred such flights around the world with her private client, nurse Eva nevertheless concluded: ‘Barriers, well, that’s life. ...Quads can’t go out expecting the world owes them anything. They’re in a wheelchair, so it’s going to be hard, but don’t complain and get bitter. ...You just make do.’

7.11 Air travel

The most significant transport barriers were to do with air travel. This was partly because, as indicated in part 1, most clients and staff mistakenly believed that ventilator-dependent individuals could not travel by air. It was also because, as on amusement park and helicopter rides, participants had reservations about not being able to sit in their wheelchairs as they could on buses with wheelchair tie-ins. In contrast with power wheelchairs, airline seats provided no foot rests, head or chest straps or individual wrist or foot straps to keep the traveller upright throughout the flight and prevent skin from becoming damaged as limbs dangled sitting high on top of an air cushion on the seat. Take-off, landing or during turbulence was especially
dangerous when feet could be left dangling, as it was impossible for an attendant to hold the client’s upper body, legs and feet at the same time.

Since all disabled passengers are required sit on airline seats, participants generally preferred travelling by road. Although this severely restricted destination choice even within their own State, they nevertheless were able to sit securely in their wheelchairs and perform their weight-shifts to prevent life-threatening skin sores.

7.11.1 Sub-standard practice and provision

As with accommodation, no standard, reliable provision existed for disabled travellers travelling by air. Jake thus declared: ‘The only thing that scares me is the airlines; they’re unpredictable’. A lack of planning or staff training by the airlines contributed to this unpredictable service which was just as frightening and stressful during the flight as beforehand when planning the journey by air with the knowledge that:

_They have no clue how to transfer people on and off the plane with these little aisle-[wheel]chairs...; they don’t know where the straps go or how the chair works._

(Jake)

Travellers found that, despite giving the airline prior notice of their disability, provision was generally never in place for them. Often the pilot needed to be called from the cockpit to assist the only male steward on board to transfer a traveller onto the airline seat. Like other service providers, cabin crew were also largely ignorant about C-SCI, and they rarely made eye or verbal contact with travellers with C-SCI, preferring instead to address attendants about how to transfer them. Ironically, when they did speak directly to travellers, their ignorance of C-SCI was very apparent as was their unwitting insensitivity, when they said: “can you just stand up and move over there” and “just hold on!” (Jake).
Furthermore, with no accessible WC on board, more humiliation and embarrassment arose as catheters had to be changed and saliva suction machines used in full view of other passengers. As a result of many of these uncomfortable and potentially dangerous 'man handling' episodes by airline staff, one traveller made the decision only ever to travel in his own van. Another with high-level C-SCI had never flown as he was too nervous about having to sit on a narrow little aisle wheelchair and being transferred by untrained airline crew. He was also concerned that he would be too heavy to be lifted by his female staff without his sling-hoist on board. As illustrated earlier, however, travelling by private van brought its own set of problems and restrictions, and significantly increased the time spent in transit which was not easy on their bodies.

7.11.2 Wheelchair damage

Often the only common airline policies were the boarding and disembarking procedures which ensured that all wheelchair-users were first on and last off the aircraft. However, these not only increased the overall time spent at airports, and out of their wheelchairs on the aircraft, but also created further travel barriers with onward journeys and flight connections. The already difficult task of 'rushing' in a wheelchair to catch connecting flights became even more problematic after being last to disembark and then having to wait for wheelchairs to be retrieved from the luggage-hold. Further delays were extremely common as around 75% of the time wheelchairs were returned damaged or broken, despite handling instructions attached and/or sending an attendant to explain how to dismantle parts.

7.11.3 Gender of attendants

The gender of the attendant giving the wheelchair handling instructions seemed to make a difference with regard to how seriously baggage handlers took the information which in turn affected the extent of damage. On numerous occasions it was noticed how the instructions of a
female attendant with over twenty years’ experience of international travel were generally disregarded by male airport baggage-handlers, whilst those of an accompanying, less knowledgeable, male friend were taken seriously. Given that most attendants were female, the apparent sexist attitudes of male airport staff created additional barriers to air travel. Consequently, with instructions ignored, more delays became necessary for repairs to be carried out. This meant that travellers were often stranded at the airport when connecting flights were missed and the scarce, pre-booked accessible ground transport already departed due to their ‘no show’.

7.11.4 Airline wheelchair loans

Even if wheelchairs could not be repaired at the airport, travellers were still delayed as they waited for the arrival of a loan wheelchair and paperwork to be processed. Yet wheelchair loans were never ‘like for like’ for power wheelchair-users which created further problems, particularly for those with high-level C-SCI, in terms of potential health issues, as this traveller’s comment below reveals:

They loaned me a manual wheelchair which was no substitute. I had to be pushed around and couldn’t lay back and do weight shifts; [it] was horrible so I ended having to leave early. It kind of put me off [vacations] for a while.

(Don)

Apart from the above issue - and the extra physical work involved for attendants pushing manual wheelchairs and regularly lifting clients to manage their weight shifts - the major reason why wheelchair damage put travellers off holidays (Yau et al., 2004) and particularly air travel was, as Andrew explained: ‘my wheelchair is my main thing... a big part of my freedom and independence’. Without it, no other possibility of independent movement existed. Travellers drove their power wheelchairs with great skill and precision using only the tiniest mouth or chin piece to control both their movement and weight-shifts. This afforded them some control over managing their health and, ultimately, gave them a feeling of empowerment. Thus, whilst
manual wheelchair-users might be inconvenienced having to use another manual wheelchair, travellers could not substitute their power wheelchairs for a manual one because, without the former, no independent movement was possible.

Whether damage occurred during transit or the holiday itself, problems with damaged wheelchairs lessened enjoyment or cut short or prevented further holidays being taken (Yau et al., 2004) for a long time afterwards. Furthermore, at around $30,000 to replace a power wheelchair, some participants were reluctant to risk air travel damage or go anywhere or do anything that might incur damage. With no income of their own, they had to rely on the State to replace their wheelchairs. However, only after five years could the most worn out wheelchairs be considered for replacement. Yet even then, the wear and tear had to be satisfactorily justified, and whilst awaiting a replacement, or repairs from airline damage, participants were largely confined to bed as their wheelchairs were their veritable ‘life-lines’.

7.11.5 Greater barriers for air passengers with high-level C-SCI

The only traveller not to have had problems flying was Lynette, the only traveller with very low-level C-SCI. Since she had a little movement in her arms, though not in her fingers, whenever she travelled by air, she would to push herself in a far more travel-friendly manual wheelchair which also had no expensive, breakable motorised parts. Moreover, Lynette was able to keep herself upright on an airline seat and, with occasional assistance from an attendant, manage her own weight-shifts. Yet assistance could only be given easily when ‘bulk-head seating’ next to the emergency exit had been procured. With no seats in front, attendants had enough room to assist with weight shifts. Yet, despite the potential serious health implications if attendants could not manoeuvre to assist with weight-shifts, travellers were not always granted bulk-head seating if other able-bodied passengers had reserved it ahead of their booking or check-in requests.
At C6/7, being able to drive and hire an ‘assisted car’ to and from the airport, and feed herself using a spoon placed across her fingers and under the middle one, meant that Lynette also avoided transportation problems if delayed at airports, as well as the embarrassment of being ‘fed like a baby’ (Chris) in public, which affected some clients’ desire to be out in public.

7.11.6 Long-haul flights

Long-haul flights, even in first class, were virtually impossible particularly for those with high-level injury because, as Ralf (C2) explained, ‘flights... any more than six and a half hours... would beat me up too much’. Thus, apart from Lynette, travellers did not dare take long flights as the longer the time spent out of their wheelchairs, the greater the strain and potential health risks. Long-haul also meant prolonged physical discomfort for some. Although many medical experts either question ‘phantom pain’ of paralysed individuals and/or can not explain it (NSEM, 2006; Smith & Sparkes, 2008b), Ralf revealed why long-haul flights were physically impossible for him:

*My back... I can feel it.... We are all different. We all have different kinds of feelings, sensations. Some quads don't have any; some have tactile sensations. A fourteen-hour flight would just beat me up too much....*

(Ralf)

The possibility of breaking up a long-haul flight and replacing it with two shorter flights with an overnight stay in between was, however, not a practical solution. For one, finding a nearby accessible hotel could prove difficult. It was also too costly in financial terms with the purchase of multiple tickets and in terms of the already limited number of days that most attendants were available. As previously indicated, even if an overnight stay were possible, in practice, it would be too exhausting and burdensome with all the packing and unpacking of equipment to stay less than two nights on both the outward and return journey, but this would create even greater financial and time-related barriers.
Although problems with long-haul appeared, at least in part, to be associated with the severity of the condition, in reality, the greatest barriers lay in the design of aircraft interiors. In an attempt to solve such barriers, a number of power wheelchairs need to be accommodated on board with 'tie-ins' so that travellers may remain in their wheelchairs during the flight. Airlines also need to provide a number of fully-reclining seats or affordable beds in economy class as: 'most quads have a time limit for sitting up, and then they need to lie down' (Nurse Eva). Additionally, airlines should introduce common policies and procedures so that: a sling-hoist is always carried on board and can be expertly used by the cabin crew to transfer disabled passengers; bulk-head seating with adjustable foot rests is automatically given to passengers with no upper or lower body movement; curtains shield bulk-head area for privacy during catheter changes, feeding and use of saliva suction machine; a supply of suitable belts is available to secure severely-disabled passengers; baggage handlers are specifically trained to load and unload power wheelchairs; and airlines have a contract with a local power wheelchair supplier so that if damage occurs, passengers have a like-for-like wheelchair loan.

Furthermore, policy-makers need to provide sufficient guidance so that service providers in all sectors can train employees to be able to interact appropriately with, and provide the correct practical assistance for, severely-disabled individuals. Likewise, all medical staff should be more informed during training about C-SCI. Nurses and attendants need to learn during their training about the practical issues of holiday-taking so that they may inform clients about travel and/or accompany them on holiday without it being so 'trial and error'. Without this, Ralf felt: 'it's all an experiment. My life has been pretty much an experiment.' To make the experience more manageable for all concerned, hospital rehabilitation programmes also need to assist patients with the skills to be able to respond appropriately to negative attention and to explain clearly to service providers their needs and the type of assistance required.
7.12 Tourism service providers

Unlike the findings of existent research on disabled tourists (eg, Takeda & Card, 2002; Mckercher et al., 2003; Avis et al., 2005; Bi et al., 2007), service providers’ attitudinal barriers were of no major concern to travellers. Similarly, with no holiday experience, non-travellers made no comment about providers, as even day trips were non-existent for most. Even the few clients who had taken a one-off, complimentary day trip had gone as part of a group of clients when attendants had selected, organised and managed the trip, including interaction/negotiations with providers.

Contrary again to research findings that providers’ negative attitudes were related to the gender of the disabled tourist, and in particular to young women (Avis et al., 2005), male and female travellers of all ages received the same reaction and treatment from all providers. Given that so few individuals with C-SCI are seen in public, the reaction was generally one of shock and even horror at seeing such highly-disabled people with ‘tubes sticking out of their necks... [that they even] were scared and didn’t know whether a quad could talk’ (NS director). Their reactions were therefore disturbingly consistent irrespective of age or gender.

Although severely-disabled Chinese travellers reported more attitudinal barriers than other disabled tourists in all sectors except in attractions (Bi et al., 2007), reference was made by travellers only to providers’ ignorance of C-SCI and their lack of competence and training in relation to their needs. As Don explained, the issue was mostly that ‘they did not know how to deal with me’, or fear of litigation if something went wrong. Thus some tourism employees had refused travellers entrance at attractions, to allow a traveller to board an airline after a ticket had been purchased months in advance for a holiday, or to take helicopter rides over the Grand Canyon. While a few unhelpful restaurateurs had refused to serve a meal once a traveller was positioned at a table, and some bus drivers had not stopped to pick up travellers at bus stops,
most providers were generally helpful if somewhat incompetent or ignorant of the law. For instance, some refused to allow travellers' duty dogs on the premises, while certain bus drivers incompetently positioned ramps leading from the road, rather than the pavement, to the bus platform.

7.12.1 Reaction to barriers

Whilst travellers possessed the drive and determination to overcome all sorts of travel barriers, non-travellers tended to have a more passive and defeatist approach. Travellers stressed how important it was though 'to be out-going...and take the rough with the smooth and...take 'can’t' out of your vocabulary' (Ralf) since holiday success was, as Yau et al. (2004) and Daniels et al. (2005) found, a lot to do with personality and the ability to troubleshoot, even if it meant considerable effort, compromise, discomfort and loss of time on their part. Therefore, when faced on holiday with a seemingly impossible flight of stairs and a wheelchair that, alone, weighed around 23 stone/150 kg, Ralf recalled being told:

'Oh, things are not going to be accessible'. People tell me that all the time, but it's pretty easy to make things accessible wherever you go and... persuade someone to take you upstairs in the wheelchair.... People are usually willing to help, but you have to be willing to go on that adventure. Any vacation is pretty much an adventure.

Successful travellers took the initiative and were assertive and persuasive (Yau et al., 2004; Daniels et al., 2005) employing a number of social and communication skills to negotiate barriers. However, apart from one traveller who described himself as shy, most appeared to be naturally confident, extrovert individuals and found it relatively easy to approach people in order to request assistance. Although disabled tourists in other studies (eg,Yau et al., 2004; Daniels et al., 2005) often used a third party to negotiate barriers for them, they insisted that: 'you have to be willing to stand up for yourself and not accept “no”' (Jake) when dealing with tourism providers.
7.12.2 Managing assistance

Faced with accessibility barriers or service providers with an 'it-can't-be-done attitude', travellers often succeeded in turning things around with an innate ability to find innovative solutions (Daniels et al., 2005) as well as a keen sense of pragmatism as: 'being friendly gets you more than being difficult' (Jake). Moreover, their well-honed social and communication skills enabled them to clearly direct providers when assistance was required as providers were often more ignorant than uncooperative. The ability to clearly 'explain how things work or how they can help' (Jake) was therefore essential in overcoming barriers.

Yet, without travellers' natural skills and qualities, and with no assertiveness training, practical problem solving or communication skills acquired during hospital rehabilitation - and little social interaction since - most non-travellers were not socially confident, assertive or skilled enough to be able to negotiate barriers. If they ever ventured out, they rarely felt able to negotiate barriers, or even were willing to spend the time and effort needed to challenge service providers as they had become too psychologically-dependent on attendants. Thus, on the rare occasion they tried to negotiate, it was usually either in a defeatist, whining tone of a victim or in a confrontational way, both of which hindered progress.

7.13 Negative public attention

All participants commented on the overwhelming amount of attention, and the particularly negative reaction, they received from the general public. Although all clients experienced negative public attention, both staff and travellers with very low-level C-SCI observed how the public reacted far more negatively to more severely-disabled individuals (Packer et al., 2007), and particularly to ventilator-dependent clients. Sometimes they were viewed with pity (Smith & Sparkes, 2008b) as their heads would be patted, money left on their laps and people would even cry on looking at them. Mostly, however, they were pointed at and received comments
suggesting that they were better off, or already, dead as they were on ventilators, or that they were ‘alien’ or ‘sub-human’ creatures. Thus, pointing at ventilator-dependent Jose as if he were a non-human, inanimate object, a passer-by shouted out: ‘Look at THIS!’ Yet, as Susan explained: ‘The most common thing... is they think I’m retarded’ because ‘people think everyone in a wheelchair has a brain injury’ (Lynette). A consequence of this perception was that the general public rarely spoke to clients or, if they did, it was to shout out insults reminiscent of the bullying currently reported by the British media and directed at people in the UK with learning disabilities and their families (BBC, 2010).

7.13.1 The paradox of disability

In contrast with the usual negative attention, travellers sometimes felt that they were completely invisible in public. For instance, non ventilator-dependent Don explained how, when he was out on his own, some people could be deliberately unhelpful and pretend they had not noticed him ‘waiting for a door and [so] they will just jump in real quick so they don’t have to hold it for me’. Likewise, in shop queues people would treat travellers as if they were ‘an ornament’ (Lynette) just sitting there in order to jump ahead of them in the queue. At bus stops also, passengers would at times rush to board ahead of travellers who had been waiting longer, or bus drivers would pull away before they had managed to wheel to the door. As with airline staff, all participants reported how most service providers, health practitioners, and people in general addressed accompanying attendants to illicit information about a client when the client was sitting next to them. This made for a difficult and confusing experience and confirmed the ‘paradox of disability’, of being simultaneously stared at and ignored (Murphy et al., 1988).

7.13.2 Invisible in their own home

The misery of feeling invisible in public was, at times, equally present at NS. For example, people who regularly came into NS often only greeted and hugged staff and ignored the client sitting with them. Feeling a social outcast even within their own home, many clients became
even more withdrawn or, on occasions, verbally aggressive in response. Consequently, a vicious circle of passive and/or inappropriate behaviour was set in motion. This led to greater social isolation as people coming into NS then felt even less inclined to interact with clients because of their behaviour which, of course, was largely a reaction to how they had initially been treated by them.

7.13.3 Reaction to uncomfortable situations

As the general public's reaction and stares were far greater towards those with severe disabilities (Parker et al., 2007), these stares, together with rude and humiliating comments, such as 'How do you go to the bathroom?' (Jose), made most ventilator-dependent clients anxious about taking day trips or even visits to the local shopping mall. Some became increasingly reclusive as they stopped going out altogether because of the attention: I don't like going out...because of all the stares you get - as if you're an alien' (Nancy). By retreating, however, they never learned the necessary coping or negotiation strategies to deal with these situations or, indeed, with any of the other barriers encountered. Admittedly, however, the confidence, initiative, perseverance, risk-taking and creative-thinking needed to overcome these barriers could not flourish in an atmosphere of psychological-dependency (Kennedy, 1987; Yau et al., 2004) that most clients had developed on their attendants and NS. Holidays were therefore particularly daunting because they lacked the confidence to deal with the local public let alone an unfamiliar one at an unfamiliar destination who must be less used to seeing individuals with C-SCI and thus even more likely 'to react'. Thus, as Len explained, even at home, 'some of them don't really go out much cos they're scared of how people will treat them.'

In contrast, travellers stressed the importance of being able, wherever they were, 'to speak your mind if someone [was] being rude and tell them that they need to get re-educated' (Ralf), rather than retreating and remaining outside mainstream society and tourism. Some travellers also
adopted various coping strategies to deal with negative public reaction. For instance, one traveller who still found the public’s constant, open-mouthed stares uncomfortable and difficult to bear, never made direct eye contact with anyone whenever he was out. Another’s coping mechanism was to nudge people with his wheelchair whenever they stood staring too long at him oblivious to the fact that they were blocking his way. Again, unlike non-travellers, and despite many negative ‘public incidents’, travellers still held the view that, in general, people were fine and that, as most ‘people are usually willing to help, you must keep a positive attitude and strive to overcome problems’ (Ralf) rather than retreat and become increasingly socially-isolated.

7.14 Summary

Many of the study’s findings supported, expanded on and added to the scant knowledge of severely-disabled tourists outlined in earlier in the literature review. As with Daniels et al.’s (2005) study, they illustrated the effect that a complex mix of linear, inter-related environmental, intrinsic and interactive barriers, which might occur at any time, could have on holiday-participation. Most, however, were connected to, or exacerbated by, external factors, such as: a lack of resources to pay for: the cost of three attendants for ventilator-dependent individuals; and the price of medical insurance as the possibility of being stranded, particularly in extreme temperatures, due to inaccessible transport or accommodation could lead to fatal health complications as could general health practitioners’ unfamiliarity with C-SCI.

Those with the highest levels of C-SCI tended to encounter greater constraints, yet benefited most and most long-term from a holiday-participation, having abandoned their pleas for suicide post-trip and re-engaged with life. However, with so few individuals with C-SCI ever able to take and benefit from holidays, policy-makers need to fund a short, one-off, local holiday for patients with C-SCI towards the end of hospital rehabilitation in order to lift their spirits and
Chapter 7 (Part 2): Themes, issues & practical suggestions

provide them with a new set of skills to be able to return to mainstream society and begin to re-build their lives. Firstly, however, narratives of travellers and non-travellers with C-SCI need to be available during rehabilitation as a resource to broaden the narrow repertoire of disability narratives that limit and restrict disabled people.

However, despite the positive approach and holiday successes of all the travellers, the two most experienced and frequent travellers, eventually became worn down by the relentless stream of barriers. Thus, contrary to expectations and the findings relating to other disabled tourists (Yau et al., 2004), the practical experience of holidaying with such a severe disability as high-level C-SCI did not make the taking of future holidays any easier, but eventually restricted even travellers with abundant resources. Thus, in contrast with Eichhorn et al.'s (2008) disabled tourists who felt restricted having to limit themselves to the same region within Europe, travellers with C-SCI became restricted to even the same hotel within the same town for every holiday, or stopped travelling altogether. Despite a constant yearning for the up-lifting and life-enhancing experience of a holiday that all travellers felt more acutely post-injury, the wealthy traveller who had not taken a holiday in six years concluded: '[as for future holidays] there are still things I want to do, but it has all become too arduous' to continue.

Thus, unless all the oppressive socio-political structures outlined in this chapter are addressed using a multi-agency approach, it is likely that, when those other few, rare travellers gain more holiday experience, they too will eventually become jaded by the accumulative stress of the constant barrage of barriers. They may therefore be in danger of being excluded, along with the vast majority of individuals with C-SCI, from holiday-participation and its life-affirming and life-changing benefits.

The next and final chapter will reflect on the research undertaken, highlighting the key research findings, limitations and significant contributions to knowledge of the study.
CHAPTER EIGHT

CONCLUSIONS

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CHAPTER EIGHT

CONCLUSIONS

8.1 Overview of chapter

This chapter concludes the study on C-SCI and holiday (non)participation. It first presents a review of the research objectives and highlights how the study has been able to address its objectives. It then presents the major research findings and considers the relevance of some for the wider policy arena. The next section outlines the significant contributions of the study before the limitations of the study and possible paths for future research are presented. The chapter concludes with some final reflections on the research.

8.2 Meeting the objectives

The research has been able to meet its objectives in the following ways:

8.2.1 Objective one: To explore the concept and theory of disability, and to document the condition and impact of C-SCI.

To achieve this objective, chapter two explored the different theories of disability and the tensions between and within them. It concluded that, although there was no current, comprehensive theory of disability, the study should take a largely social model approach but include analysis of the individual as well as the social and societal. Furthermore, chapter two provided an overview of the physical condition and psychological impact of C-SCI that might affect holiday-participation.

8.2.2 Objective two: To conduct a critical review of literature to:

- investigate non-participation in holiday-taking and potential interventions to facilitate participation
- identify constraints to holiday-participation for disabled consumers and, in particular, mobility-disabled individuals.

The second objective was first achieved in chapter one with an examination of the literature on social holidays, and later in chapter three with a critical review of key literature, which provided a theoretical framework of constraints to holiday-participation for mobility-disabled tourists, together with a number of possible interventions to facilitate participation.

8.2.3 **Objective three:** To document the research process of working with and the attempt to ‘give voice’ to previously unheard, silent voices of tourism.

Chapter four addressed objective three by providing a detailed account of the study’s emancipatory philosophy and research approach with regard to working with a socially and medically-vulnerable research population. It also explored the challenge of foregrounding the research participants’ voices by problematising the extent of influence of the writer/researcher’s own voice and interpretations in the narrative representation of data obtained from semi-structured, in-depth interviews.

8.2.4 **Objective four:** To listen to and present in narrative form the lived experiences of holiday (non)participation of twelve individuals with C-SCI (six non-travellers & six travellers).

Objective four was achieved in chapters five and six with the presentation of the narratives of six non-travellers and six travellers respectively. These narratives offered rarely-heard accounts of direct, personal, lived experience of C-SCI and issues associated with holiday-taking as well as the impacts of (non)participation. Individually and collectively, the narratives attempted to broaden the current, limited repertoire of disability narratives that have influenced the type of stories disabled people hear and tell and which ultimately limit them and the way they lead their lives.
8.2.5 *Objective five*: To present emerging themes and issues of the experience of (non)holiday-taking for individuals with C-SCI in relation to the reviewed literature; and to offer practical suggestions that might minimise holiday constraints in order to afford them the opportunity to take a holiday within mainstream tourism or, for those who have already participated, to offer an enhanced tourism experience.

The fifth and final objective was addressed in chapter seven which provided a detailed analysis of the complex mix of inter-related environmental, intrinsic and interactive barriers (Smith, 1987) that affected holiday-participation. Furthermore, it highlighted the strategies travellers with C-SCI used to negotiate environmental barriers, and offered practical suggestions that might provide potential solutions to the current exclusion from holiday-participation experienced by most individuals with C-SCI.

8.3 Key findings

The key findings of the research are linked to the five main research questions identified in chapter one and will be presented here in the order in which the questions were posed:

*What are the issues associated with the condition of C-SCI, and how might they affect holiday-taking?*

The following summarises the issues associated with the condition of C-SCI that might affect holiday-taking:

- Potentially fatal medical complications may arise as a result of common side-effects associated with C-SCI, such as skin sores and urinary tract infections or being exposed too long to high or low temperatures. These, however, can evolve from or be exacerbated by: the choice of hot or cold-weather holiday destinations, poor travel conditions; inadequate care in general hospitals; and patients with C-SCI not having
received the necessary instruction during hospital rehabilitation to equip them with the knowledge, skills and inclination to take personal responsibility for directing their own daily healthcare management. Furthermore, making fact-finding telephone calls for ventilator-dependent individuals are often problematic due to tourism providers' lack of disability training and ability to recognise and take calls from individuals with delayed speech.

- The process of transferring high-level, ventilator-dependent travellers from wheelchairs onto other seats, and sitting on seats with no belts, is more problematic than for those with very lower-level injuries. For health and safety, an extra airline seat needs to be purchased for their ventilator. Thus, together with seats for the three accompanying attendants, a total of five seats needs to be purchased by one client which often renders air-travel cost-prohibitive. Furthermore, attendants are reluctant to shoulder the extra responsibility of accompanying ventilator-dependent individuals on holiday since they could lose their nursing licence should serious or fatal medical complications occur.

- The physical and psychological impact of traumatic C-SCI tends to be so overwhelming, yet the psycho-socio support during hospital rehabilitation often completely inadequate, that feelings of despair and pleas of suicide are common. Many become angry and/or withdrawn, passive and psychologically-dependent and thus too afraid to venture out. Most families, friends and partners eventually disappear from their lives leaving 95\% of NS males and 100\% of NS females without anyone to initiate or help finance holiday-taking or to accompany them and enhance holiday enjoyment.
With regard to holiday-participation, what factors (a) facilitate, (b) inhibit or (c) exclude individuals with C-SCI?

(A) Factors which facilitate holiday-participation include former or new partners' initiating and accompanying the individual on holiday, which tends to be exclusive to males, and which reduces the overall costs, the number of attendants required and, importantly, gives them the initial confidence to leave their familiar environment. Furthermore, perseverance, assertiveness and good social, communication, creative problem-solving skills to negotiate barriers - and even an element of denial and delusion in relation to the potential seriousness of some of the health risks involved - facilitate participation. However, these skills are more often lacking in those who acquired C-SCI at a very young age having spent the least time in mainstream society in order to acquire such skills.

(B) Factors which inhibit participation include: ignorance regarding the possibility and practicalities of holiday-taking due to the dominant discourse of disability and inadequate rehabilitation practices; a lack of skills, confidence and risk-taking to manage holidays which, naturally, do not easily flourish in an atmosphere of psychological-dependency; fear to venture out in case health is affected due to a lack of holiday experience, information and knowledge of their own condition; no power wheelchair accessibility information in mainstream tourism marketing or understanding of C-SCI by providers; and no media representation of role models of tourists with C-SCI or contact with real role-models since those few, rare travellers with C-SCI often consider non-travellers to be too depressing to be around. Consequently, no opportunities arise to enlighten non-travellers through the sharing of holiday stories and travel tips. Finally, negative public reaction, stares and comments - and non-travellers' defeatist reaction to them - greatly inhibit participation.
(C) Factors which exclude individuals with C-SCI from participation include: ill-health, due to often avoidable side-effects of C-SCI outlined above; a lack of resources to finance a holiday, due to inadequate state benefits and a lack of access to employment, and to pay for up to three attendants and medical/travel insurance; a lack of genuine travel companions to physically and financially assist them and reduce the number of paid attendants; and even a lack of familiar attendants because of their often strained working-relations with clients who have not come to terms with their ‘situation’; and finally power wheelchair-inaccessible transport, buildings and facilities as well as discriminatory rules and practices.

What is perceived to be the impact of: (a) non holiday-taking for individuals with C-SCI; (b) holiday-participation for individuals with C-SCI?

(A) The impact of not taking a holiday within the first year or so after injury resulted in non-travellers believing that life as a severely-disabled person could never be enjoyed again. With nothing to look forward to or distract them, they became overly focussed on their condition and, with it, more fearful of ‘the unfamiliar’ affecting their health. Consequently, they rarely left NS and thus became increasingly depressed about the ‘hopelessness’ of their situation. Having often felt rejected or perceived by others as ‘non-human’, they became too despondent to want to connect with others in or outside NS who might distract them or be potential travel companions. Moreover, they became overly demanding and self-centred, showing little regard for attendants. To protect themselves from clients’ daily pleas for assisted suicide, attendants often withdrew socially from clients, which left them increasingly socially-isolated. This all took a heavy toll on staff’s morale at work and on the director’s ability to retain staff.

(B) Travellers with C-SCI found that holiday-taking became more important after becoming disabled. It offered them a pleasurable distraction from their difficult, humdrum and socially-isolated existence. It gave them something to look forward to, a goal, something to occupy their
time with planning, and, importantly, something to lift their spirits. They felt ‘alive’ again on
holiday, reconnecting with the world outside and even ‘less disabled’ having been part of the
mainstream again which impacted on their general well-being and interactions with others,
including attendants. Yet, most importantly, holidays offered a glimmer of hope during the
darkest days of despair post-injury. They showed them that, even as a severely-disabled person,
they could still find enjoyment which gave them hope for their future. For those with the
highest level of C-SCI, holidays provided a literal ‘life-line’ because, post-holiday, no request
for assisted suicide was ever made again, and the psycho-social benefits lasted a life-time.
These included: improved relations with attendants, a happier living/working environment at
NS and staff no longer wishing to resign; clients’ discovering old and new interests, living back
in the community, entering other parts of mainstream society and, above all, having the desire to
live, rather than merely exist, as a disabled person.

Who are the stakeholders, and what are their roles in affecting holiday-taking for individuals
with C-SCI within mainstream tourism?

The following summarises the stakeholders and their effect on the holiday-participation of
individuals with C-SCI:

- **Hospital rehabilitation professionals**: provide no holiday information or experience of
day trips/holidays; no workshops to acquire skills to negotiate barriers, communicate
effectively with attendants, tourism providers and healthcare professionals, or to take
responsibility for directing their own daily healthcare management

- **General hospital medical staff**: lack sufficient knowledge/practice of C-SCI, hence
individuals fear venturing outside their neighbourhoods in case they become sick and
need to be hospitalized

- **Attendants**: lack holiday information and training to inform/accompany them on holiday

- **Policy-makers**: provide inadequate state benefits to fund the considerable extra cost of
an annual holiday and medical/travel insurance necessary for high-level C-SCI given
the lack of access to paid employment; likewise, European social tourism policies tend
not to accommodate those who require/pay for three accompanying attendants
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- **Tourism service providers:** are generally ignorant of/lack training with regard to the condition and needs of those with C-SCI (eg, providers abort information-gathering telephone calls following initial silences due to ventilator-dependent individuals’ delayed speech; inaccessible transport, built environment (as width of door-frames under 32 inches; too few ‘wheel-in’ showers; lack of 10 inch clearance under beds for sling-hoists); discriminatory regulations/practices; airlines charging extra for carrying essential equipment yet not supplying extra belts to secure the whole body or space for a few power wheelchairs secured by wheel ‘lock-downs’; and airlines loaning unsuitable *manual* wheelchairs after airport baggage-handlers frequently damage/break power wheelchairs.

- **Tourism marketing managers:** provide no simple ‘one to six’ accessibility user-rating guide for use across all sectors or specific *electric/power* wheelchair information with layouts/dimensions of rooms/bathrooms/facilities

*What are the possible solutions to the barriers constraints to holiday-taking experienced by individuals with C-SCI?*

Various practical solutions to counter discriminatory socio-political structures were suggested in chapter seven, such as: all reasonably-sized hotels should have available a sling-hoist and a number of bathrooms with ‘roll in’ showers that can be used by any guest; a simple ‘one to six’ accessibility user-rating system should be used across all sectors with ‘six’ being fully power wheelchair-accessible for someone with high-level C-SCI; and extra belts and a number of spaces for power wheelchair with ‘lock downs’ for aircrafts. If changes are not effected, then the accumulative stress of a relentless stream of barriers that comes with the more holidays an individual has, will eventually result, as with the wealthy travellers, in either highly-restricted or total non-participation. Furthermore, a number of practical solutions emerged from the study that could potentially have a bearing on policy. One finding is the value of a narrative approach post-C-SCI, the importance of which has already been highlighted by those working in the ‘helping services’ dealing with bereavement and suicide (eg, White, 2000; Parton & O’Byrne, 2000).
In the context of this study, the narratives were considered important not solely as a vehicle to raise consciousness and challenge the assumptions of the various stakeholders - and family and friends - and to enlighten them about C-SCI and the practicalities or impact of (non)participation, but also how participants achieved understanding of and challenged their own limiting fears and preconceived notions regarding participation. Narratives of travellers and non-travellers could therefore be included in a patient's resource pack during hospital rehabilitation so that they, their families and the staff have access to an alternative discourse of disability that might have the potential to inform change.

Another possible and equally important policy-relevant practical solution is the taking of a short, one-off local holiday towards the end of hospital rehabilitation. Rehabilitation programmes will need extra funding so that they can provide patients with a goal of a holiday and the practical support to equip them with the skills necessary to undertake the detailed planning of the trip and the negotiation of barriers. Importantly, the acquisition of such practical skills prior to leaving hospital will greatly facilitate their social re-integration.

8.4 Contribution of the thesis

Hammersley and Atkinson (1995:17) state that research is and remains 'the production of knowledge'. This thesis has gone some way to produce new 'truths' and challenge old assumptions about holiday-participation for severely-disabled tourists. Furthermore, many of the findings are able to transcend this particular group of consumers to reflect the tourist experiences of other physically-disabled and/or socially-disadvantaged groups. They offer wider knowledge about the role of tourism consumption experiences in general society, in particular revealing how individuals with severe disabilities are unrecognised by the tourism industry since its policies and practices generally take into account only the needs of able-bodied tourists. Thus such 'ablism' means that those who participate in tourism are
predominantly able-bodied tourists and that the tourism industry is discriminatory in its lack of provision for disabled tourists, particularly for severely-disabled tourists.

Additionally, since tourism knowledge, to date, largely presumes inclusion, it therefore does not engage with the risks, denials and delusions often necessary for participation to be possible; neither does it engage with those disabled people who have never participated as a result of oppressive socio-political practices and structures. Consequently, it appears neutral on oppression and exclusion and thus discriminatory in practice and theory, which may even raise questions about the credibility of tourism knowledge. The thesis therefore makes a contribution to academic tourism knowledge in its exploration of the complex, inter-related issues of both ‘the absences’ from and ‘the presences’ of tourism in relation to severely-disabled individuals. Moreover, the thesis contributes to tourism theory as it builds on and develops Smith’s (1987) theoretical framework of barriers in relation to severely-disabled consumers and non-engagement in leisure travel.

The inter-disciplinary approach with disability studies and critical tourism also allows the thesis to make a contribution to tourism literature on qualitative methodologies in its detailing of the ethical and methodological challenges involved in working with such a socially and medically-vulnerable research population. Furthermore, in its desire to reach multiple audiences in order to challenge preconceived assumptions about disabled people and offer practical suggestions for change to stakeholders, ‘accessibility’ was paramount. This meant going beyond the standard presentation of ‘findings’. It thus explored the value of narrative to reach a wide audience and to illuminate both the potential of severely-disabled people, details of their lived experience of (non)participation and, importantly, their travel needs. In line with the study’s emancipatory philosophy, the focus was on the voices of the participants. The role of researcher in reporting their unheard stories was thus demonstrated and the many challenges exposed - ethical and
otherwise - in the writing process whilst attempting to ‘give voice’ to their previously silenced voices and interpretations.

Finally, the thesis makes a contribution to tourism practice in its provision of practical suggestions to stakeholders which are designed either to enhance the holiday experience of experienced travellers with C-SCI or to afford those who have never travelled the opportunity to take a holiday. A number of concrete issues arose from the data that point to the implementation of practical measures. For example, airlines need to provide space on board for a number of power-wheelchairs, secured by wheel ‘lock downs’, so that passengers with C-SCI can remain in the relative comfort and safety of their wheelchairs and manage their own weight-shifts. In addition to the usual lap belt, a number of other belts should be carried by airlines and provided on request so that the head, chest and legs of passengers with high-level C-SCI can be secured to prevent them from falling and damaging skin or affecting breathing. The WTO needs to take the lead in dismantling barriers and promoting a multi-agency approach to facilitating change. Furthermore, the tourism academy must look outwards to other professions, eg medical and social care colleagues, to be able to address ‘the absences’ of tourism effectively and facilitate greater participation.

Policy-relevant findings also emerged from the study. Since severely disabled people have even less access than other disabled people to employment, yet incur greater holiday costs in the hiring of or transporting equipment, and paying for up to three attendants, any social tourism policies/state benefits should reflect this. Thus financial provision needs to be made accordingly so that all disabled individuals are financially able to take an annual holiday. Again, with policy implications, to meet the unspoken desire for, and to overcome fear of holiday-taking and the world outside, hospital rehabilitation programmes need to equip patients with the practical skills necessary to be able to plan and then take an accompanied, short, local holiday before they leave hospital. Without this experience, and the longer individuals with C-
SCI remain non travel-active post-rehabilitation, the less able they become to imagine anything beyond their window-sill horizons and, consequently, they enter a downward spiral of depression and social isolation. Finally, in contributing to wider knowledge, the importance of a local holiday during hospital rehabilitation may be equally relevant for different disabled groups as well as for those recovering from other forms of trauma.

8.5 Limitations

Three major limitations were recognised which may lend themselves to possibilities for further research. Firstly, research was exclusively undertaken in the USA, a modern, spacious and rich country with an enhanced level of physical access although no National Health Service. Thus, the experiences of holiday (non)participation and social inclusion or exclusion may be wholly, or in part, different for individuals with C-SCI in non-Westernised, industrialised countries, and/or in those countries with free health care or with a different cultural attitude to disability.

Secondly, fieldwork focused solely on those who had lived with C-SCI for a considerable period of time - generally twenty years or over - and had largely accepted their condition. The response to holiday-participation may be different from those relatively recently-injured individuals, or those in the latter stages of, or just post, hospital rehabilitation.

Thirdly, data on participation was collected exclusively from the testimonies and memories of travellers’ past holidays rather than alongside participant observation of their actual holiday-taking and interactions with tourism service providers and other tourists. The latter might have offered an additional lens through which to observe issues of participation that participants might not have been aware of, had forgotten or even found insignificant or embarrassing to relay.
8.6 Suggestions for future research

The limitations of the study lend themselves to possibilities for further research. Further research could be undertaken to determine whether having a National Health Service in, for example, the UK has any bearing on the ability of an individual with C-SCI to take local and national holidays, or whether being from a culture that takes a different view of disability from that of most Western, industrialised countries impacts on one’s participation and social (re)integration. Furthermore, interviewing tourism providers and other tourists, and involving the researcher in participant observation of the planning, taking and aftermath of a holiday of a number of individuals with C-SCI, would offer an additional lens on the types and causes of barriers encountered as well as on their negotiations and potential practical solutions.

With such a dearth of tourism research focusing on severe disability and also on women with C-SCI in sociology and psychology, it is important that future research addresses issues of non-participation that are particular to severely-disabled women. Again, touching on some policy-relevant findings of the study, further research could also examine and evaluate the quality and impact of non-sporting leisure activities and the social-psychological support offered to patients, and their families, within hospital rehabilitation in order to determine whether patients are being equipped with the skills necessary for both holiday-participation and social adjustment and re-integration into mainstream society.

Finally, with the possible introduction of travellers and non-travellers’ narratives as a resource to be used in one hospital rehabilitation programme but not in another, parallel longitudinal studies could be conducted to explore the impact of the narratives on patients and also on staff and family members. Within a timeframe the studies could examine the ways in which the following are manifested post-injury: the (undisclosed) desire or lack of desire for a holiday; the fear of holiday-participation and the outside world; and the actual planning and taking of a first
holiday and the initial and long-term impact of (non)participation on self-concept, quality of life, general wellbeing and social re-integration.

8.7 Final reflections

As this final chapter draws to an end, it must be acknowledged that this thesis has developed a dual focus. On the one hand it addressed, as intended, the complex plethora of inter-related individual, social and societal barriers to holiday-participation for individuals with C-SCI and, in view of the life-affirming/changing benefits of participation, it proposed practical solutions and much policy-driven structural change to enhance participation. At the same time, it found that for these changes to take place effectively, the dominant narrative of disability needs to be challenged as 'a law cannot guarantee what a culture will not give' (Mary Johnson). In other words, as discrimination is often very subtle, with personal attitudes more difficult to change than societal ones (Daruwalla & Darcy, 2005) 'there will be no simple revolutionary changes in medicine or in politics which will deliver liberation [for disabled people]' (Williams, 1996: 208). Indeed, how much real progress has been made since the introduction of the ADA (1990) or the DDA (1995) is questionable as discrimination, prejudice and poverty are still commonplace for many disabled people and even more so for severely-disabled people; co-operation is thus necessary between disabled and non-disabled people (Shakespeare, 2005).

Part of this process of co-operation may well be in the making available collective stories (Richardson, 1990) and counter-narratives (Nelson, 2001) of disability because, as Smith and Sparkes (2008a: 19) observe, these:

can provide alternative maps and different emplotments regarding disability and impairment that refuse and displace the tragedy story, that challenge and resist social oppression and that allow different body-self relationships to emerge. Thus, if we change the stories we live by we quite possibly transform and change our lives and society too.
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Certainly, it is essential that policy-makers also effect physical changes to transportation and the built environment as well as changes to hospital rehabilitation programmes and state benefits. Yet, barriers to holiday-participation for individuals with C-SCI - via personal prejudice and national values - will not easily fade unless society revises its preconceived notion of severely-disabled people and challenges their absence from tourism. Counter-narratives may, therefore, be an effective, yet non-threatening, vehicle to facilitate this because, as traveller Ralf recognises, real change can only be realised if people, in general, 'get re-educated'. Thus, it is hoped that those responsible for tourism education - the tourism academy - might be some of the first to take up Ralf's call to 're-educate' in the same way as he proposes that:

...airlines should try to educate their people more, and the people in the hotels and attractions could use some more education too regarding our type of disability. I think education is a big part of it, and that's the same thing with society.
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