Understanding the resilience processes involved in social participation amongst visually impaired adults in the UK

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A thesis submitted to the University of Birmingham for the Degree of Master of Philosophy

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September 2016

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ABSTRACT

The current thesis explores the construct of resilience amongst visually impaired people who participate in social life. Three studies were used to investigate the resilience factors and processes involved in social participation for visually impaired people living in the UK. Study one set out to identify the factors associated with an increased risk of social isolation. Taking social participation as a proximal indicator of social participation, a secondary analysis of survey data compared the social support status of participants taking part in three surveys (Network 1000, RNIB needs survey and Household Survey England). The results indicate visually impaired people who are registered are least likely to have access to social support. Study two, a two round Delphi study sought the views of twenty-two experts to define social participation as well as the risk and protective factors underpinning social participation and specifically, those relating to visual impairment. The findings suggest that whilst independence and confidence were amongst the protective factors located at an individual level, a number of risk factors located across a visually impaired person's ecologies pose a challenge to their participation. The findings also revealed the emergence of resilience processes. The final study (Study 3) further explores resilience processes using data collected by six visually impaired people whilst participating in their local communities. Reflecting the findings of the Delphi, the findings indicated that the personal attributes of individuals played an important role in being able to participate independently such as planning ahead and positive attitude even when things go wrong.

ACKNOWLEDGEMENTS

I would like to thank my family and friends for showing me unending support and encouragement. With special thank you to my friend Sharron Hiles who would constantly enquire whether I was actually in the library and my wonderful colleague Sue Keil who took the time to read my first draft in its entirety. To my RNIB manager Dr Paul Herriots – thank you for believing in me.

I would also express my gratitude my supervisors Professor Graeme Douglas and Dr Ian Davison. I hope their guidance and patience has been rewarded.

Finally, I thank the participants who gave their time and enthusiasm to this project.

DEDICATION

This thesis is dedicated to my grandmother Amelia Louise Edwards.

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CHAPTER 1: Introduction

Background to the thesis

Social participation (and its lack of), has been a topic of concern for advocates of visually impaired people for decades. Whilst a lack of participation is not an inevitable consequences of visual impairment, taking part in 'normal' community activities does pose numerous challenges for those who strive to maintain their independence. However, whilst isolation is all too common an experience for visually impaired people, many are also engaging in community life in spite of these challenges. The theory of resilience provides a useful framework for understanding how some visually impaired people participate in their communities in spite of those challenges. This thesis seeks to apply resilience theory to examine the resources promoting the social participation of visually impaired people.

This thesis came about after I began employment as a researcher for the Royal National Institute of Blind People (RNIB), a sight loss charity providing information and services to visually impaired people and their families. Although visual impairment is not always obvious or apparent, in my previous research roles outside of the visual impairment sector there were no employees with sight loss. In contrast, my visually impaired colleagues at RNIB were working at all levels of the organisation, travelling independently to attend meetings, conferences and engaged in other activities related to their employment. IT was used in the same ways as sighted colleagues with the exception of assistive technologies which facilitated access to online resources. On a social level, visually impaired colleagues would discuss their holidays and other participatory activities.

Yet through my own research activities, I was acutely aware of the isolation and difficulties with social participation encountered by many visually impaired. Empirical studies focusing on visually impaired people suggests that there are significant barriers to social participation. I wanted to investigate the factors enabling my colleagues to take part in social life so that other visually impaired people could be helped. I suspected that visually impaired people who appeared to maintain 'normal trajectories' shared similar personality attributes (Dweck, 1999), which were probably absent in individuals who were not doing so well. My initial search therefore became to identify the personality attributes which facilitated successful functioning.

My hunch was bolstered by the discovery of the relatively nascent body of research on *resilience* theory which emerged in the 1970's. Resilience can be broadly defined as the study of the human capacity to achieve positive adaptation within the context of adversity (Luthar and Chichetti, 2000) and commonly referred to as the ability to 'bounce back' (Rutter, 1985) or beating the odds (Rutter, 1990). Early studies of resilience focussed on psychopathology in mainly children and adolescents considered to be at 'risk' due to their genetic or environmental situations. Interest turned to those young people who in spite of their adverse environments went on to become successful adults. At this the stage the phenomenon was largely considered to be a personal trait resulting in descriptions of individuals as being 'invulnerable' or 'invincible' (Anthony, 1974; Werner and Smith, 1982). This seemed to be a good fit with my own proposition, since pioneers in the field also shared my concern with identifying 'resilient' traits (Masten and Garmezy, 1985). However, as the body of research on resilience burgeoned, it became apparent that whilst personality traits were important correlates of healthy functioning, factors external to the individual such as secure attachment to caring adults could also be used to explain positive outcomes. Resilience is now widely recognised as a dynamic process rather than a static trait which enables individuals to withstand disruptions and reintegration to homeostasis (Richardson, 2002).

Having reviewed the literature on resilience it became apparent that there were several problems with my initial hunch. Placing personality at the centre of my investigation and taking a variable based approach to resilience masks interactions between and within explanatory variables found at the various domains of a person's social environment (Ungar, 2004). My early assumption also implied that individuals deemed to be less successful are somehow responsible for their poorer social outcomes since they must inherently lack the necessary traits, and that 'everyone can make it if they only try' (Schoon and Bartley, 2008; page 24).

My attention then turned to reviewing research on resilience and visually impaired people. I found that there were very few published empirical investigations adopting the resilience framework. Whilst there is an abundance of studies exploring discrete factors posing barriers to and facilitators of a wide range of aspects of social life, there has been little attempt to build an understanding of how these factors lead to obtaining a positive outcome.

Terminology

Before moving on to describe the structure of the thesis it is necessary to discuss the language and terminology describing the population of interest. The decision was taken to use the term ‘visual impairment’ over terms such as ‘blind’, ‘partially sight’ or ‘disabled’ in appreciation of the impact that language and terminology has on the identities of people living with little or no sight. Importantly, language and terminology shapes the ways visually impaired people are regarded by others which as the thesis progresses, is a key aspect of this study.

Language contributes to the construction of the world. The language used to define disability and therefore those often referred to as disabled, shape our everyday understandings of impairment (Barton, 2001). The basic tenet of this argument is the post-struturalist and later, social constructionist belief that language is used to uphold a society's dominant ideology. In capitalist western societies the dominant ideology is one of individualism, where the self and body is prized. This prevailing ideology is legitimised and transmitted through the use of language which conceptualises the value of the self through physical ability. Notions of normalcy are embedded within the 'public consciousness' through the process of socialisation (Bogle, 2007). Since the language used to denote the self is defined by abelist society, the disabled body is defined in relation to its semantic opposite the 'able body'. Wendell notes that,

> *'Disability is socially constructed, predicated on notions of difference and signifying the simultaneous distinguishing and positioning of groups [disabled versus non-disabled] vis a vis one another'* (Wendell, 1996 p.23).

Foucault suggests that the use of such binary oppositions is a means of maintaining power whereby the group 'without' are correspondingly those without power (Gregen, 1999). Wider cultural assumptions around individuality, personal autonomy and self-determination within a society are expressed through everyday phrases such as 'standing on your own two feet', 'staying one step ahead', 'standing up for yourself', 'walking tall' and 'making great strides' (Swain et al, 2003:22)'.

Bolt (2005) who has written extensively on the language of visual impairment suggests that there are three distinct evolutionary phases in the terminology used to describe visual impairment: the ablement phase, disablement phase and the impairment phase. Bolt regards the ablement phase as being rooted within the dominant ideology of individualism and ableist notions of normalcy. The term 'blind' was not used in this thesis as it provides a good example of the ocularcentric nature of language. Derived from an Indo-European expression to denote confusion and obscurity, it illustrates the internalisation of the dominant language. A person who is unaware of their surroundings is derided as being blind (Marks, 1999). In addition, Bolt provides literary examples of writers such as Dickens (1845), Kipling (1891) and Sontag (1967) who describe blindness using metaphors of darkness and an absence of light (Bolt, 2005). Yet this bares little relation to the experiences of visual impairment. Less than a fifth of people with a visual impairment (18%) have no light perception (Bruce et al, 1999) and 10% with no light sensitivity at all.

The social model which is described in more detail later in this thesis, provided a challenge to the everyday language of disability. According to Bolt, the rise of the disability movement and the influence of the social model resulted in a linguistic turning point marked by the disablement phase. This phase is characterised by impaired people fighting back, self-discovery and recognition of the inadequacies of the existing terminology. During this phase the language used to describe people with physical and mental impairments underwent a process of 'terminological appropriation' (p13). The term visual handicap can be located to this period not as a pejorative term but as *‘a response to, rather than an aspect of, ableism’* (Bolt, 2005). This phase is also typified by the use of politically correct terms such as visually challenged which is a reflection of a period of transition whereby albeist society are uncertain of the correct terms to use whereby whilst not wishing to offend. The term 'visual disabilities' was also posited as a possible acceptable term but is problematised by the word 'disability' which is itself a construct of 'abelist ideology' (Bolt, 2005) since it relies on its opposite 'ability' to be defined (Linton, 1998).

The term visual impairment represents Bolt's third phase of terminological evolution and is the term used throughout this thesis since it is the least ambiguous and erroneous in meaning to its predecessors. Visual impairment as Bolt notes, 'denotes nothing more than impairment and is therefore pertinent to the discourse of the social model of disability. It enables recognition of the fact that people are not with but frequently confronted by disabilities' (p.19). Bolt does not see the term visual impairment as 'static but progressive' (page 23). Bolt’s rationalisation for the use of visual impairment over other terms is deeply entrenched in social model readings of disability and as will be discussed later in the literature review, the social model of disability is not the only view of disability.

However, visual impairment and analogous terms at least provides a foundation on which to assess other factors which lead to disability. Similarly, the terms ‘disability’ and ‘disabled people’ are used throughout the thesis to describe the state in which people with impairments are disadvantaged by the interaction of biopsychosocial factors.

Thesis Structure

This introduction thus far suggests that there is a basis for further a detailed investigation into the factors and processes which promote the social participation of visually impaired people within a resilience framework. With considerable evidence to suggest that a lack of social participation is a problem and few studies taking a multidisciplinary approach to understanding positive outcomes, a study is indeed required. To address these issues the thesis is divided into 9 chapters. The aims and content and section of the chapters are in the order they are presented are described.

Literature review (Chapter 2 and 3)

The literature review (Chapters 2 and 3) is divided into six parts and takes the reader through a discussion of the complexities of the main constructs - visual impairment, social participation and disability. The thesis continues by drawing the three constructs together by describing the challenges to social participation for visually impaired people. The review concludes with a discussion of resilience, a theoretical framework for understanding how the challenges are overcome to result in a positive outcome. Details of the review in the order they are presented in the thesis are provided below:

Part I Visual Impairment (Chapter 2)

Part I describes the demographics of the visually impaired population. The numbers and main causes of visual impairment are described as well as the heterogeneity of the population as a result of the various ways people acquire visual impairment. The ways in which defining the condition in legal of functional terms impact on eligibility to rehabilitation services. The role of rehabilitation as an important source of support for increasing social participation is also provided.

Part II: Social participation (Chapter 2)

Part II progresses the review by delving deeper into the concept of social participation. It describes how in spite of being an important determinant of health and wellbeing, there is no single agreed definition of the construct. Two studies which attempt to explore definitions of social participation are discussed: Lavasseur's systematic review of investigations using definitions of social participation and Hammel's focus groups with disabled people on the meaning of social participation. Both studies emphasise different aspects of social participation, the former underscoring what people are doing and who they are doing it with, whilst the latter prioritising the values attached to the social activity being undertaken. The analysis of the two published studies highlights the differences in research outcomes depending on the use of objective and subjective data collection methods.

Part III: Social participation and theory (Chapter 2)

Part III of the review explores the concept of social participation within the context of disability theory. A critical examination of disability theory was deemed necessary to understand the sources of on the lived experience of people with impairments. In this part of the review social participation is positioned at the centre of disability studies by reconceptualisating this key pivotal construct as 'taking part in society's 'normal functionings'. A detailed discussion is undertaken of the three main models of disability which are underpinned by explanations of why people with impairments are prevented from functioning fully in society. On the one hand the so called medical model locates the adversities encountered by people with impairments as an individual issue and implicitly views impairment as the risk to be overcome. At the other end of the theoretical spectrum, the social model mentioned earlier in this chapter, regards the restrictions to participation as being firmly rooted within a given societies political, cultural and economic processes (Oliver, 1994). This chapter argues that both models arguably have merit in appropriate settings but are solely inadequate for disability researchers to reproduce the accounts of disabled people. A third model, the biopsychosocial model of disability bridges explanations of the cause of disability by suggesting that restrictions to social participation are influenced by interactions of both individual and environmental factors. This third model is increasingly recognised as providing a more accurate reflection of the experiences of disability.

Part IV: Visual impairment and social participation (Chapter 2)

Part IV of the review focusses specifically on visual impairment and social participation and provides evidence that this population do indeed encounter numerous challenges whilst attempting to participate in social life. Reflecting the discussions on disability theory, this section illustrates that the source of challenges to social participation involve both impairment and environmental factors and in many cases a combination of the two.

Part V: Resilience (Chapter 3)

The theory of resilience is introduced in part v of the review which presents a brighter and more optimistic way of addressing the challenges described in earlier sections of the review. The chapter begins by describing the merits of adopting a strengths based approach such as resilience rather than taking a deficit which can promote low expectations. The chapter progresses by discussing the development of conceptualisations of resilience over four successive waves of investigations (Richardson, 2002; O’Dougherty et al, 2012). Links are drawn with disability discourse in as much that like disability, the construct of resilience has undergone a similar process of definitional refinement. Resilience was also initially regarded as an innate property of individuals and is now viewed as a multi-systemic, interactional process. Key resilience terms are also introduced as well as the theoretical models used to explain resilience mechanisms. This section then looks at empirical investigations with a specific focus on visually impairment and resilience theory. It discusses how with few exceptions, the topic of resilience has seldom been applied to research on visual impairment.

Chapter 4: Literature review summary leading to research questions

Chapter 4 summarises the literature by drawing out the emerging themes which are that social participation is an expected ‘norm’ in society and that whilst some people with a visually impairment have been able to buck the trend; a lack of participation is *the* norm for many. Whilst disability theory suggests that normal expectations are lowered for people with impairments, other factors located across systemic levels are likely to influence social participation. Likewise, resilience theory indicates that the assets and resources people draw on to withstand these challenges are also likely to be located across systemic levels. However, whilst Interactional frameworks such as the ICF and SEM allow for disabling and resilience processes to be captured there are issues relating to the conceptualisations of key concepts which require resolution. This part of the review concludes by rationalising the discussion in the previous chapters and leads to the research questions.

RQ1. Which visually impaired subgroups are most vulnerable to an increased risk of a lack of participation?

RQ2*: How is a successful outcome defined?*

a) What are the indicators of a successful outcome (social participation)?

b) What are the characteristics of someone 'doing well'?'

RQ4: How can the resilience processes involved in social participation be described?

Chapter 5: Methodology

In chapter 5, I discuss the ways in which a combination of opportunity, pragmatism and the drive for greater subjectivity, led to the use of a mixed methods design. I describe how the emergent design was principally driven by the research questions each of which, had different epistemological groundings. The use of quantitative methods in study 1 to operationalise RQ1 is rationalised. I argue that quantitative methods facilitate both comparisons with and generalisations of large populations. Since the purpose of RQ1 was to identify factors associated which an increased risk of a negative outcome, a quantitative method was the logical approach. I describe how the opportunity to conduct a secondary analysis on existing survey data on visually impaired people presented itself. The data was focussed on the perceived level of social support which was used as a proximal indicator of social participation. Post analysis reflections are described which were that quantitative methods such as the secondary analysis can only reveal so much about complex phenomena such as disability and resilience. I describe how RQ2 and RQ3 required greater context and subjectivity in combination with the dual requirement to consolidate views on a) the definition of social participation and b) the risk and protective factors involved in social participation. The chapter continues by describing the use of a two round Delphi (study one) which was chosen due to its propensity to generate interpretative data in round 1 whilst encouraging agreement amongst panel members in round 2. The chapter continues by describing how after the completion of study 2, it became apparent that even the Delphi, with its interpretative first round, was too limited an approach to capture the complexed and multifaceted nature of resilience. Further deliberations led to the conclusion that phenomenological inquiry would be best suited to obtain first person experiences of the complexed interactions of resilience processes. Following a discussion of the narrative inquiry which was adopted for study 3, the chapter progresses by rationalising the mixing of research approaches and culminates with a description of the three resulting studies.

Chapter 6: Study 1 - Identifying individuals at risk of social support

In chapter 6, I describe study 1, a secondary analysis of the social support levels of registered visually impaired people in comparison with unregistered, long term disability and illness and the wider UK population. The chapter begins by describing the link between social support and social participation and its role as a protective factor across resilience studies. The research problem is stated and the method and analysis is described. The findings are presented which indicate that overall the registered population were most likely amongst the populations in the analysis to encounter some lack of social support making them more vulnerable to the experience of the negative outcome (a lack of social participation). However, visually impaired people who are unregistered are more likely to experience a severe lack of social support. Within the registered population attributes such divorce, living alone and living with long term disabilities or illnesses in addition to visual impairment were also found to increase individual vulnerability to isolation.

Chapter 7: Study 2 - Delphi Study

Chapter 7 presents details of the Delphi study which harnessed the opinions of twenty-two experts within the field of visual impairment. The advantages of the Delphi are described after which the chapter continues by presenting the themes emerging from round 1. In round 1 experts were prompted to identify the characteristics indicative of a visually impaired person who was successfully participating in social life. The risk and protective factors influencing social participation were also identified at this stage. Round 2 consensus involved the ranking of the themes which are also discussed.

Chapter 8: Study 3 - Narrative enquiry - Audio diaries

Chapter 8 presents data from the audio diaries of six visually impaired adults which were collected over the period of a week which provide rich descriptions of participatory events as they experience them. The chapter begins by describing the ways in which the narratives or stories people tell can reveal the processes inherent in social life which can be missed using other methods. The recruitment of participants and the process of analysis is described. The chapter describes provides in contextually specific detail on the ways in which risk and resilience processes operate whilst visually impaired individuals participate independently in their communities. The chapter concludes by describing the models of resilience mechanisms present during participation.

Chapter 9: Discussion and Conclusion

In the final chapter of the thesis (chapter 9) the findings of the three studies are synthesised and their contribution to understating of resilience is stated. This chapter also discusses the research implications and areas for further research.

CHAPTER 2: Literature review part 1 to 4 – visual impairment and participation

In the previous chapter I stated that visual impairment is not always obvious or apparent and that there are misconceptions about what visually impaired people can and cannot see. There are also many myths about visual impairment and it is the hope that these will be debunked as the thesis progresses. Whilst the ultimate goal of the thesis is to achieve an understanding of resilience amongst visually impaired people, a useful starting point is a discussion on the population data. This first part of the review therefore furnishes the reader with basic information on the population estimates of visual impairment in the UK and its main causes. This section will demonstrate that the term visual impairment is not a condition per se but a term describing the consequences of a number of medical conditions. Because of the broad range of conditions, the diverse ways in which people become visually impaired and the likelihood of having additional disabilities, there is considerable heterogeneity within this population. This section describes how legal definitions which classify visually impaired people for policy and administrative purposes such as the registration process fail to take into account differences in an individual's ability to function in a range of contexts and environments. This can effectively deny access to statutory services designed to support the integration of the participation of visually people in their communities. The role of rehabilitation in helping visually impaired people to set goals, one of which is social participation is also discussed.

2.1 Part I: Visual impairment

2.1.1 Legal definitions of visual impairment

The term visual impairment is an umbrella term describing a broad spectrum of medical conditions which limit the function of the eye or visual system and are un-correctable by glasses or contact lenses. It is estimated that around 1.8 million people in the UK are living with a level of sight that significantly impacts on their daily lives (Epivision, 2009). The causes of visual impairment are attributable to four main conditions: Age Related Macular Degeneration (AMD), glaucoma, cataracts, diabetic retinopathy. Other conditions include retinitis pigmentosa and neuro ophthalmic disorders which account for the remainder of conditions (Access economics, 2009). Visual impairment can affect anyone at any time although the vast majority with a visual impairment are older. Some conditions have been found to be more prevalent amongst certain ethnic groups. This is illustrated in the excerpt from RNIBs website:

> *‘The black population aged under sixty has a greater risk of developing age-related macular degeneration (AMD) compared to the white population of the same age, whereas the white population has a greater risk of developing AMD in the later years of life. Overall Asian people are at lower risk than white people of developing AMD. Asian people have a greater risk of developing cataracts compared to the black population and white population. Black and Asian populations have a greater risk of developing diabetic eye disease compared to the white population. The risk of glaucoma is much higher for the black population compared to the white population. The white population has the greater risk in developing refractive error compared to the black population. (RNIB, 2015)*

Estimates are however, complicated by the wide range of terminology used to define visual impairment (European Blind Union, 2003). The complexities of language and terminology then have implications for defining the numbers of people with visual impairment in the UK. The ‘legal’ definition of sight loss which is accepted by the state with regard to eligibility for registration and entitlement to state benefits. Legal definitions of visual impairment use a combination of distance and field measure calculations to assess visual function (Charles, 2007). Visual function is assessed in two ways namely acuity (sharpness or clarity of vision) and field (range). Visual acuity, relates to central vision for example that which is used to read a book or watch television, and is the typically measured by an ophthalmologist using a Snellen eye chart. Visual field, referring the range is measured using a field of vision test. Table 1 (below) shows the distance measures used in calculating of visual acuity. The first number in the measure is the furthermost distance at which the person being assessed can clearly see an object. The second number represents the distance at which a person with normal vision could see the same object. For example, to be certified as severely sight impaired, a person can see an object at 6 feet or less an object that a person with normal vision can see at 18 feet.

Table 1: Visual acuity criteria for sight impairment

Visual impairment (6/18 – 6/60)			
Low vision		Blind (<6/18 - 3/60) NPL	
Moderate Vision	Severe visual impairment 6/60 – 3/60	Light perception	No light perception

Functional vision

Several authors express the view that simply establishing visual function does not sufficiently explain how a person may function in specific contexts and environments. Praat and Keil (2003) for instance, argue that *'...for the most part, clinical condition or impairment is not very closely associated with a person's ability to function in their environment'* (2003, p44). This view is mirrored by Opthalmologist Kenneth Jernigan (2005) who states that in his opinion, blindness *'can best be defined not physically or medically but functionally or sociologically'* and continues to write that: Individual's with similar levels of acuity will function in different ways in different contexts. In other words, the tests and measures decontextualises situations in which vision is utilised in everyday situations. These differences may also be attributable to the wide range of reasons people become visually impaired. Arguing along similar lines, Colenbrander (1996) goes as far as saying that to define an individual as legally blind is the equivalent of defining a patient with a severe heart ailment 'legally dead', that is to say, the label lacks the sensitivity needed to accurately reveal anything about the lived experience of visual impairment.

A further problem is that the vast majority of people living with a level of sight which impacts on their daily lives fall below the legal criterion for state entitlement. The aetiology and onset of visual impairment are diverse, ranging from occurrence at birth (congenital), trauma or as a primary or secondary consequence of disease (adventitious). Some people will experience an eye condition that develops slowly while others will experience a sudden loss of vision. Other conditions may only present problems for individuals when completing particular tasks, as in the case of colour blindness or at certain times of the day when light is low. Around half of people with visual impairment are also living with other types of health conditions. This diversity combined with cultural, environmental and individual factors can make it difficult for people with a visual impairment finding others with the same visual concerns (Milian, 2001). This heterogeneity also makes visually impairment a complex condition for researchers in terms of methodology.

2.1.2 Congenital and acquired visual impairment

An important distinction however can be made between individuals with congenital and acquired vision loss since both sub-populations are likely to have different mental health requirements (Skellington Orr et al, 2006, Dodds, 2001). It is important to note that congenital visual impairment does not necessarily mean the absence of any functional vision. Dale and Sonksen (2002) also stress the importance of distinguishing between cerebral congenital disorders (potentially complicated) and conditions in which there is no known involvement of the central nervous system in the visual disorder diagnosis (potentially uncomplicated). Pring and Tadic (2010) note that because individuals with peripheral conditions which are potentially uncomplicated have lower chances of learning disabilities, this population are useful for investigations on the psychological impact of visual impairment.

The presence of visual impairment at birth will have a significant impact on cognitive and motor development given that most of what we learn are acquired through visual information. Children with visual impairments typically demonstrate delays in reaching developmental milestones (Sherrill, 1998). Goodman and Wittenstein (2003) argue that developmental delays are not inevitable and are due to a lack of external input and fewer opportunities to engage in group activities which provide the stimulation available to sighted children. Lowenfield (1981) suggests that children with visual impairment require special experiences to make sense of what they are learning because they have less opportunities for incidental learning. Indeed neuroimaging studies examining how the brain copes with the absence of light have shown that neural pathways are diverted and *'…respond to other experiences from other sensory channels*.' (Pring and Tardic, 2010).

Although individuals who acquire sight loss later on in life will have had the 'benefit' of seeing the world around them, the experience of losing one's sight will have its own specific challenges. The psychological impact of losing one's sight is often described as a bereavement (Baus, 1999). Baus describes the first stage as starting with shock and denial in which the person is in denial about the loss of vision and fearful of further deterioration. Baus notes that this stage is marked by paralysis which protects individuals from the strong emotions they are facing. The second stage is characterised by a recommencement of emotions such as anger and distress. Which are directed to the outside world. The third stage suggested by Baus is that of depression and despair and the realisation that life will no longer be the same. The fourth and final stage is characterised by growing acceptance of the changed relationships with oneself and the world. During this stage individuals display a gradual willingness to participate in life situations. Baus indicates the four stages represents an ideal case although each individual will *'pass through them in their own particular way'* (p.43).

Where the registration process is working well contact is made through local authority social services and rehabilitative work begins to support individuals through the process of adjusting to the visual impairment. The World Health Organisation (WHO) describe rehabilitation as

> *'…a set of measures that assist individuals who experience or are likely to experience disability to achieve and maintain optimal function with their environment.' (2011, p96).*

Although tailored to meet the needs of each individual, rehabilitation for visual impaired people typically includes the training in the use of low vision aids and orientation and mobility. However, even after registration many can experience a wait for an initial contact with social services which depending on where people live can be several months (Douglas et al, 2008). A lack of key support services such as emotional support and counselling, mobility, rehabilitation and general support with daily living (Pey et al, 2006; Douglas et al, 2008; Nzegwu, 2004; McBride, 2000) in addition to a lack of organisation around the provision of information is found to exist (Douglas et al, 2008). The same survey found that those of working age were particularly less satisfied with the information they services they received which is particularly necessary for obtaining information about job retention or retraining for employment.

Problems of obtaining information about available services are greatly exacerbated due to the inaccessibility of information materials (Sibley, 2009). The lack of accessible information is a key barrier to inclusion for visually impaired people and is a pervading theme in all aspects of social life. Even amongst medical staff the general expectation amongst clinicians and other health service staff was that patients with a visual impairment could ask relatives or carers to read information on their behalf. Aside from obvious privacy and loss of independence issues, research has shown that visually impaired people cannot always be sure that those 'doing' the reading are doing so comprehensively or interpreting the information correctly (Edwards, 2011).

The services older visually impaired people receive are largely dependent on the knowledge and awareness of the social care professionals conducting the assessment of need (Charles and Manthorpe, 2009). In addition, staff interpretations of the 'Fair Access to All' (FACS) policy and departmental processes mean that some receive services that others in different geographical locations do not (Charles and Manthorpe, 2009). The needs of visually impaired persons residing in care homes are also under researched (Cattan et al, 2010)

This part of the review illustrates that although there are almost 2 million people living with visual impairment, the term represents a very disparate population. The needs of individuals will vary considerable depending on the condition, when and how they become visually impaired and whether additional disabilities or illnesses are present. Contextual and environmental factors may also impact on a person's ability to take part in social life, a factor which is not adequately accounted for in legal assessments of visual impairment. As a consequence, statutory services designed to support the social participation of visually impaired people may exclude those falling under the threshold for assistance. The next part of the review discusses the reasons why social participation is regarded as a central goal of rehabilitation and that in spite of its importance a universally agreed definition does not exist.

2.2 Part II: Social participation

This section of the review discusses the concept social participation. Its central position within this thesis indicates that construct is regarded as a desired outcome for all visually impaired people. Indeed, social participation is as a key determinant of health, wellbeing and morbidity and found its way on to the social exclusion agenda in the UK. Research and policy interest in the construct has also increased since the inclusion of the term ‘participation’ in the WHO framework of disability (ICF). In spite of the high profile of the construct, there remains a lack of consensus on the conceptualisation of social participation and its distinction to the term participation. Efforts by researchers to create working definitions of social participation such as Lavasseur (6 distal proximal levels) and Hammel (social participation equating to social values) are discussed.

2.2.1 A universal goal

Social participation is regarded as a universal goal not just in rehabilitation terms but for all citizens in democratic and civil societies. At an individual level social participation is a key determinant of health, happiness, perceived quality of life, morbidity and mortality. Particularly for older people social participation is associated with healthy aging and greater independence with activities of daily living (Berkman et al, 2000). Researchers Dieckhoff and Gash (2015) contend that on a macro systemic level sustainable democracies require social participation for cohesive societies. They suggest that social participation is required to enable people to interact with each other across boundaries of economic status. In addition they maintain that socially active people have stronger social networks which provide access to social and economic resources such as information about jobs. Thus, social participation can provide psychological, physical and economic benefits. Despite being an important health outcome however, there is surprisingly little consensus on its meaning, its differentiation from other ‘social’ terms and how it should be assessed. This has important consequences for its measurement, the ability to compare results across research studies and as noted by Lavasseur et al (2010) can results in *‘blurred or incomplete policy efforts’(p.2142).*

2.2.2 Origins of social participation

Fougeyerollas (2010) regards the interest in social participation as emerging in post war Scandinavia as a response to the institutionalisation of people with mental, intellectual, sensory and severe motor disabilities. Advocacy professionals working to promote community integration and the right of disabled people to engage in activities that were most similar to those valued in their social and cultural environment. In the 80s and 90s however, criticism that integration did not provide opportunities for disabled people to interact within their communities. Fougeyrollas suggests that as a result, community based integration was developed which made reference to the active contribution of disabled people as community members who should be able to participate in activities normally valued by the overall population and engage in positive interactions with others (McColl, 2001; Thorn et, 2009; Ware et al, 2007). Simultaneously a drive for greater independent was being pursued by disabled people themselves. The Movement of independent living (ILM) was initiated by people with sensory and motor impairments who wanted to emancipate themselves from the control enforced by the professionals in their lives.

In the UK social participation gained political currency in the UK when in 1997 the newly formed Labour government made 'tackling social exclusion' a key theme of its government charter. Social exclusion overlaps with previous conceptual accounts of disadvantage and deprivation (Morgan et al, 2007) such as poverty, marginalisation and the somewhat depreciatory term 'the underclass’. There are however important differences. Whilst poverty is uni-dimensional and generally refers to a lack of material resources (Silver and Miller, 2003), social exclusion is a multidimensional phenomenon, encompassing not just economics and capital assets but a wider range of aspects of social and political life such as social participation and political engagement.

The cross departmental Social Exclusion Unit (SEU) was formed and its mandate was to ‘develop integrated and sustainable approaches to the problems of the worst housing estates, including crime, drugs, unemployment, community breakdown, and bad schools etc.’ (Social Exclusion Unit 1997, p2). (See Platt, 2011). Participating in the following areas of social life are regarded as important in the avoidance of social exclusion:

- Consumption: the capacity to purchase goods and services;
- Production: participation in economically or socially valuable activities,
- Political engagement: involvement in local or national decision-making
- Social interaction: integration with family, friends and community.

A lack of participation in any one or more dimension is taken to be an indication that individuals are experiencing a deep exclusion (Levitas, 2006). More recently however and as I discuss further in this review, social policy under the successive governments appear to have abandoned efforts to address social exclusion, attempts to address the causes of social exclusion are under threat.

2.2.3 Defining Social participation

Literature on economics, health and social care and is now full of discussion on how participation should be defined. Burchardt (2000) defines participation as *'…the opposite of isolation.'* (p390) although Barry (1998) points out that social isolation is not the same as social exclusion. According to Barry, whereas social isolation is the phenomenon of non-participation (of an individual or group) in a society's mainstream institutions, social exclusion on the other hand, is the '*subset of cases in which social isolation occurs for reasons that are beyond the control of those subject to it*.' (p.iv). Platt (2011) describes participation as *'opportunities for normal social interaction and the enjoyment of communal activity, including such things as celebrations of significant religious events and being able to extend hospitality to children's friends, neighbours and family… (page 138*)'. Others such as Fougeyrollas (2010) have suggested that social participation can be defined by a person's social roles since social participation is relates to people's actions in relation to others.

In reviewing the literature, two prominent studies have attempted to provide clarity on the language of social participation. The first by Levasseur and colleagues (2010) involves a systematic review of literature on participation and ageing. After coding 43 original definitions of social participation published between 1981 and 2009, the authors found that that definitions related to various levels of participation. Definitions of social participation could be categorised according to six proximal to distal levels of involvement with others in society: 1) doing an activity in preparation for connecting with others, 2) being with others, 3) interacting with others without doing a specific activity with them, 4) doing an activity with others, 5) helping others, and 6) contributing to society (Figure 1). The concept of social participation is often conflated with other terms such as social engagement. Levasseur's analysis therefore is helpful in making the distinction between 'participation' which encompass all 6 levels and 'social participation' which only involves being in actual proximity to other people (levels 3-6). Similarly, social engagement is often used interchangeably with social participation whereas in Lavasseur's study social engagement clearly relates to activities which are not obligatory but require active and meaningful engagement (levels 5-6).

Figure 1: Proximal to levels of social participation from Levassauer et al, 2008

<table>
<tr><td>Doing an activity in preparation with others</td><td rowspan="6">Participation</td><td rowspan="2" colspan="2"></td></tr>
<tr><td>Being with others (alone but with people around)</td></tr>
<tr><td>Interacting with others (social contact) without doing a specific activity with them.</td><td rowspan="4">Social participation</td><td rowspan="2"></td></tr>
<tr><td>Doing an activity with others (collaborating to reach the same goal)</td></tr>
<tr><td>Helping others</td><td rowspan="2">Social engagement</td></tr>
<tr><td>Contributing to society</td></tr>
</table>

Levasseur and colleagues also note that the studies included in their analysis used both objective outcomes to measure social participation such as the number of contacts or activities undertaken, and subjective measures such as an individual reporting satisfaction with a particular activity.

The second study conducted by Hammel and colleagues (2009) used a more subjective method which involved focus groups with disabled people, their families, rehabilitation professionals, healthcare funders and policy makers on their views on the meaning of social participation. The inclusion of these stakeholders provided a different perspective of social participation based on insider perspectives to the more objective outcomes of Lavasseur's study. People with disabilities in Hammel's study conceptualised social participation as a cluster of values rather than *'…a set of defined pre-set or normative set of activities…'* (*page 1449*). These values differed for individuals across contexts and environments. Similar to Levassuers taxonomy, Hammel's definition of social participation resulted in six cadres. However, rather than being characterised by proximal to distal levels the categories refer to participatory values which are underscored by dignity and respect. These were 1) Access and opportunities; 2) Social connection, 3) inclusion and membership; 4) Having an impact and supporting others and 5) Personal and societal responsibilities. Hammel's findings suggest that individual values can be considered alongside Levassuer's taxonomy so that the proximal to distal levels are only meaningful in as much as these values are present.

Figure 2: Hamell et al participation values

Both studies emphasised different aspects of social participation. Lavasseur's work conceptualised social participation as a series of categories characterised by what people are doing and who they were doing it with. Hammel's study on the other hand, defines social participation by the series of values attached to it. It is feasible that the both sets of findings can be applied to social participation. That is to say, whilst conceptually social participation is about the types of activities being pursued and with whom, those activities must include the values suggested by disabled people for it to be deemed meaningful. The studies highlight the different outcomes when using objective and subjective reports of social participation.

Summary

This section has shown that a common definition of social participation is still lacking. There is broad agreement however that social participation involves interactions with other people. This feature which delineates social participation from the concomitant concept participation. What is contested is whether social participation can be understood by a person's social role in relation those with whom they are interacting, the activities people are doing and with whom or the value people attach to the activities being undertaken. The following part of the review examines social participation from the perspective of disability studies to understand the factors which causes a lack of social participation.

2.3 Part III: Social participation and disability theory

In the previous chapter I discussed that in spite of being an important goal in rehabilitation and in wider society, ambiguity exists surrounding the conceptualisation and operationalisation of social participation. This section aims to explore social participation from a disability perspective by positioning it as a central concept within disability discourse. In doing so the section will reveal the reasons why in spite of its importance, people with impairments do not have the same opportunities to participate in their communities. To this end this section reconceptualises social participation as 'taking part in society's functionings'. The section focusses on the main models of disability and how they explain the causes of restrictions to taking part in society experienced by people with impairments. It describes how a lack of participation can be regarded as the person with an impairment's own fault (medical model), and alternatively how a lack of participation can be viewed as a consequence of environmental restrictions (social model). This section culminates with a discussion on the more recent view that restrictions to taking part in society's functionings are the result of a transactional process between the body and society.

2.3.1 Social participation and conceptualisations of disability

Models in science are heuristic tools which aid our understanding of the social world. For social researchers models provide a means of organising data about particular phenomena under study. Gabel and Peters note that models *"…clarify and organise a set of practices and tools for testing and deconstructing theories" (2004, p.588).* Llewellyn and Hogan (2000) note in their lengthier description on models that:

> '…*a model represents a particular type of theory, namely structural, which seeks to explain phenomena by reference to an abstract system and mechanism. Models of disability are not synonymous with theory as their usage does not involve data collection, but they may have some usage as generators of hypotheses. It is important to remember that models may help to generate an explanation in some way, but they do not themselves constitute an explanation.*' (page 157)

Models have been central to discussions on disability theory and used to explain the disadvantages experienced by people with impairments. As a consequence, the concept of participation has become a key concept within disability theory since its inclusion in the ICF. Under the ICF restrictions to participation are defined as a complex interplay of biological, psychological and environmental factors. This biopsychosocial perspective of disability offered a new way of understanding the ways in which people with impairments are included in society. Prior to the biopsychosocial model, two theoretical frameworks, the medical and social models dominated thinking and theorising about disability. These models are discussed below, an understanding of which is important for understanding the experiences people with impairments which emanate from the perceptions of society toward them. Although seemingly abstract, '*models provide an insight into the attitudes, conceptions and prejudices…'* others toward disability *(Michigan rights coalition, 2014)* which also translate into policy, service provision and general treatment of people with impairments.

2.3.2 Lack of participation due to impairment – the medical model

Biomedical models of disability or the medical model as it has come to be known, is the theoretical view that disability is caused by the body or impairment (Oliver, 1996). In other words a person's failure to participate in the full functionings of society is solely due their condition. For example, a visually impaired person being unable to access an online job application would be regarded as their problem to be overcome. In order to eradicate the problems the responsibility lay with the individual to make adjustments through treatment, repair or rehabilitation. Reflecting its roots in the emergence of the medical profession, the medical model is concerned with clinical diagnosis and treatment. (Shah and Mountain, 2007). The scientific process of objective and observable measurement of individual mind and body characteristics, differentiating between 'normal' or standardised functioning of the body with those who are judged to have deviated from the norm *'…so as to locate those who are candidates for repair'* (Silvers, 1998, p.94). An example of the medical model in action would be the legal definition assessment criteria of visual impairment.

The medical model has undoubtedly led to dramatic medical advances, particularly in the treatment of chronic pain relief, disease and acute physical injury (Waddell and Aylward, 2010). For example, epilepsy, one of the most common neurological disorders worldwide (WHO, 2013) illustrates how understandings and perceptions of the symptoms of a condition have been transformed through medical intervention (Shah and Mountain, 2007). Epilepsy, as early as 4000BC has been historically regarded as indicative of demonic possession but is now understood to be caused by a sudden burst of electrical activity in the brain (Magiorkinis et al, 2014). The European Blind Union (2003) also notes that the medical model does have utility in terms of planning and estimating numbers of populations:

> *'The medical definition of partial sight is a useful tool for estimating the number of people in a given area suffering from one or more forms of visual impairment. This facilitates planning for the development and resourcing of present and future services. However, this application should not be considered to be any more than a guideline and should not be used as a criterion for inclusion of individual persons in services.' (2003, page 8)*

The problem with the medical model as Waddell and Aylward (2005) suggest is that where patients fail to recover as expected, applications of the medical model become progressively less appropriate. For this reason the medical model is far from benign. Since the medical model is concerned with biological pathology and treatment, it must as a consequence distinguish between normal and deviance. The resulting juxtaposition between normality and abnormality pathologises people with impairments which has consequences for how they are viewed and treated. This may seem an issue of semantics but is real enough when considering the language used in the predecessor of the ICF, the ICIDH (Wood, 1980). The ICIDH describes impairment as *'Any loss or abnormality of psychological, physiological, or anatomical structure or function'.* Disability is defined as, *'Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'* and handicap as *'Any disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal, depending on age, sex, social and cultural factors, for that individual.'* (page 29). Common to all three parts of the ICIDH is that disability is equated with abnormality and illness. Even though disability is separated from impairment, disability is regarded as emanating from the impairment ignoring extraneous factors that might contribute to restrictions to activities. The ICIDH is but one example of the medical model of disability in practice. The UK Disability Discrimination Act (1995) which although welcomed as move toward equality for disabled people also employs the normal / abnormal dualism (Doyle, 1996) by describing disability as *'A person has a disability for the purposes of this Act if he has a physical or mental impairment which has a substantial and long term adverse effect on his ability to carry out normal day to day activities.'* (DDA). This creates a corporeal standard ideal of the normative body which Swain and colleagues (2003) allude to in their reflections below:

> *'The medical model reflects wider cultural assumptions around individuality, personal autonomy and self-determination within a society in which great value is placed upon*

> *'standing on your own two feet', 'staying one step ahead', 'standing up for yourself', 'walking tall' and 'making great strides' (page 22)*

Consequently, this normative ideology which was legitimised by powerful legal and medical institutions such as the WHO has permeated into everyday thinking about disability and how people with impairments should be treated as noted by Barnes and Mercer (2003)

> *'…a marked divide between able bodied has been established at the cultural level. Able bodied normalcy is embedded in the everyday thinking as a privileged or desirable state of being.' (page 21)*

Barnes and Mercer argue that people with illnesses or impairments are separated from everyday life. That is to say, 'normal' expectations for societal participation such as employment, family responsibilities and independent living are adjusted for people with impaired bodies (Fisher and Goodley, 2007). Separation rather than integration is demonstrated in the case of specialist educational schools and sheltered employment.

2.2.3 Lack of participation due to societal failings – the social model

The civil and human rights movements of the 1960's, both in Europe and the United States, saw the politicisation of large groups of disenfranchised people. In the UK, the disability movement largely through the auspices of the Union of the Physically Impaired against Segregation (UPIAS), was given strength by the academic writings of academics such as Vic Finklestein (1980, 1981), Colin Barnes (1991) and Michael Oliver (1983). Themselves disabled and heavily influenced by Marxist and structuralist sociology (Lang, 2001), the publication '*Fundamental principles of disability'* (1975) set out an alternative definition of disability. It argued that disability is not with the cause of individual impairment but is the outcome of socio-political systems. These systems effectively exclude individuals with physical or mental impairments from participating in the mainstream activities of everyday social life (Barnes, 1999; Peters, Gabel and Symeonidou, 2009). An important distinction made by social model theorists is the separation of the terms impairment and disability. Under the social model, the term 'disabled' operates as a verb to describe the exclusionary processes that occur when a society imposes '*…various barriers, economic, political and social, constructed on top of [the] impairment*' (UPIAS 1976, page 3). Impairment is merely an expression of the physical condition and is described by Finklestein as a '*private matter*' (Thomas, 2004). Under the Social model therefore, disability is conceptualised as an issue of interaction, a grouped entity rather than an individualised one, a phenomenon that only occurs when a person enters the social realm. The removal of the biological body as constitutive of 'disability' and its replacement with societal barriers means that under the social model it is not the individual who requires remedy but society which is in need of restructure making disability a collective responsibility.

2.3.4 Influence of the social model

The premise that disability can be defined by societal failings has been attributed to developing understandings of disability since the latter half of the 20th century. It is largely regarded as a catalyst for change and has, as Barnes suggests, '*opened up the way for disability organisations to gain a greater political platform'* (). The social model provides an analytical framework for organisations to assess the impact of their policies and practices and how well exclusionary barriers are being addressed. It has influence at both national and international social policy levels demonstrated by the many countries which now have anti-discrimination legislation (Doyle, 1995; Duckett and Pratt, 2007). Jolly (2012) argues that the social model helped campaigners fight for benefits such as Independent Living Fund, Disability Living Allowance and Incapacity Benefits. At an individual level the social model has created resistance amongst ordinary disabled people who are able to attribute the problems associated with disability to society rather than themselves (Crow, 1996; Morris, 2000). Liz Crow (1992) reflects on the empowering role the social model has had in her own life and the ways in which the perspective has enabled her to challenge assumptions and expectations ascribed to people with impairments:

> *'For years now the social model has enabled me to challenge, survive and even surmount countless situations of exclusion and discrimination. It has been my mainstay, in the same way as for the wider disabled people's movement, enabling a 'vision' of ourselves free from the constraints of Disability and providing a direction for our commitment to change. (Liz Crow, 1992)*

2.3.5 A false dichotomy

In recent years however there have been a number of fundamental criticisms of the social model. Crow's praise of the social model in the excerpt above is in fact a prelude to her growing disenchancement with the model as a holistic explanation of the experiences of disability. Both the medical and social model use a Carthesian separation of the mind and body. Whereas the medical model emphasises the body as the aetiology of disability, the social model ignores the body completely. Both provide metanarratives of disability, the medical model being one of biological determinism and personal tragedy (Macey, 2001; Shakespeare and Watson, 1996, Dewsbury at et al, 2004) and the social model providing a meta-narrative which assumes people with impairments are united under a banner of social oppression. Online blogger Bogle (2011) likens the social model is akin to blunt instrument which is used to explain disability:

> *'The Social model uses a similar tool to the second wave feminists who considered everything as political and everything can be considered in relation to women. The Social model advocates tend to consider everything in relation to the barriers that disabled people are required to circumnavigate in their lives. (Bogle, 2011)*

The social model has also been criticised for failing to accommodate diversity identities such as race and gender which are '*rooted in real impaired bodies*' (Williams, 1999). Williams notes that the needs and experiences of middle class women with rheumatoid arthritis are very different to those of a young wheelchair user. Nick Watson's 2002 study on self-perception and identity illustrates the failure of the universal assumption that people with impairments are unified by their experience of discrimination. The study found that the majority of respondents did not in fact regard disability as an important part of their self- identities. Differences existed between themselves and people without impairments only in as much as they faced discrimination. For example Arnie, a respondent in the study, discussed his frustration when faced with difficulty accessing buildings with his wheelchair, but did not define his life as being disabled because of this. Watson notes that:

> *'Self-identity and subsequently agency, for Archie is achieved through a practical demonstration of his skill and abilities and it is through this agency that he is able to reaffirm his own sense of biography and challenge identities ascribed to him on the basis of his impairment. Identity for these informants is more about the rejection of group boundaries than their reaffirmation and the presentation of the self involves a rejection of difference.' (p515)*

Further, rather than destroying the 'disabled' and 'able-disabled' binary oppositions that exist within medicalised language pertaining to disability, the social model merely reinforce it. The reluctance of respondents in Watson’s study to embrace the label 'disabled' may in part be due to the fact that despite the disability movements attempt to change the denotation of the word disabled, the negative connotation attached to the language of disability remain the same.

> *'To paraphrase Butler (1990, 325), they [respondents] reject a description of themselves as ‘disabled people’ in the terms articulated by those who write in disability studies. An identity as a disabled person, in disability studies, is created through a regulatory regime that, inadvertently, constructs a ‘normal’ body and in endorsing the existence of such an identity, disability studies perpetuate the notion of difference between disabled and non-disabled people, reinforcing the dichotomy.' (p. 524).*

Although the social model is the antithesis of the medical model they are therefore essentially opposite ends of the same philosophical dichotomy which polarises debates on disability (Douglas, 2007).

2.3.6 Rectifications of the social model

Academics have sought to refine the social model by incorporating aspects of self-identity (1996). Crow, has argued that the social model *‘must bring back impairment’* to acknowledge the role of impairment as contributing to disability. French and Swain's (2004) attempt this through the development of their 'affirmative model' to counter the view of impairment as a personal tragedy. This model of disability presents '*positive social identities for disabled people grounded in the benefits of lifestyle and life experiences of being impaired and disabled'* (Swain and French, 2000 p.569). Carol Thomas (2004) also reintroduces the body to social refinements of the social model through her work on *'impairment effects.'* (Thomas, 1999). Thomas acknowledges that the body (psychosocial wellbeing) is affected by the structural barriers encountered. However, others influenced by post modernism and post structuralist thinking, have argued that whilst the social model has made a valuable contribution to disability discourse, there is a need for more contemporary and realistic interpretations of disability. Tom Shakespeare and Nick Watson, two of the most vociferous critics of the social model, argue that impairment and society cannot be examined in isolation and that in doing so can do more harm than good:

> *'People are disabled by their bodies. This is straightforward and uncontroversial. The British social model approach, because it over-eggs the pudding risks spoiling the whole dish.' (2001, page 17)*

2.3.7 Lack of participation due to the space in between – biopsychosocial models

Postmodermism, which rejected the universality claims of dominant paradigms in favour of micro realities caught the '*intellectual gaze'* (DePoy and Gilson, 2010) of academics looking for alternative ontology of disability. This at a time when scientific enquiry more generally was moving away from parsimonious reductionism to more contextual, whole systems thinking. Shakespeare notes that:

> *'Disability is the quintessential postmodern concept, because it is so complex, so variable, so contingent, so situated. It sits at the intersection of biology and society and of agency and structure. Disability cannot be reduced to a singular identity: it is a multiplicity, a plurality.'* (2001, *page 19).*

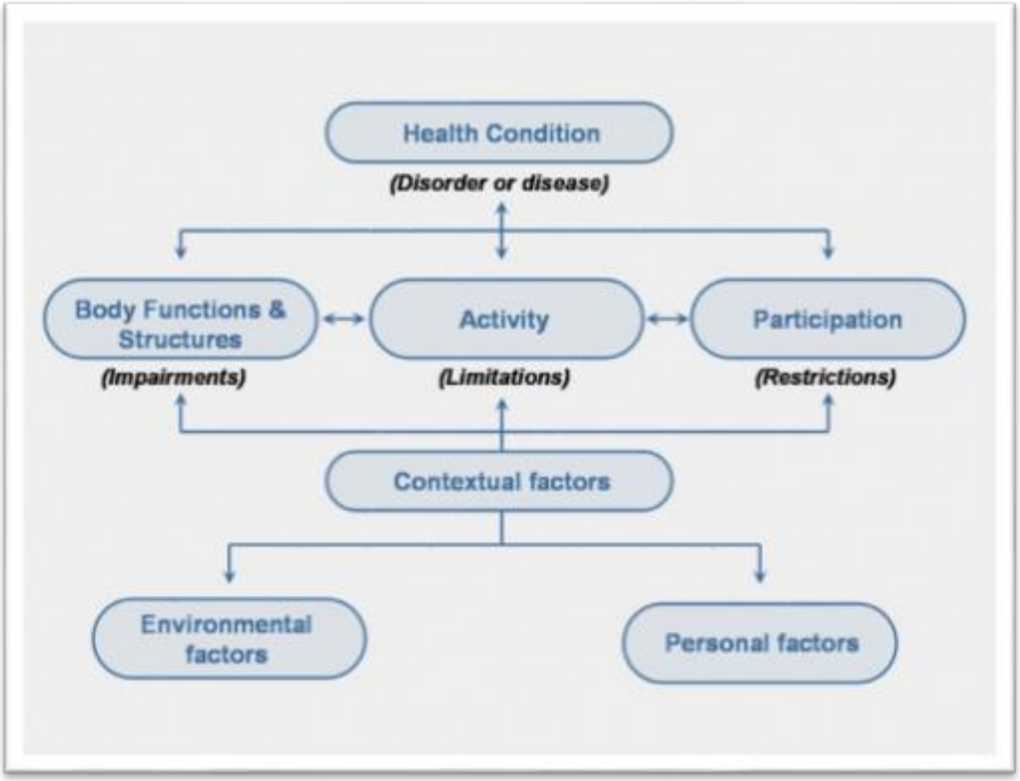
With what Gabel and Peter's (2004) suggest represents a '*presage of a paradigm shift*' within disability discourse, the ICF adopts a framework which effectively links the social and medical model. Approved by the World General assembly in 2001 and described as a biopsychosocial model (Shakespeare and Watson, 2010). The ICF recognising that the disablement process is influenced by both the environment and the body and eradicates the disability dualism present in the social versus medical discussions of disability. (Douglas et al, 2007, Shakespeare and Watson). Making this point, Douglas et al (2007) notes that the ICF:

> *'…avoids polarizing the medical and social models of disability and yet captures the essence of both through its language of impairment (relating to the body and its function), activity (concerned with individual performance) and participation (involvement at a societal level) ' (page 2).*

The earlier ICIDH has now been effectively split into two resulting in the ICF and the International Classification of Disease [ICD-10] which is designed to be used in conjunction with the former (Duckett and Pratt, 2007: p.9). In his review of the ICF and other models, Jette notes that under the

ICF, three levels of human functioning are emphasised: body, whole person and whole person in the environment. Participation replaced the term handicap to describe an individual’s involvement in ‘life situations’. The term ‘activity’ replaced the term ‘disability’ to describe the execution of a task or action by an individual. In other words, whereas activity relates to a person’s ability to engage in a particular task, participation refers to the observable performance (Hamell et al, 2008).

Figure 3: ICF Framework



Whilst the ICF does not attempt to explain disability, it provides a mechanism for framing multiplicity of factors and processes rather than those which are exclusively social or individual in nature using neutral language. The ICF is recognised in 191 countries has obtained acceptance even within the disability movement

2.3.8 Critiques of the ICF

There has now been time now for practitioners to consider and report on the merits of the ICF definition of participation. Whilst generally accepted as a useful tool for systematising assessment processes for use in various disciplines and sectors, difficulties with operationalising the framework have been identified. It is argued that the framework still regards disability as starting with impairment rather than society. Alma et al (2012) argues that whilst the ICF offers a comprehensive model of objective disability, it does not address the subjective perceptions of people with disabilities such as quality of life. Further, the ICF attempt to provide a generic tool for understanding disability risks generalising individual experience (Guralnik and Ferrucci, 2009). Dijkers (2000) also contends that the term 'life situation' is so broad that there will likely never be consensus as to what life dimensions should be included. Practitioners have also identified difficulty distinguishing between activities deemed as an 'activity' or 'participation'. It is also felt that there is an over emphasis on individual performance which are assessed objectively on a specified list. Hammell and colleagues (2008) argue that this does not take into account availability of opportunity and resources. That is to say, individuals may be able to execute a task but may not have the opportunity or the inclination to perform it. Piskur (2014) also notes that social participation and participation are often used interchangeably and that no definition of the former is provided within the ICF guidance.

Summary

This section of the review has placed social participation at the core of disability theory, the academic field of which attempts to explain the nature and consequences of the inequalities experienced by people with impairments. The so-called medical model suggests that a lack of participation is caused by impairment restrictions. Social participation from this point of view becomes an individual responsibility whereby people with impairments must make adjustments to participate, despite the social barriers. Conversely, the social model regards restrictions to taking part in social life as the responsibility of society. It is society which needs to remove structural, cultural and political barriers to ensure that people with impairments are included in their local communities and in wider society. However, both models are problematic as some people with impairments do regard their bodies as restrictive at times and do not consider themselves disabled by an oppressive society. Both the medical and social model therefore are limited in their ability to capture the essence of participation for people with impairments. The biopsychosocial model bridges these two opposing views of the nature of restrictions to social participation. This third model suggests that the factors influencing social participation are multifactorial and interrelated. Reflecting on definitions of social participation in previous chapter, if social participation is related to roles, is the exclusion of visually impaired people in society from particular roles in society explained by their visual impairment (medical model), low expectations (social model) of both? The same question can be posed for conceptualisations of social participation as types of activities and the values attached to those activities. It is likely that the concept of social participation is a combination of all three.

The following section provides examples of some of the ways visually impaired people are hindered from taking part in social life. The section not only provides evidence of the restrictions to social participation but also the realisation of the medical model, social and biopsychosocial model in the lives of visually impaired people.

2.4 Part IV: Visual impairment and social participation

In the previous section of the review theoretical models of disability were used to explain restrictions to participation in social life for visually impaired people. The section concluded that both a person's impairment and their environment have a role to play in shaping their participatory experiences. Part II of the review described the impact on development for cognitive visual impairments and the psychological impact experienced by those who lose their vision in later life. However, the thesis thus far, the restrictions or challenges experienced by visually impaired people have not been described in detail. This section of the review provides evidence from the full spectrum of individual's lives. Reflecting the cross systemic nature factors influencing social life and therefore social participation, the evidence is presented in a hierarchy from the micro to the macro level. The evidence presented in this section is taken from the subjective accounts of visually impaired people as well as objective survey data,

2.4.1 Impairment and its impact on social participation

In Lavasseur's conceptualisation of social participation, interaction with other people at varying proximal levels are emphasised. However, Lavasseur recognises that basic activities of daily living performed in the home, often alone, commonly precipitate social participation (Levasseur et al, 2010). For example, Christiansen (2005) suggests that being appropriately dressed and having good personal hygiene can influence the perceptions of others making this activity an important prelude to social participation. Christiansen also notes that being able to accomplish basic tasks such as such as preparing meals, reading and self-care are often symbolic for people with physical and cognitive limitations and contribute to positive self-identities. However, the presence of a visual impairment presents challenges with even the most basic everyday tasks such as personal care and general home management (Pey et al, 2006; Beer et al, 2006; Douglas, et al, 2006). The comments of a female participant in the Network 1000 study (2006) illustrates the way in which her confidence is linked to being unable to see how she looks to others:

> *"Apart from the actual physical frustration of not being able to find the right thing in the cupboard etc., I think self-confidence is hard because I cannot see what I look like in the mirror. I try to put eye make-up on but I have to rely on someone else to tell me whether it looks ok. Also when clothes shopping I don't know what I look like in the mirror. And that affects self-confidence if you can't see what you look like." (Female participant, Network 1000*

> *survey 2006: page 58)*

A survey conducted by Pey and colleagues (2006) found that well over two thirds (79%) of visually impaired respondents had difficulties with identifying food and medication labels, 33% found preparing a meal difficult as did 43% with household cleaning. Further, over half had difficulties dealing with mail, shopping, and setting the controls on household appliances. Whether these challenges are what Thomas (1999) refer to as impairment effects or whether these difficulties have a social cause such as a lack of inclusive design in the home, have been debated in disability literature. However, it is not difficult to begin to understand how interaction may be hindered given that these activities precipitate participatory activities.

2.4.2 Familial challenges

Family members are often the touchstones for support by providing information, emotional and practical support to loved ones such as providing transport and attending appointments. They also provide the building blocks for developing familial and non-familial relationships through early learning and the development of social skills. As such, families can be very influential in facilitating or hindering successful self-identities and subsequent participation. However, as highlighted by Winkler (1975) '*Blindness in a single individual inevitably becomes a family affair*' (page 19). On learning of the diagnosis of a loved one, family members often go through their own grieving process (Tuttle, 1986). In cases where a visual impairment is acquired during adulthood, changes in the balance of power and family dynamics can put a strain on marital relationships. Financial hardship can result if one or other person is no longer able to earn, either as a result of becoming a carer or in cases where a visually impaired person themselves having to drop out of the labour market. Family members must also deal with their own fears and stereotypes about impairment and disability. Stephen Kuussisto *(1998)*, in his memoirs 'Planet of the Blind' reflects on his mother's attitude to his impairment which suggests she may have struggled with accepting her son's visual status:

> *'The very words blind and blindness were scarcely to be spoken around me. I would see to this by my exemplary performance. My mother would avoid the word, relegating it to the province of cancer.' (page 7)*

Overprotective care from family, friends and professionals, is a critical issue for the personal and social autonomy of visually impaired people of all ages (Cimarolli, 2002; McBroom, 1997; Thomas Pocklington Trust, 2008). Negative support such as overprotection can lead to learned helplessness, a person's perception that they have no control over events and situations (Seligman, 1975). Such individuals have poor personal autonomy and independence, less successful adaptation to vision loss and higher levels of depression (Cimarolli et al, 2006).

The absence of any familial support is also a challenge for visually impaired people particularly amongst older adults. Visually impaired people are generally more likely to live in single occupancy households than the general population, or as a couple with no dependent children (Bruce et al, 2007; Meager et al, 2008; Clements and Douglas, 2009). Meager et al (2008) note that although the age profile of the visually impaired population is an older one, age explains only part of the tendency to live alone.

The family unit also provides a useful illustration of the intersectionality of disability with socio-cultural economic factors. Rahi and colleagues (2005) study of parent's access to eye care services found that parents from low income and from minority ethnic groups were significantly less likely to access services than their white counterparts. Rahi suggests this may indicate difficulty '…*navigating successfully through the healthcare system.'* (p. 217). However, others contend that service provision is not always sensitive to the cultural, religious beliefs and linguistic needs of minority groups (Ali et al, 2006; Johnson and Morjaria-Keval, 2007; Percival and Hanson, 2007).

2.4.3 Education

Schools also have an important role in promoting the inclusion of visually impaired children. It is at school, as within the family that a child learns the skills of being an adult (James et al, 1998). On a theoretical level greater inclusion has been facilitated by the move to educate children with 'special needs' in mainstream educational settings. In 2013 RNIB reported that 60% school aged children were educated in mainstream schools (Keil and Clunies-Ross, 2003). Academically students with a visual impairment tend to do well with virtually no difference in attainment levels with their sighted peers. They are also more likely to have obtained higher levels of educational attainment than pupils reporting other types of disabilities (Meager and Carta, 2008; Chanfreau and Cebulla, 2009).

Academic success however tends to be achieved in spite of commonly reported problems relating to inequitable access to the national curriculum (Keil et al, 2006). Keil's research (2006) observed that at key stage 4 which covers pupils at GCSE level, just one of the 37 generic titles identified by three English examination boards was available in large and giant print. Just one title in five was available in braille. Similar problems have been reported in further and higher educational settings (Keil, 2004, Owen-Hutchinson et al, 1998, Waterfield and West, 2002; Thomas et al, 1996; Hewett et al, 2011). Hewett's study of 14 year olds transitioning into adulthood illustrates a far from utopian situation in which the needs of visually impaired students appear to be an afterthought rather than incorporated into the examination infrastructure. Some students in the study described chaotic situations in which there was a lack of planning and uncertainty surrounding the provision of extra time and accessible examination papers. This could negatively impact on employment outcomes:

> *'The majority seemed happy with the examination arrangements they had experienced. There were, however, some problems reported, such as confusion over how much extra time the person was allowed for taking their exams (this guidance seemed to be provided by the QTVI assigned to them at school), problems in modified papers and difficulties in enlarged papers being too large for the desk, as these would typically be in A3 size'. (Hewett el, 2011)*

In terms of social interaction with fellow pupils, Buutljens and colleagues (2002) note that the *'practicalities and legalities'* of ensuring the curriculum often obscures the issue of social inclusion. Pupils experience 'impairment effects' at school such as difficulties finding friends in noisy corridors but also problems as result of the negative attitudes of others. Being teased and bullied were experiences reported in a number of studies on young visually impaired pupils in mainstream schools (Rosenblum, 2000; Gray, 2005; Pilling, 2005). Swedish researchers Bjork and Fellenius (2015) found that sighted pupils were more likely to initiate interaction with visually impaired peers who had some functional vision. Apart from their visual status setting young people as being different, overprotection is also evident within the schools context. Young people have reported being kept indoors during play times due to safety concerns (Gray, 2005) or prevented from taking part in sporting activities because teachers did not know how to include them. Yet, as discussed earlier it is through play in which young people learn to express the personalities and develop their social skills. The presence of a teaching assistant and use of low vision aids was noted by young visually impaired people as factors which made them feel different to their peers and could be a barrier to social interaction with sighted classmates (Franklin et al, 2001). Developing a circle of friends is not only necessary for self-esteem but for protection from bullying. However, making friends requires having good social skills which enable individuals to react and respond appropriately both at school and in the workplace. For sighted pupils social skills are usually developed through visual observation and play. For visually impaired pupils these skills have to be formally taught. In the absence of social skills training the result can be social isolation which as described by Sacks:

> *'I vividly remember observing the isolation and emotional pain that many blind and visually impaired children experienced in regular public school classrooms. These students lacked the social skills to start and carry on conversations, to play games effectively, and to join and feel part of a group.' (Sacks et al., 1992)*

2.4.4 Relationships and social networks

Feeling loved and a sense of belonging is a fundamental aspect of what makes us human (Burmeister and Leary, 1995). Relationships and social networks increase a person's social capital which in turn increases opportunities for participation through the exchange of information about for example, employment or other useful resources. Making friends and developing peer and romantic relationships with similar others is also intrinsically linked with our sense of identity. For visually impaired people, making and maintaining relationships with friends outside of the family unit can be fraught with physical and cultural challenges. For example, a starting point for initiating contact with someone new or conveying expressions of interest is often the use of subtle non-verbal cues such as eye contact, a smile or a handshake. A visually impaired person is likely to miss opportunities to pick on a person expressing their interest in becoming friends. Frame (2004) describes the difficulties experienced by visually impaired people with regards to initiating romantic interaction:

> *'Flirting and initiating potentially romantic interaction is something that most people do without thought. Someone makes eye contact and smiles at you; you chose to return the smile and gaze or to ignore it. Someone who never sees the initial smile or gaze has no choice but not to respond.' (Frame, 2004: 63)*

Difficulty forming friendships is not just a matter of visual function and the inability to pick up non-verbal behaviours. Research suggest that sighted people are uncomfortable with the idea of developing peer and intimate relationships with visually impaired people. Fichten and colleagues study (1991) found that when sighted students were asked whether they would date visually impaired peers, the students expressed concerns about being judged by sighted others for their choice of partner. Fichten hypothesised that as Goffman (1963) had earlier theorised, the phenomenon of stigma spreads to individuals who are associated with people with perceived lower social worth. The reflections of a participant in a separate study (Milian, 2001) appear to corroborate Goffman’s theory:

> *‘”It got rougher in junior high school when dating became a big thing, because, you just didn’t want to date a blind person. And even if you could get a girl to go out with you she’d be ridiculed by all her girlfriends. Once I got this girl to go out with me. The father informs me when I get into the house that no daughter of his is going to date anyone who is less than half a man.” And he says to me, you are not leaving this house with my daughter”’ (Milian, 2001)*

Disability writers Wendell (1996) and Lonsdale (1990) suggest that meeting a romantic other is more difficult for women with impairments who are perceived as unable to fulfil traditionally ascribed gendered roles such as housekeeping and child rearing. Wang and Boerner (2008) found that young and middle-aged visually impaired adults felt their vision had interfered with their relationship goals. These feelings were also echoed amongst older adults in a separate study (Reinhardt, Boerner, & Benn, 2003). This may explain in part, the tendency to live alone as noted earlier by Meager and Carta (2008). Data from the Network 1000 survey does indicate that visually impaired people are less likely to participate in social activities involving social networks. For example, 'going out for a drink is a social activity undertaken by 87% of the working age general population (BHSP, 2004) (ONS, compared to just 55% of visually impaired people of the same age. Similar trends were observed for attending evening classes and local group meetings, and attending religious worship.

Some disability academics have accused the movement of de-prioritizing the topic of sex and love amongst people with impairments (Finger 1992; Shakespeare, 1996). American disabled feminist Anne Finger (1992) laments the absence of sexual rights from discussions:

> 'Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about - and formulate strategies for changing - discrimination in employment, education, and housing than to talk about our exclusion from

sexuality and reproduction' (1992):

2.4.5 Labour Market Participation

The link between social participation and employment is well established (Jahoda, 1981; Paugam and Russell, 2000). Paid employment provides access to the financial and social resources necessary for full participation. Visually impaired people in paid employment report greater number of social networks (Roy et al, 1998) and consequently more social interactions (Cimarolli and Boerner, 2005) than their unemployed counterparts. That being said, whilst visually impaired people achieve as well as their sighted counterparts there remain significant disparities between the labour market participation rates of visually impaired and people without disabilities. Clements and Douglas (2009) found that over half (59%) of visually impaired people qualified to degree level or above, were in paid employment. This was compared to 86% of the general population with the equivalent qualifications. Similar proportions were reported by Meager and Carta (2008)[1]. Having at least one other disability in addition to a visual impairment results in even lower employment rates for blind and partially sighted people (Clements and Douglas, 2009; Meager, 2009; Sefton, 2006). For black and minority ethnic people the employment rate is even lower. Sefton’s (2006) analysis of the British Labour Force Survey data found that just 15% of BME people reporting a visual impairment were in paid work (Sefton et al, 2006). The Network 1000 study found that amongst visually impaired respondents, 30 - 49 year olds were most likely to be in some form of employment, whilst 50 - 64 year old reported the lowest employment rate amongst visually impaired people (22%). The latter group are also more likely to describe themselves as being long term sick or disabled (45%) or retired (19%) indicating a greater distance from the labour market. People with lower levels of visual function were less likely to be in employment (Douglas et al, 2007)

Working age participants in the Network 1000 who were employed in the first wave of interviews (Douglas et al, 2005) but unemployed when researchers revisited them a year later provided subjective accounts accounts of their employment experiences. Whilst deteriorating health or sight loss was cited as the main reason for being out of work, negative employer attitudes were also cited as a reasons for being unemployed (Douglas et al, 2009.) This belief of participants that they

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[1] Meager and Carta use different definition of sight loss resulting in figure of 48% of people with difficulty seeing and who report having a disability are in paid employment compared to 50% of people with other types of disabilities and 75% of the general population. Those who report having a seeing difficulty but did not report having a disability had a significantly higher rate of employment (83%) than even the general population.

experienced direct discrimination by employers is given credence by an earlier DWP report (2004) in which 92% of employers felt it would be either 'difficult' or 'impossible' to employ a blind or partially sighted person. Further, research on 'unconscious bias' illustrated that when the general public were shown pictures of people with no visible impairments these were favoured over pictures of those with a visible impairments. Such attitudes are likely to affect the recruitment of disabled people (ENEI, 2014).

A respondent from a study by Percival and Hanson discusses how being unemployed had changed his identity from a 'go getter' to a more passive existence:

> *'Oh, I would love to work . . . it eventually falls off the agenda. Terrible really because, you know, I was such a go-getter person, a mover and shaker and all the rest of it and I've sort of been reduced to a passive state.' (Mr Gower, age 55, unemployed, council flat)*
> *(Percival and Hanson, 2007: page 59)*

In addition, both employers and many visually impaired people are often unaware of the Access to Work programme (Saunders and Sadro, 2015). Access to Work since 1994 has provided financial assistance with travel, equipment and workplace adjustments. Its low awareness however, has prompted the programme to be dubbed *'the best kept secret in the DWP" (Sayce, 2011).* Once in work the likelihood of losing one's job within two years of losing their sight is high (Bruce and Baker, 1999). As noted by RNIB '*Long-term exclusion from the labour market places blind and partially sighted adults out of work at acute risk of disadvantage'*. (RNIB, online).

Negotiating disabling public spaces

Issues relating to travel, transport and mobility, necessary perquisites to social participation, are major concerns for visually impaired people (Douglas, 2007; Pavey et al, 2009). People with a visual impairment wishing to travel independently must navigate their way through their environments in order to participate in the labour market, pursue leisure activities as well as fulfil everyday activities. As Jenkins and colleagues (2015) note, environments are not simply places people *"want"* to access, but *'are where many of the occupations that fill people's lives occur* (p. 8645). Yet the nature of the environment has a direct impact on levels of participation for visually impaired people (Clarke et al, 2011; Nagi, 1991). Hall and Imrie (1999) liken the journeys of a disabled traveller to *'obstacle courses* *characterised by a range of social, attitudinal, and physical environments'* (p409). In the absence of functional vision, the visually impaired lone traveller must make sense of what is happening around them by using tactile, olfactory and auditory senses. Obstacles such as cars parked on pavements, uneven slabs, overhanging branches, dogs mess, poor colour contrast and poorly designed traffic are just some of the potential hazards which must be negotiated. (Pavey et al, 2009; Edwards, 2011). Even familiar areas can present challenges when changes occur. The design of buildings can also have a debilitating effect as discussed by Kuusisto (1998):

> *'The whims of architecture have enormous power over my experience of vision: a postmodern shopping mall with its cantilevered floors and mirrored walls – all lit by indirect lighting and high intensity bulbs – can reduce my momentum. The darkness of restaurants and bars tightens my chest. I edge along without poise, feeling the sudden reverberations of alarm that come with not seeing. … How does one become inured to unpredictable moments of helplessness? (Kuusisto, 1998: 11–12)*

Areas which are poorly served by public transportation services can have a negative impact on an individual's ability to maintain social relationships and accessing employment (Edwards, 2004; Pavey, 2009). Gallagher (2011) identified that poor transport provision was a major barrier to social interaction and contributed to the isolation experienced by particularly older people with a visual impairment. A combination of the fear of travelling alone (Pavey, 2009) and difficulties negotiating hazardous environments can adversely impact on a visually impaired person's ability to participate in social and cultural activities.

2.4.6 Cultural perceptions of visual impairment

Guide dog owners being refused entry to restaurants and taxi's and the so called 'does he take sugar syndrome', a phenomenon describing the propensity of sighted people to communicate with sighted companions, rather than directing conversation to the person with the visual impairment, are just some experiences which can promote negative feelings such as embarrassment and anger amongst visually impaired people (Butler and Bowlby, 1997; Douglas et al, 2006; RNIB, 2015). Again, this demonstrates how a negative factor (community) in one situation can adversely affect another (the body). The socio-spatial impact of such interactions can result in what has been described by Leder (1990) as the *dys-appearing body*, a phenomenon whereby individuals are made to feel consciously aware of their bodily difference. This difference is not just as result of functional limitations but by the attitudes of sighted people. The result can be a reluctance to enter public spaces and engage in social interaction as described by Morris (1991):

> *'Going out in public so often takes courage. How many of us find that we can't dredge up the strength to do it day after day, week after week, year after year, a lifetime of rejection and revulsion? It is not only physical limitations that restrict us to our homes and those whom we know. It is the knowledge that each entry into the public world will be dominated by stares, by condescension, by pity and by hostility' (Page 25).*

It is not difficult to understand Morris' reluctance when surveys of the UK general public consistently find that embarrassment and awkwardness are common reactions to visually impaired people (Future labs, 2009). Just two years after the 2012 Paralympics which was thought to have positively transformed representations of disability, two thirds (67%) of the British public reported feeling uncomfortable talking to disabled people (Aiden and McCarthy, 2014). Familiar with the more stereotypical signifiers of visual impairment such as a white cane or guide dog, the general perception of the sighted public is that visual impairment equates to no sight at all. Perhaps as a consequence, sighted people have difficulty understanding why people who have some functional vision may require help and assistance (Percival and Henson's, 2005, Butler and Bowlby, 1997). A congenitally blind female participant in Butler and Bowlby's (1997) research on visually impaired youth living in Bristol and Leeds discusses misconceptions of her visual impairment:

> *"If you've just been in into town you don't want to be hassled by carrying [white] stick around with you and that makes asking for help difficult. People just think you're stupid. They don't believe you when you say you can't see very well 'cos you look so… so… normal, I don't know, capable I guess." (Butler and Bowlby, 1997)*

Interestingly, the young woman uses the term 'normal' and 'capable' and in doing so consciously or unconsciously uses the language of difference, that is to say, impairment equates to abnormality and incompetence (Bolt, 2005). The perceptions of sighted people can be a challenge for many people who do not wish to be regarded as different, particularly when their visual impairment is not immediately apparent to others. Participants in Butler and Bowlby's study (1997) went to the extent of avoiding social situations which could reveal the extent of their visual function. Others attempt to pass as sighted. Conversely, visually impaired people are also often forced to present a vulnerable identity in order to receive assistance. Percival and Hanson (2005) note:

> *'.. people whose disability is not necessarily noticeable, such as those with vision impairment, may have to draw attention to their disability in order to 'justify' entitlement to support services, an added dilemma that profoundly affects proud, self-conscious, sometimes reticent younger people.' (Page 55)*

2.4.7 Macro societal challenges to participation

In 2010 the UK coalition government introduced a range of measures under its austerity programme which have resulted in drastic cuts to welfare and public services. Disability related benefits which Jolly (2012) noted were implemented as a consequence of the social model such as the Independent Living Fund (ILF) and Disability Living Allowance (DLA) have been scrapped and replaced with the Personal Independence Payment (PIP). On the face of it, PIP emphasises choice and control, two of the core values emphasised by Hammel's disabled participants as necessary for social participation to be considered meaningful. However, Sims and Whisker (2014) argue that choice and control is compromised when there are competing forces such as private markets and limited or zero availability of services from which to choose:

> '*Looked at critically, it is characterised by competing demands such as the increase in choice and escalating demands versus fiscal entrenchments, and appeals for greater citizen involvement versus the extension of private markets for social cares services' (p.140).*

Whilst the then Minister for Disabled, People Esther McVey says that PIP will '*better reflect today's understanding of disability*' (DWP, 2013), many have suggested PIP is as a cost cutting exercise. For example the lower rate available to DLA claimants how been scrapped under PIP arrangements.

The climate of austerity is not just affecting disability benefits. Under the Work Capability Assessment, people with impairments and indeed anyone claiming Employment and Support Allowance (ESA) are required to prove how entitled they are by undertaking a fitness for work assessment. There has been wide spread criticism on the way the assessments were administered using a computer program by testers with little knowledge or understanding of disability. The Harrington review (2010) described the assessments as 'impersonal and mechanistic'. Given the discussion earlier in the view regarding discrepancies between acuity measures and functioning with sight loss in real life situations, it is not surprising that the assessments have been castigated.

Analysis of the cuts have shown that the poorest and disabled people are bearing the greatest impact of the reduction in public spending. Think tank Demos (2010) notes that disabled people are most likely to be affected because of their greater propensity to use public services:

> *'…are disproportionately reliant on health, social care, housing and transport services, and also, as a result of low employment rates and the additional costs associated with living with an impairment, are more likely to live in poverty and/or rely on benefits for a large proportion of their incomes.' (Wood and Grant, 2010, p.11).*

There is considerable evidence that this is the case for the majority of visually impaired adults. In 2012 Nat Cen conducted analysis comparing visually impaired people with the general public along a number of indicators (McManus and Lord, 2012). The study found that after controlling for gender and age, visually impaired people were more than 1.5 times more likely to experience economic restrictions. Economic restrictions included being able to eat meat or fish at least every other day and keeping the home warm. The earlier Network 1000 study also observed that visually impaired people who had dependent children living at home, were twice as likely to receive working tax credit compared to their counterparts in the general population. The receipt of housing benefit and council tax benefits were also found to be higher than found in the general population. These benefits supplement low incomes and are indicative of poverty amongst some visually impaired people. In addition the much maligned 'bedroom tax', which effectively places a deduction in housing benefit for people not deemed to require additional room, has unduly impacted on visually impaired people who require additional space to house bulky access technology or accommodate carers (Hanson and Percival, 2005). The concern amongst disability advocates is that visually impaired people may be forced to move away from areas in which they have familiarised wayfinding routes and become detached from their support networks. The cuts are also impacting other aspects of a person's ability to participate. Keil (2015) has already identified a reduction in visual impairment support in schools which was directly attributed to the reduction in local authority funding. Disability groups have also expressed concerns about reduced staffing in train and tube stations which is likely to impact on the visually impaired traveller's ability to receive assistance.

Correspondingly, the cuts have been accompanied by ministerial rhetoric implying that fraudulent claims within the benefits system are endemic. This has been reflected in media reporting creating a narrative of disabled people as lazy, scroungers and benefits cheats. (Happer and Philo, 2013). An analysis of media coverage comparing stories on disability between 2010 /11 with 2004/5 conducted by the Glasgow business school (Briant et al, 2011) showed an increase in negative reporting on disability. Media reporting of disability has indirectly influenced the perceptions of the general public on disability. For example, when asked what proportion of claimants were fraudulent, the general public estimated that the figure fell between 10% and 70%. The actual estimate published by DWP (2014) was in fact less than 1% (0.7%). A rise in reported hate crimes perpetrated against disabled people have increased by 25% in the year 2014/15 and is also felt to be attributable to negative reporting. Thus, apart from financial restrictions to participation, visually impaired people are participating in spaces shrouded with an atmosphere of mistrust and suspicion.

In the midst of the cuts the UK hosted the 2012 Paralympics which Liz Crow (2014) describes as 'the *light to the dark of benefits.' (168).* Hailed as a success for presenting positive images of disabled people, a counter narrative emerged which portrayed Paralympians as superhuman. Crow's critical analysis of media reporting during this time observed that there were two distinct but related narratives in operation.

> *'Through the summer of 2012, two opposing sets of images dominated the British press. Welfare benefits reform met the Paralympics, the former casting disabled people as scroungers, the latter as superhumans. Seemingly independent yet intertwined, the images have profound consequences for public perception of disability and the lives of disabled people.'*

The superhuman and the benefits scrounger may actually make life for people with impairments harder because most it does not reflect the truthful version of the experiences of most people with disabilities. Omitted from the narratives is that observation that Paralympians are likely to be claimants who rely on benefits to enable them to attend training sessions.

Summary

This section has presented just some of the difficulties experienced by visually impaired people as they attempt to participate in their communities. These challenges are situated across a person's unique environments including the individual level which indicating that the medical model and social model do not adequately account all of the barriers to social participation. For example, at the interpersonal level, preparing to take part can be hindered by the absence of vision which presents difficulties with activities such as self-care. Similarly, family members, school teachers, health professionals and people in the community can inhibit the development of a wider social network due to their own beliefs about impairment or safety worries. The evidence also suggests that Government policy no longer seems committed to addressing social exclusion of which social participation is a central concept. Instead social policy appears to be contributing to the exclusion of visually impaired people by reducing opportunities and alienating people with impairments through its use of rhetoric. So although according to Hammel's research participant's, choice and control is a key aspect of social participation, this particular value is increasingly it would seem being eroded. Further, these challenges are not isolated to the systemic layer in which they have their source but can often have knock on or cumulative, corporeal effect in other areas. This was illustrated by Morris's suggestion that going out in public often takes courage to deal with the challenges.

The next section of the review introduces the concept of resilience which instead of focussing on the problems associated with a lack of social participation, is concerned with identifying the resources, both intrinsic and extrinsic, which might interpose those challenges.

CHAPTER 3: Literature review part 5: Resilience theory

The previous chapter described some of the problems which can disable or hinder participation for visually impaired people and was a reminder of the biopsychosocial impact of those problems. The section inevitably focussed on negative aspects of living with vision impairment. This section of the review however, presents a more positive perspective by introducing the concept of resilience. Although, challenges or risk factors are recognised as being fundamental to resilience, resilience is concerned with understanding the resources that enable individuals to overcome those challenges. This section also draws parallels with developments of conceptualisations of disability. Like conceptualisations of disability, thinking on resilience has shifted from regarding the phenomenon as an individual trait to a series of processes involving multi-systemic and dynamic interrelationships between the individual and their environment. These development of resilience theory are discussed in line with four distinct waves of investigations. The theoretical models used to describe how resilience works are also discussed.

3.1 Deficit vs asset based approaches

Part one of the review highlighted the daily challenges or risks to isolation encountered by visually impaired people. Whilst it is important to identify those challenges and their root causes, understanding these problems is only useful if solutions can be found to help individuals cope in spite of them (Embrace, online). Focussing solely only the risks to isolation without providing solutions can create a sense of inevitability or fait accompli by reinforcing low expectations. Yet as noted by Burchardt and Huerta (2009) in their paper on social exclusion, *individuals are flourishing despite extraordinarily tough experiences and environments…' (page 59)*. Some individuals have described their visual impairment as merely an inconvenience and others as a gift (Hull, 1992). Many are moving around their communities in spite of the problems described in earlier sections of the review. Resilience theory is concerned with identifying the strengths and resources utilised by individuals who in spite of difficulties, are able to enable circumvent barriers to participation.

The body of research on resilience offers a way of understanding why some people are able to rise above statistical prediction. It is an altogether more positive way of looking at a problem as opposed to just focussing on risk. Resilience theory also implies that the life course of individuals can be changed. The concept has been described in a number of different ways – the ability to return to a state of homeostasis after catastrophic events, to bend but not break, beating the odds (Rutter, 1990,

2000) and the ability to 'bounce back' (Rutter, 1985). The common thread among definitions is an individual's ability to produce positive outcomes whilst encountering adverse situations.

3.2 Wave one: Invulnerable individuals

In a similar fashion to conceptualisations of disability, conceptualisations of resilience have also progressed from being individualistic in nature to an appreciation of the complex interplay between the whole person in their broader environment. Early studies of resilience in the 1970's were in fact focussed on individuals who were most at risk of mental illness. Studies focussed on individuals suffering from schizophrenia and looked at those who displayed maladaptive behaviour patterns compared to others who showed more atypical adaptive behaviours. The atypical group were found to have had pre-illness life histories of relative competency in relation to employment and social relationships (Garmezy, 1970; Zigler and Glick,1986). Although the term resilience was not explicitly used in these early studies, Luthar et al (2000) in their critical review of resilience notes, *'these aspects of pre-morbid social competence might be viewed today as prognostic of relatively resilient trajectories' (p3)*. These studies spawned others which focused on the children of mothers with schizophrenia and how some of these children went on lead successful lives as adults whilst others in comparable situations were less well adjusted (Garmezy, 1973; Gramezy and Streitman, 1974; Masten, 1989).

Werner's seminal forty year investigation of children growing up in a poor community in Hawaii (1992) explored the social outcomes of 540 participants in child cohort study to identify those who had succeeded despite poor prediction. At age 30 one third of the cohort were found to have had delinquent records and two thirds who as children experienced risk factors such as impairment, chronic poverty; parents who had no education and troubled family environments, had developed serious learning and behavioural problems by age18. One third however had developed into 'caring' adults. Werner's study found that stressful life events which increased the likelihood of having a criminal record or broken marriage took place in early childhood. The most common characteristic of those overcoming risk for both males and females were high levels of achievement orientation. In other words, individuals were determined to succeed in spite of their situations. Other factors also had a greater or lesser affect at different life stages. For example, problem solving and communication skills were more influential during middle childhood. The presence of a caretaker parent role in the absence of positive parental support was also found to be important at this life stage. Intrapersonal factors such as high locus of control and self-esteem were more prominent protective factors at adolescence. Gender differences were also found to exist in that boys were found to more resilient in early childhood and late adolescence and girls more so in middle childhood and adolescence.

Similarly, Pilling's longitudinal study (1990) investigated the outcomes of individuals at age 27 who all met the criteria of ‘disadvantage’ as children. Two samples were taken from the 1958 birth cohort study, the first on the basis that they had achieved the top bands of educational achievement at age 16 years; had achieved high income and high status jobs and owned their own homes. In contrast the second group had not succeeded in adult life. A mixture of quantitative and qualitative techniques indicated that the achievers had experienced protective factors that were not reported by their relatively less successful peers, namely family cohesion, high parental aspirations and interest in their child's progress. Schools or particular teachers who had shown a strong commitment to individuals over an extended period of time were also found to be a significant protective factor. The study also indicated that the earlier the disadvantage had occurred and the longer it persisted, the less the likelihood that protective factors would counter it.

These works have been accredited with playing a crucial role in the emergence of childhood resilience as a *'major theoretical and empirical topic.'* (Luthar et al, 2000). Research on resilience widened in scope to investigate not just psychologically adverse situations but resilience in the midst of a range of adverse situations such as extreme poverty (Pilliing, 1990 Werner, 1992; Garmezy, 1991) natural disaster (Hestyanti, 2006) and terrorism (Bonanno, 2005). This first wave research is widely recognised as establishing the descriptors of resilience many of which were already familiar from the discipline of psychopathology (O’Dougherty Wright et al, 2013).

Table 2: Resilience vocabulary

Resilience	Positive adaptation in the face of risk or adversity; capacity of a dynamic system to withstand or recover from disturbance.
Risk	An elevated probability of an undesirable outcome
Risk factor	A measurable characteristic in a group of individuals or their situation that predicts a negative outcome on a specific outcome criteria
Cumulative risk	Increased risk due to: (a) the presence of multiple risk factors: (b)multiple occurrence of the same risk factor: (c) the accumulating effects of ongoing adversity
Distal risk	Risk arising from a child's ecological context but mediated through more proximal processes
Proximal risk	Risk factors experienced directly by the child
Cumulative protection	The presence of multiple protection in an individual's life
Psychosocial competence	Effectiveness or capabilities in the adaptive use of personal and contextual resources to accomplish age-appropriate developmental tasks
Protective factors	A predictor of better outcomes particularly in situations of risk or adversity
Adversity	Disturbance to the function or viability of a system; experiences that threaten or adaptation or development
Vulnerability	Individual (or system) susceptibility to undesirable outcomes; the diathesis in diathesis-stressor model of psychopathology
Asset, resource on compensatory or promotive factor	A measurable characteristic in a group of individuals or their situation that predicts a positive or desirable outcome, similarly for low and high levels of risk
Developmental tasks	Psychosocial milestones or accomplishments expected for people of different ages in a given historical or cultural context, often serving as a criteria for judging how well a person is doing in life

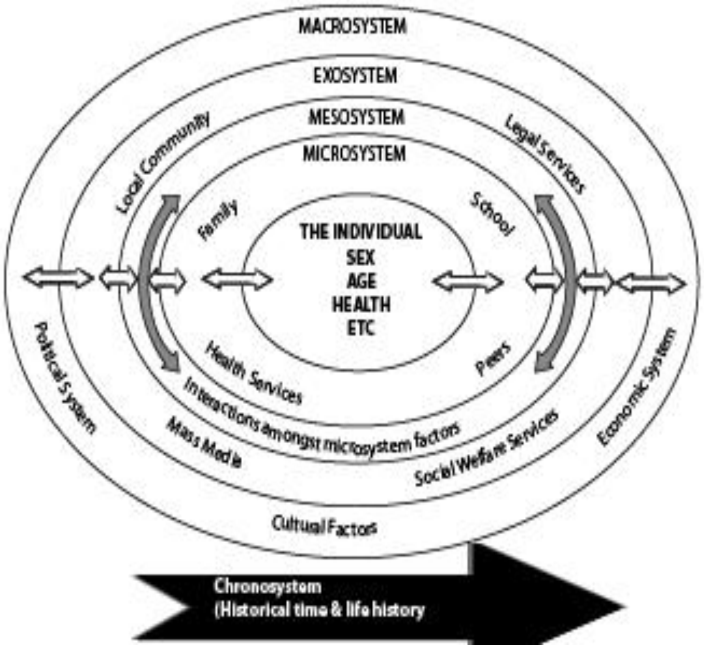
Adapted from O'Dougherty, Wright and Masten and Narayan, 2013.

Despite the multiplicity of adverse situations covered in resilience studies and the range of measurement and analytical techniques employed (Luthar et al, 2000), studies concur that factors which provide protection from adversity can be organised into three broad clusters: Individual attributes such as problem solving skills, high aspirations, locus of control, self-esteem, positive peer relationships; Familial characteristics - caring and supportive relationships such as quality time with child, parenting style, providing good role models, harmony between parents and; Community or aspects of an individual's wider social environment e.g. positive school experiences, good networks with others. (Heiman, 2002).

3.3 Wave two - Ecological systems of resilience

Early studies did not however, provide an *'integrative understanding of resilience in development'* (O'Dougherty et al, 2013). That is, whilst they identified discrete risk and protective factors, an appreciation of how these factors resulted in a positive outcome was not fully understood. As in the disability field, scholarly efforts were increasingly influenced by ecological perspectives which regard human adaptation as the outcome of complex relationships nested within multiple levels. Second wave resilience studies moved beyond the identification of resilience promoting factors and are firmly embedded within a systems theory approach to human development (Cowen, 2000; Masten and Obradovic, 2008). During this phase resilience is recognised as a dynamic process rather than a static trait which enables individuals to withstand disruptions and reintegration to homeostasis (Richardson, 2002). Studies were widely influenced by systems theory and the social ecological perspectives of Urie Bronfenbrenner. Bronfenbrenner's Social Ecological model (1979) specified the complexities of individuals developing within embedded systems (Wendel and McLeroy, no date). Bronfenbrenner suggested that an individual's environment can be separated into five nested sub-systems, likening them to a set of Russian dolls nested within each other. The first layer, the microsystem includes the relationships and interactions the individual has in their immediate surroundings such as with family, school systems, neighbours and work colleagues. The microsystem also includes the individuals own biological ecosystem. Within the microsystem individuals actively take part and therefore bi-directional relationships within this layer have a strong influence. The second layer, the mesosystem involves the interrelationships between two or more microsystems. For example, the relationship between the individual's family and school. The mesosystem has been described as 'the microsystem's system' (Cardenas and Lopez, 2010) and as with the microsystem, the individual actively takes part. The third layer represents the exosystem in which the individual is not an active participant but where events have an indirect influence. For example, the parent of an individual receiving a pay rise which might facilitate family holidays or where a bus strike might impact on the ability to travel to an travel appointment. The fourth layer is the macrosystem in which ideological patterns and organisations of social institutions common to a particular culture or subculture are manifested. The macrosystem involves the systems of belief and values such as the economy, cultural values, religion and political systems. The fifth system, the chronosystem, includes the transitions and shift of events over the life course of the individual. Factors within this system can be internal such as physiological changes such as getting older or the sudden loss of sight, or external life events such the death of a spouse.

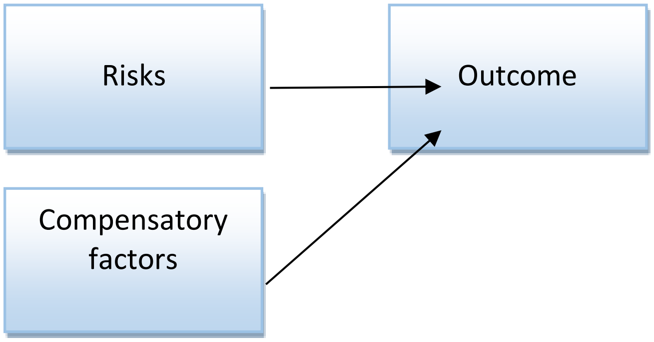
Figure 4: Bronfrenbrenner's Ecological framework



Influenced by social ecological theory, the focus of empirical studies in the third wave shifted from the earlier focus on identifying protective factors to understanding underlying protective processes. Rather than simply studying which child, family, and environmental factors are involved in resilience, researchers are increasingly striving to understand how such factors may contribute to positive outcomes (Cowen et al., 1997; Luthar, 1999). Three main models have been used to describe how promotive factors may counteract, protect against or inoculate youth from the negative effects of risks (Masten et al., 2007; Luthar, 2003). Compensatory and protective models of resiliency are the two most commonly studied in the research literature (Fergus & Zimmerman, 2005; Garmezy et al., 1984; Masten, et al., 2007). A third model has limited empirical support, but also provides an explanation for how youth may overcome the adverse consequences of risks.

In the *compensatory model*, protective factors neutralise risk exposure in a counteractive fashion. Zimmerman and colleagues (2013) note that compensatory factors have '*an opposite, direct, and independent effect on outcomes*' (p.215). Thus, compensatory factors contribute additively to the prediction of outcomes and in quantitative analysis are entered into a regression analysis after risks are accounted for in the equation. Parental support, for example, was found to compensate for risks associated with fighting and being around violent adults (Zimmerman, et al., 1998). In this study, parental support predicted less violent behaviour among their adolescent children and this effect was independent and in the opposite direction of the risks.

Figure 5: Compensatory model



The *protective factor model* posits that promotive factors moderate the impact of the risk rather than neutralise it as in the compensatory model. Two types of protective models are risk-protective and protective-protective. Risk-protective models indicate that promotive factors operate to moderate or reduce the association between risks and negative outcomes. Protective-protective models operate to enhance the effects of either promotive factor alone for predicting an outcome. Protective models are tested using interaction effects in regression or multi-group analysis in structural equation modelling. Hurd and Zimmerman (2010) provide an example of a risk-protective model in their study of adolescent mothers. They found that natural mentors helped protect adolescent mothers from the negative effects of stress on their mental health. A study of self-esteem and cultural identity among Native American youth provides an example of a protective-protective model (Zimmerman et al., 1995). Researchers found that self-esteem increased the negative association between cultural identity and alcohol use in an interaction effect in a regression analysis.

Rutter (1987) also introduced the *challenge model* of resiliency. This model operates as an inoculation against risk, the idea being that a modest amount of exposure to risk can help individuals overcome subsequent exposures. Rutter (1987) suggest however that it is vital that the initial risk exposure must be challenging enough to help individuals develop the coping mechanisms to overcome its effects, but not too taxing as to overwhelm any effort to cope. For example, interpersonal conflict that is resolved amicably can help individuals learn how to overcome social tensions to avoid a violent response in some later more heated social disagreement (e.g. avoidance of involvement in a gang fight).

These models guide data analytic strategies and can inform the design of intervention by defining strategies to enhance promotive factors.

3.4 Waves three and four: Application to interventions and Brain mapping

Third wave resilience studies are characterised by the testing of resilience process ideas on experimental prevention and intervention strategies. Rather than predicting risk, the goal became to change the life course of vulnerable individuals (Bernard, 1991). These studies placed less emphasis on individuals and more on the effectiveness of resources found in their environments such as educational (Hawkins et al, 1999) and home life (Forgatch et al, 1999; Wolchick et al, 2002) settings. During this phase conceptualisations of resilience in social constructionist terms was also introduced, incorporating the impact of culture on outcomes (Ungar, 2004). The fourth and most recent phase of resilience research encompasses new technologies such as wave brain imaging and bio genetics (Cicetti and Toth, 2009; Kim-Cohen and Gold, 2009).

3.5 Resilience in visual impairment literature

The concept of resilience has received surprisingly limited attention within the field of visual impairment. A search for the terms ‘resilience’ and ‘visual impairment’ in the Birmingham University search engine ‘FindIt’ yielded just 23 studies of which had a specific focus on resilience theory. However, a plethora of studies were found which tended to focus on the areas protective factors earlier in this section as being consistent across studies. Individual attributes, familial characteristics and community. Examples of individual characteristics are studies on coping strategies, (Ben Zur, 2002; Ben-zur and Debi, 2005; Garnefski et al, 2010), Social comparison (Lifshitz et al, Beatty, 1992), Self-concept (Martinez and Sewell, 1996; Alexander, 1996), locus of control (Roy and MacKay, 2002), Self-esteem (Dodds, 1993; Alexander, 1996; Griffin Shirley and Nes, 2005; Garaigorobil and Bermara, 2009), Social skills (Elksnin and Elksnin; Haager and Vaughn, 1995) and confidence (Stockley and

Richardson in 1991).

Literature within the visual impairment sector appears therefore to be closest to investigations in wave one resilience studies. That is, although key protective factors have been identified, a nuanced exploration of the processes in which those protective factors operate in relation to risk has yet to be undertaken. Since attention to the underlying mechanisms of resilience is viewed as essential for advancing theory and research in the field, this does suggest the need to widen the evidence base within the visual impairment sector. In addition, such information has been used in wave four investigations to as well as for designing appropriate prevention and intervention strategies for individuals facing adversity (Cicchetti & Toth, 1991,1992; Luthar, 1993; Masten et al., 1990; Rutter, 1990).

Young and colleagues (2008) have commented on the absence of published resilience studies on deaf children. They considered whether the topic had simply passed the field, whether investigations are taking place without being labelled as such, or whether there are ontological explanations for its absence (Young 2008). Whilst the rebranding of resilience related studies of visual impairment has not yet occurred, it is clear that there is a gap in literature on of the processes which facilitate greater social participation.

Summary

This chapter has introduced the theory of resilience as a means of highlighting the resources available to individuals who overcome the negative effects of risk exposure. Successive waves of resilience investigations have established that the resources which promote a previously judged positive outcome are not only located at the individual level but are also extrinsically located across systemic levels. In this regard the conceptualisation of resilience has taken a similar trajectory to that occurring in disability studies. That is, both constructs are no longer regarded as individual traits but a complexed interaction of factors. Due to these similarities it is tempting to regard resilience as the positive end of a disability vs resilience continuum. In other word the factors creating disability or disablement can be regarded as negative and those promoting resilience as positive. The theoretical models of resilience suggests that its mechanisms work by either neutralising risk factors as in the compensatory model, inoculate the individual against risk as in the challenge model or protecting as with the protective model. This section has also highlighted the paucity of published investigations of resilience in the context of visually impairment. This paucity is somewhat tempered by numerous studies which have focussed on already established protective factors without being packaged as such. In this regard resilience related studies within the visual impairment sector are akin to wave one studies, which although ultimately recognise resilience as involving intrinsic and extrinsic factors, had yet to examine the ways in which these factors operate. An understanding of understanding how these factors function in combination with risk as in wave two studies, would provide the potential to test the effectiveness of resilience promoting factors in intervention programmes such as those characterised by wave three studies.

The following chapter summaries the literature review by discussing the main themes and areas presenting opportunities for further empirical investigation. The discussion then leads to the research questions to be addressed in the thesis.

CHAPTER 4: Literature review summary leading to research questions

The review thus far has discussed the many conceptual issues surrounding the definitions of the main concepts visual impairment, social participation and disability. This was followed by evidence of the physical, social and structural challenges to social participation experienced by visually impaired people. The concept of resilience as a theoretical framework for understanding how some visually impaired individuals navigate these challenges and thrive in site of them was then presented. This chapter brings together these discussions by describing the main themes emerging from the review which centre on the multifaceted nature of the key constructs. In doing so this section legitimises the application of the equally dynamic construct to the study of social participation whilst foregrounding the experiences of people with a visual impairment. However, as revealed in the review, applying a resilience framework has some requirements with regard to clearly specifying the resilience terminology employed in planned studies. The discussion leads to the formulation of the research questions.

4.1 The interactive nature of being human

A dominant and pervading theme emerging from the review is that efforts to capture the lived experiences of human development cannot adequately be achieved without taking into account biological, psychological, social and cultural influences. In the case of visual impairment, quantitative measurements and assessments may be useful for legal and administrative purposes or gauging entitlement to benefits but have limited utility in providing truthful accounts of the ways in which individuals manage their lives on a day to day basis. The problem is that people with visual impairments are not a homogenous group and differ in the ways they become and experience their conditions. What may be an easy task for one individual may seem insurmountable to another. Individuals do not exist in isolation and reflects the general acceptance that a wide range of internal and external factors can potentiate the participation of visually impaired in their communities. This marks a move away from the medical and social model dualisms. Increasingly, researchers are focussing on the interrelationships between and within different domains of functioning which determine negative or positive outcomes. These interactions are not linear or unidirectional and can best be captured using a biopsychosocial models although others call for constructionist approaches.

Researchers and professionals within health and disability have largely adopted the ICF as its framework for capturing the complexities of real life outcomes and for the purposes of organising observations, planning, and designing intervention strategies (Gilbert, 2002). Similarly, resilience researchers lend primacy to the interactions between assets and resources to explain resilient outcomes over person centred approaches. Biopsychosocial models such as the SEM have been adopted by resilience researchers to frame the trajectories of individuals who thrive in spite of adversity. The literature strongly suggests therefore that to capture detail on the experiences of disabled people, researchers must take into account interrelationships across multiple levels of a person's social ecology.

4.2 Defining key resilience terms

The review also highlighted the problems associated with defining the major concepts at the core of the research topic. Consequently there is the need for researchers to clarify definitional terms used in resilience studies. It is generally accepted that for resilience to be detected, individuals must both be exposed to some kind of adverse event or threat *and* achieve a positive outcome in spite of it. The applications of resilience theory across a diverse range of life situations has resulted in varied conceptualisations its key terms. Prominent resilience academics suggest that these key terms need to be explicated by researchers in order for resilience studies to be valid. The literature therefore suggests that the development of a set of working definitions within the context of the current study is required. Further, the literature indicates that there remains considerable ambiguity on the definition of social participation (LeVasseur et al, 2010; Alma, 2011). Resilience commentators have cautioned that resilience may be present in circumstances which are not typically considered as such. Resilience terms such as risk, positive outcomes, vulnerability and adversity are socially constructed and are typically defined in cultural and historical terms, based on societal expectations. Since research questions are the starting point for operationalising research investigations and represent a shift from the abstract, conceptual level to the empirical task of measurement, these issues must be resolved. Luther and others (2000) have noted that a failure to resolve these issues will undermine the field, laying it open to tautological criticisms (Kaplan, 1999; Tarter and Vanyukov, 1999). Luther and colleagues also note the importance of justifying the definitions used:

> *'…researchers must explicate the approaches they use to define both adversity and competence and provide cogent justifications for choices made on conceptual and empirical*

> *grounds…' (Luthar, Cicchetti and Berger, 2000, p.546)*

The remainder of this chapter addresses some of these conceptual issues as they relate to the thesis and lead to the research questions.

4.3 Defining risk and vulnerability

A central resilience term is risk. Risk refers to the chances of adversity or challenge translating into an actual negative outcomes. The literature review provides justification that visually impaired people are indeed at an increased risk of isolation and barriers to participating in the 'normal' functioning's of everyday life. Evidence provided included discrimination in employment and reduced levels of socialising. The review also showed that indirect factors such as economic hardship can influence participation levels. It is clear however, that not all people with a visual impairment experience the same levels of risk. This inequality of risk can often be obscured in studies grouping people with sensory impairments together. Even studies with a sole focus on visually impaired participants can mask heterogeneity within the visually impaired population partly linked to the many ways people experience their conditions. Whist identifying individuals who are particularly vulnerable to the risk of isolation is necessary for targeting those same individuals for intervention, assuming that all are equally vulnerable can risk patronisation and overprotection. Luthar (2000) also make this point:

> *'Some individuals may see themselves as being relatively well off, even though scientists may define their life circumstances as being highly stressful.' (page 12)*

The current study therefore must avoid assuming that all visually impaired consider themselves as disadvantaged.

A second risk related issue requiring clarification is the source of the risk. As Young et al (2008) are careful to note when quoting Rutter (2000), *'one of the methodological problems with much research on resilience is that it does not actually clearly enough define or justify that source risk'*. As discussed above, visually impaired people are disproportionately at risk of isolation when compared to the general population. Further, the literature indicates some variables are associated with an increased risk of isolation such as severity of visual impairment. Is the visual impairment as an individual attribute itself is a risk factor? The literature on disability theory with particular reference to the medical model, suggests that visual impairment is not in and of itself a risk factor but that it is the interactions with other factors which increase the risk to isolation. Young and colleagues (2008) make this same point in relation to deafness. By arguing that *'…deafness in a range of familial, social and institutional contexts may interact with variables and processes that render its disadvantaging effects more likely' (page 10)*. Visual impairment is a demographic characteristic, an individual difference and for the most part is immutable, in the same way as skin or eye colour usually cannot be changed. Whilst a visual impairment may make individuals *vulnerable to* risk, it is the interaction between the impairment, body and society - the disabling processes, which is the trigger. Howard, Dryden and Johnson (1999) differentiate between 'at risk' and 'vulnerable' children. The authors suggest that 'at risk' students are those presenting at school with one or more indicators. These include disruptive behaviour, social and emotional problems, learning difficulties, living in low-income families or eligibility for government financial assistance. Vulnerable students on the other hand was used to describe children with biological, cognitive, effective or sensory disorders for example, autism, ADHD, hearing or visual impairment and physical or mental disabilities. Visual impairment therefore is an attribute which may indicate a person is particularly vulnerable to risk, but it is not the source of the risk. Young and colleagues (2008) suggest that it is perhaps this type of analysis that is absent from studies of disabled people. The paucity of studies on resilience in the visual impairment field has resulted in a gap in our understanding of the interactions and processes which render particular groups of visually impaired people more or less likely to experience isolation, the negative outcome. This leads to the first question which is:

RQ1. Which visually impaired subgroups are most vulnerable to an increased risk of a lack of participation?

4.4 Defining adversity

Many empirical resilience studies have focussed on extreme adversities such as major disasters (Davis, 2002) and terrorist attack (Bonnano, 2005) and the literature in no way suggests that visually impaired people are any more likely to experience these major traumatic events than non-disabled people with perhaps with the exception of poverty which was identified in the review. Increasingly however, studies are applying resilience theory to the everyday struggles which are embedded into the lives of most people. Davis et al (2009) refer to these adversities as modest disruptions or daily hassles. The challenges described in the review certainly suggest that visually impaired people face a range of daily stressors. For example, aggregately visually impaired people experience disproportionate levels of unemployment when compared to the general population. When added to discrimination in their local communities and a lack of social support these factors are likely to have a cumulative effect. I would argue that given the evidence from the literature there seems no compelling reason to reject the premise that visually impaired people face adversity which contribute to a lack of social participation. Hinckman et al (2014) however, are careful to highlight the difficulties of assessing the impact of stressors because they are so relative and are felt differently by different people. In other words, stressors which may be inconsequential or moderate disruptions to one person may constitute a major disruption to another.

4.5 Defining positive outcomes

Social participation, one of the central concepts in this thesis, is taken to be the positive outcome since it is a right of individuals as well as an expected 'norm' in democratic societies. If as Burchardt (2000) suggests isolation is the opposite of social participation, the literature does indicate that visually impaired people are at risk of the latter. Given the association of isolation with poorer health outcomes, I suggest that it is not unreasonable to define social participation as the positive and desired outcome. This is of course whilst recognising that resilience outcomes may also be present in circumstances which may not be typically considered as such. An example might be people who are actively participating online although it could be argued this represents a limited view of participation. However, positive outcomes such as social participation are socially constructed and are typically based on societal expectations. Studies have been criticised for their definition of successful outcomes which are often dictated by western notions of normalcy. This leads to question 2:

RQ2***: How is a successful outcome defined?***

> ***a) What are the indicators of a successful outcome (social participation)?***
>
> ***b) What are the characteristics of someone 'doing well'?'***

4.6 Identifying resilience mechanisms

There is strong internal consistency across multiple studies of the protective factors correlating with a positive outcome. There is a considerable degree of consistency across studies on the protective factors enabling individuals to moderate or avoid risk (Masten, 1985; O'Dougherty Wright et al, 2012; Masten and Narayen, 2012). Given the absence of resilience research in the visual impairment sector it is not clear from existing literature whether there are protective factors which are unique to the experiences of people living with a visual impairment In addition, uncovering the processes which promote positive outcomes is also necessary. Young et al (2008) in their analysis of resilience studies relating to deafness noted that to *'…advance resilience theory researchers the identify risk and protective factors but to identify processes' (2008)* which as noted above, is less discussed in the visually impairment literature. The ultimate aim of the thesis therefore is not merely to identify discrete risk and protective factors as they are experienced by visually impaired people, but to develop theory on the mechanisms involved in adapting to adverse situations. This leads to questions 3 and 4:

RQ3: What are the risk and protective factors associated with social participation for individuals with a visual impairment?

RQ4: How can the resilience processes involved in social participation be described?

4.7 Chapter summary

The literature reviewed indicates that visually impaired people do experience daily struggles, challenges and even adversities which warrant the application of resilience theory in a new empirical study. Applying the resilience framework and its accompanying lexicon to any new investigation does however require definitions of the core concepts to be clearly explicated. The review of the literature was able to clarify some ontological issues, such as the need to regard risk and resilience as dynamic and multi-factual influencers of social participation. However, a lack of consensus on the meaning of the pivotal construct social participation which is operationalised as the desired outcome, and the dearth of previous studies of resilience in published investigations of visual impaired people requires resolution.

The issue of risk is addressed in RQ1 which recognises that a lack of social participation is by no mean an inevitability amongst visually impaired people although the condition does make this population more vulnerable to the negative outcome. Since it cannot be assumed that all visually impaired people have the same level of risk, this first question sets out to understand the characteristics which increase or decrease the risk of the undesired outcome. Within the context of this thesis risk factors constitute environmental variables with the potential to increase the occurrence of the undesired outcome (a lack of social participation).

Whilst social participation is regarded as the desired and positive outcome, some clarification on its definition is necessary and is addressed in RQ2. This question seeks to characterise the positive outcome by identifying the attributes of a visually impaired person who is participating in community life. Protective factors are the assets and resources drawn upon (consciously or unconsciously) by the individual to challenge, moderate or absorb the impact of risks to social participation. Although across disciplines, resilience literature has established a consistent set of protective factors which have been found to protect against risk, RQ3 attempts to identify those which are unique risk to visual impairment. Finally, the overarching context of resilience is viewed as the process or processes enabling individuals to achieve social participation in spite of the challenges encountered. RQ4 attempts to explain these the ways in which protective processes protect, challenge or compensate risks to social participation.

In the following chapter I develop the methodology in response to the research questions and discuss the ways in which the research design evolved as the requirement for greater subjectivity was exposed.

CHAPTER 5: Methodology

The previous chapter synthesised extant literature by discussing the emerging themes. Operational concerns, obscurities and gaps in existing knowledge were also identified, Information garnered from the review was then used to reconceptualise key resilience terms such as risk, protective factors and positive outcomes, culminating in the emergence of four research questions. This chapter discusses the ways in which the research design was led by the research questions each requiring increasing subjectivity which became increasingly apparent as the resulting studies progressed. As a result, the research was emergent in design with the first investigation determining the design of ensuing studies. The use of a mixed methods design in this thesis reflects earlier discussions on the tendency of dualisms to polarise explanations of human behaviour which usually involve a combination of extremes. Similarly, the human experience cannot be expressed in entirely quantitative or qualitative terms. As such, a full exploration of resilience required a methodologically eclectic design to capture data on the complexities of living with a visual impairment. The critiques of mixed method designs are addressed, followed by the rationale for each of the three studies.

5.1 The need for greater subjectivity

Throughout this thesis I have discussed the multidimensional and dynamic nature of the factors influencing social participation for visually impaired people. In chapter two I argued that the experiences of people are the result of the interrelationships of both internal and external factors. Understanding how these interrelationships affect individuals at as they participate in their communities requires a combination of quantitative and qualitative research methods. To this end a combination of complementary methods were employed to address the different requirements of each of the distinct research questions. To recap these were to:

RQ1. Which visually impaired subgroups are most vulnerable to an increased risk of a lack of participation?

RQ2*: How is a successful outcome defined?*

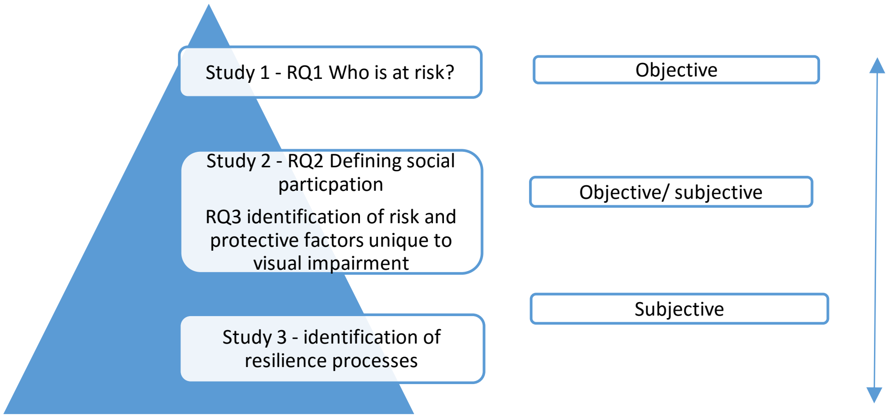
- ***a) What are the indicators of a successful outcome (social participation)?***
- ***b) What are the characteristics of someone 'doing well'?'***

RQ3: What are the risk and* protective *factors associated with social participation for individuals with a visual impairment?

RQ4: How can the resilience processes involved in social participation be described?

The research design employs both positivist and interpretivist approaches for pragmatic, opportunistic and reflexive reasons. RQ1 was concerned with the identifying factors which increase the risk of the negative outcome. The logical approach was therefore to apply a quantitative method to compare large population of visually impaired people. The opportunity to conduct a secondary analysis on a 1000 visually impaired respondents who had taken part in the Network 1000 survey discussed earlier in the review. The data focussed on the respondent's perceived social support, a central component of social networks and therefore a proximal indicator of social participation. However, as with the complexities of disability theory and resilience, both constructs are conceptualised by the interactions of multiple factors. On reflection, the analysis of the single variable social support was limited in its ability to expound resilience amongst visually impaired individuals. It became apparent that subsequent studies would require insights from the personal experiences of individuals to access the ontological truth of resilience. Figure 6 shows the progression of the research design which takes on a funnel approach. Starting with RQ1 which is closed, generalisable and objective and progressing outwards to accommodate the requirements of RQ2 and RQ3. Both the second and third questions required a method that could facilitate greater degree of openness to that of used in RQ1 but which would also accommodate the streamlining of data using quantitative methods. RQ3 which explores the complexed nature of processes required complete openness, participant control and context dependent data at an individual level.

Figure 6: Progression of methodology from objectivity to subjectivity - Funnel approach



5.2 Mixed methodology – the third paradigm

Combining approaches in scientific studies is often referred to as the third paradigm, differentiating it to qualitative and quantitative approaches. Employing a mixed methods design involves collecting, analysing and integrating of quantitative and qualitative in a single study or series of studies. Mixed methodologies are used when a single method is unable to address a research problem as in the current thesis. Addressing a number of research questions in one study with different epistemological underpinnings is not uncommon as Brannen (2005) points out:

> *'…it is rare for a researcher working on a project to pose only one research question. Indeed any piece of research is likely to comprise a complex of research questions. While the key research question or questions in one piece of research may be underpinned by realist assumptions, some research questions may be underpinned by interpretivist assumptions, for example how people make sense of their actions… (2005, p6) '*

It has been argued that mixing quantitative and qualitative methods is 'inherently incompatible' a view stemming from the so called 'paradigm war' of the 1980's. Single method purists on either side of the quantitative and qualitative divide, argued that the positivist and interpretivist paradigms are grounded in philosophical assumptions which are essentially at odds (Guba & Lincoln, 1994). Positivism is believed to transcend subjectivity, universality and generalisability with its top down inductive approaches. Interpretivists on the other hand, value subjectivity, multiple realities and the generating of theory from bottom up. However, I would argue that neither quantitative nor qualitative methods provide full access to reality but that a combination of paradigms provide complementary insights to create a bigger picture (Brannen, 2005: 12-14). This view is also held by proponents of mixed method designs who suggest that the paradigms can be used harmoniously and that on both epistemological and practical grounds, the incompatibility thesis is a false divide (Johnson and Onwuegbuzie, 2004; Howe, 1988). The paradigm war reflects earlier discussions in the literature review which highlight the propensity for polarised debates to obscure important issues occupying the middle ground. Cornell psychologist William Trochim puts forward the view that qualitative and quantitative methods are not as distinct as purists might like to believe:

> *'In some areas of social research, the qualitative-quantitative distinction has led to protracted arguments with the proponents of each arguing the superiority of their kind of data over the*

> *other. The quantitative types argue that their data is hard, rigorous, credible, and scientific. The qualitative proponents counter that their data is sensitive, nuanced, detailed, and contextual. For many of us in social research, this kind of polarized debate has become less than productive. And, it obscures the fact that qualitative and quantitative data are intimately related to each other. All quantitative data is based upon qualitative judgements; and all qualitative data can be described and manipulated numerically.' (2006: Online)*

Within the field of resilience mixing methods is increasingly the dominant design structure particularly in cross-cultural studies. For example, in the National Resilience Project researchers found that the quantitative methods in the study revealed *'…heterogeneity in how resilience is understood and negotiated across cultures and contexts',* whilst the qualitative aspect of the study showed that '*…not all constructs held the same importance in all cultures'* (Ungar and Liebenburg, 2011). Resilience researchers recognise therefore, that quantitative and qualitative methods address different parts of the whole, both having a place in addressing the research questions by revealing different aspects of the phenomenon under investigation.

The following section of this chapter rationalises the use of the methods in the three studies and how the studies fit together within the thesis to respond to the research questions.

5.3 Study 1 – Secondary data analysis

RQ1. Which visually impaired subgroups are most vulnerable to an increased risk of a lack of participation?

The decision was taken to use quantitative methods in relation to RQ1 which explores the likelihood and probability of the risk isolation. Assessing risk is generally a quantitative endeavour which involves estimating the possibility of the occurrence of an event with negative consequences. This involves establishing the normative value of the wider population in comparison to the sub-group. The quantitative characteristic of risk is reflected in the commonly used definition of resilience as 'beating the odds'. The task in this study is to identify the factors enabling visually impaired individuals to beat the odds. Risk assessments are by no means an exclusively quantitative endeavour. Resilience studies, particularly those working within the constructionist paradigm have used qualitative measures to identify risk. However, since the objective of RQ1 is to compare the visually impaired population with the general population, this information can be practically achieved through the analysis of data collected from a large number of visually impaired people. Quantitative data such as surveys enable statistical inferences to be made as well as providing baselines and references. Such data provides the ‘big picture’ by enabling descriptions of the characteristics of individuals. Although large datasets can be achieved using qualitative methods, the costs of doing so would be prohibitive. Further, as noted in Trochim’s quote above, the application of some form of quantification would still be required to make meaningful generalisations.

The survey design presents a means of obtaining generalisable information from populations but are also costly and time consuming. An alternative, secondary analysis of survey data, presents opportunities to access information collected by other researchers on the population of interest. Often research decisions are based on pragmatism as well as luck. In this instance, researchers working on the Network 1000 survey (Douglas et al, 2006) were based in the department in which this thesis is being undertaken and provided access to the large dataset of visually impaired people collected as part of their research. The researchers had collected data on the perceived social support levels of around 1000 visually impaired people but had not been reported in the published report. Not only was this a pragmatic approach, ethically the results needed to be analysed to ensure that time taken by respondents to respond to the research was not wasted. Whilst social support cannot be strictly used as a proxy for social participation, or in other words an absence of social support does not strictly equate to an absence of social participation, the two variables are strongly associated. In successive studies social support has been found to be a strong predictor of social interaction. Across resilience studies covering a range of contexts, social support is a key protective factor in enabling individuals to withstand stress. Social support therefore may reveal which groups of visually impaired people do or do not have access to this valuable protective resource. A lack of social support may indicate that they are at a greater risk of isolation. To provide a baseline and reference the network 1000 data was compared with data collected in the Health Survey England, as well as other disabled populations.

The secondary data analysis was not selected on positivist assumptions but because it was the most appropriate and pragmatic method to answer the research question. Whilst providing the benefit of revealing the social support status of outcomes of large numbers of people at any one point in time which was the intended outcome, more detail was required. If the task had been merely to establish the risk of isolation within visually impaired population the limitations of quantitative methods would not have been called into question. However, since the research question was part of a wider set of questions, study one had the tendency to generate more questions than answers. What of the individuals who in principle possessed the attributes which should make them more vulnerable to isolation but were not lacking in social support? It was evident that greater context was needed particularly since RQ2 required specificity on the construct of social participation.

5.4 Study 2 – Delphi study

RQ2*: How is a successful outcome defined?*

a) What are the indicators of a successful outcome (social participation)?

b) What are the characteristics of someone 'doing well'?'

RQ2 sought to clarify definitional terms within the context of visual impairment. This stage was required to avoid imposing normative assumptions about the characteristics considered to constitute a positive outcome in to the study. RQ2 therefore required a means of accessing the opinions, thoughts and ideas of individuals with experiential knowledge of the factors involved in social participation. Any emerging data needed to be sufficiently rich and detailed to develop themes. This requirement called for a qualitative approach. However, agreement on the emerging themes and outcomes also required some degree of reduction and quantification. For this reason the Delphi method was used, a technique which combines quantitative and qualitative methods in one study making it somewhat of a methodological paradox.

RQ3: What are the risk and* protective *factors associated with social participation for individuals with a visual impairment?

Similarly RQ3 was also addressed in the Delphi for the same reason. On the one hand it would seem that the epistemological basis of the Delphi is a positivist one. That the researcher has the position of being detached from the participants, produces statistical measures and reduces the responses to a set of figures. However the Delphi can also be considered within the constructivist paradigm (Fitzsimmoms and Fitzsimmons, 2001) since the data is generated by the experts and their contributions are recognised at an individual level.

The use of the Delphi method also gradually introduces the concept of participation to the overall study in a way that the earlier secondary analysis was unable to achieve. Discussions on participation in research and particularly research with disadvantaged groups as is the case in the current study, is often related to reducing the power relationships between the researcher and the researched. A consequence of the redress of power is data that is closer to the experience of participants.

5.5 Study 3 – Phenomenology

RQ4: How can the resilience processes involved in social participation be described?

In the final study RQ4 set out to identify and describe resilient processes. As Luthar and colleagues note (2000) the identification of processes should be the ultimate aim of resilience researchers:

> *'Once researchers have determined that the odds of maladjustment are high in the presence of a certain risk, it is entirely logical—indeed, worthwhile—to try to determine the factors associated with relatively positive child outcomes, as well as to examine the proximal processes by which the distal risk marker confers vulnerability on affected groups of children'. (Page 10)*

Narrative analysis, a method firmly rooted within the interpretive paradigm was used to address RQ4. There were several reasons for opting for a solely qualitative method. The secondary analysis of RQ1 required the identification of risk at the macro level and RQ2 and RQ3 required the views of a group of experts in the Delphi to gain consensus on key terms at a community level. RQ4 required data which was more specific in focus and required the gathering of deep information at the individual level. Previous research indicates that the term resilience is conceptually fuzzy (Liebenberg and Ungar, 2008) complicated by its embeddedness within local contexts. Human development is rarely linear and predictable. The chaotic nature of social life is influenced by local and wider macro societal factors are unique to the individuals who experience them. An individual's experience of resilience is subjective and therefore require research methods which can capture this subjectivity. Ungar (2004), arguing for a social constructionist approach to researching resilience states that it promotes an understanding that resilience is multidimensional, chaotic non systemic, non-hierarchical and is relative and contextual (Ungar, 2004). Phenomenology and its associated methods are used for accessing subjective experience and gaining access to people actions and motivations. The goal is to describe the lived experience of the phenomenon under investigation. Phenomenology can illuminate the *'chains of events or factors and processes that protect over time rather than static variables* (Davidson, 2008: 116). Secondly, the paucity of resilience studies within the context of visual impairment means that resilience is still an emerging concept within the field. Whilst some studies have explored protective factors, few have looked at processes through which resilience manifests. Further, although resilience studies have shown that factors such as social support and self-esteem contribute to resilient outcomes, the ways in which they might operate for visually impaired individuals is unclear. The absence of literature which might otherwise have been used to provide a foundation for quantitative exploration predicates the use of qualitative methods. Only after these factors have been identified and described through qualitative means, which may challenge normative assumptions, can they then be validated using quantitative techniques.

Thirdly and related to the principles of emancipatory research. The use of qualitative approaches to resilience enables research participants to tell their own story as opposed to having the researcher impose taken for granted assumptions onto them. In this way the resulting findings are more likely to be authentic and meaningful. Endeavouring to make the study as unstructured as possible also reduces the power relations between the research and the researched. This was noted by researchers working on the Negotiating Resilience Project, a cross cultural study of youth in Canada India and South African communities. The use of visual methods for studying positive psychosocial development in stressful social ecologies was used. Since visual diaries were not appropriate for visually impaired participants, audio diaries were a suitable alternative and can provide the insight and participant control by enabling visually impaired participants to collect the data produced. As such, this method produces inductive data which is grounded in the reports of the person experiencing disability whilst meeting the calls of emancipatory advocates without the overtly political standpoint.

Summary

The research approach was designed to address the questions and resulted in three separate studies. This chapter has discussed how the research design was determined by the logical decision to use a quantitative method to address RQ1 which was concerned with identifying risk. This first question required a method that could facilitate the management of large population data to make assumptions about visually impaired people at risk. In parallel, the opportunity to conduct a secondary analysis of survey data arose resulting in study one. Since research questions 2 and 3 required greater specificity the Delphi which combines quantitative and qualitative techniques was used. Research question 4 which addressed the why and how resilience processes operate, required interpretative methods and therefore narrative techniques were employed. As a consequence the methodology was flexible and emergent in design, progresses from the use of objective methods to more subjective ones. The chapter has also argued that it is possible to combine the use of quantitative and qualitative approaches in research and that this is not unusual in studies investigating resilience.

The following chapter describes the method and results of study one, which examines variations in risk amongst visually impaired individuals. The chapter provides full detail of the methods and research findings.

CHAPTER 6: Study 1 – Identifying vulnerable adults and social support

In the previous chapter I discussed the way in which the research questions determined the methodological approach used to explore resilience. The first of those questions which addresses the issue of vulnerability and risk is explored in this chapter. This chapter explores the levels of access to social support amongst people with visual impairments which across resilience studies has been found to be a key protective resource. Of relevance to this thesis is the strong correlation between social support and social participation. The aim of the study was to identify the characteristics of individuals within the visually impaired population who are most vulnerable to the risk of social isolation the undesirable outcome. The study also aimed to identify specific factors associated with an increased risk with a view to identifying individual's requiring intervention. The perceived social support levels reported by 802 registered visually impaired people were compared with those of the general population using a logistical regression analysis. Their results were also benchmarked against data from people with long term 'disabilities' or illnesses and other people with self-reported visual impairment. The findings indicate that registered population people are particularly vulnerable to some lack of social support although the unregistered population were more likely to report a severe lack of support. Whilst age was not significantly associated with levels of social support, living alone and having a long term disability or health problem (in addition to their visual impairment) were. The study also has questions about the whether the seven item social support scale used as a measure of social support is a good predictor of social exclusion for older people.

6.1 Social support as a protective factor

Understanding how people with a visual impairment participate successfully in their communities first requires an exploration of risk. In other words, to understand whether individuals are participating one must first explore the negative outcome. In the context of this thesis social participation is regarded as the positive outcome, the corresponding negative outcome is isolation. Existing research indicates that isolation is a significant problem for visually impaired people (Thomas Pocklington, 2014).

Social relationships and networks have been shown to mediate the impact of isolation and represent an important role in most of our lives. Feeling loved and having a sense of belonging features immediately after our basic need for food and safety in Maslow's hierarchy of needs (1943). Resilience studies consistently demonstrate that the presence of positive social relationships are a critical component of resilient outcomes (Beardslee, 1989; Masten, 2005; O'Leary, 1998). Successive resilience studies have also shown that social support is a key protective factor because of its ability to help individuals alleviate against the stress. Carver (1998) discusses the steeling effect of social support to help people cope with stress:

> *"A person experiencing a traumatic event finds that help from others is readily available; that the significant others in his or her life can be counted on and that the result can be a positive change in the sense of the relationships involved. The person may experience a strengthening of the sense of security in those relationships . . . Perhaps, then, the person who experiences ready availability during a period of adversity acquires an enhanced sense of security in relationships. In principle, this would permit the person's future exploration to operate a more secure base." (p. 252)*

The strengthening effect of social support is just one way in which the construct is believed to work and others are discussed below. Thus, social support is a resource that all individuals can benefit from regardless of visual status. However, the evidence from the review of literature indicates that people with visual impairments require more helpful support from others to mediate the physical and psychosocial aspects of living without sight. The problem is that developing and sustaining social networks, the mechanisms through which social support is provided, can be difficult for this population as discussed in chapter 2. Positive support from family and friends who are often the primary source of support can mediate the negative aspects of living with a visual impairment. Whether providing a listening ear, advice, information or practical support such as providing transportation to and from events such support makes individuals feel that they are cared for and feature in the thoughts of others. This is particularly important since the earlier review suggests exclusion is a common experience for disabled groups. Importantly, social support emphasises relationships and the act of providing social support indicates that recipients are included, valued and accepted in the lives of others at an interpersonal and community level. The link between social support and social participation is also pertinent to this thesis. Social support has been associated with increased participation in sports activities (Graham et al, 2011) and health promotion interventions (Berkman, 1995). Social support is linked also to reduced levels of social anxiety.

6.2 What is social support?

Congruous to the previous concepts discussed in this thesis, social support is a complex phenomenon which encompasses various types of support provided through an individual's social networks when needed. Support can be emotional, instrumental, informational, appraisal and provide companionship (Cohen and Wills, 1985). An individual need not have actually received support, (often referred to as enacted social support), but merely have the subjective belief that support would be provided if required (perceived social support). A third aspect of social support is integration which is the extent to which individuals are connected to social networks. It is these social networks which provide the structure through which social support is provided. Networks may include for example, work colleagues, fellow church goers or club members. The distinct components of social support serve different roles in coping with stress and have different patterns of correlations with health, personality, and personal relationships. As such the components of social support are surprisingly weakly related to each other (Lakey and Drew, 1997). For example, perceived social support does not necessarily equate to the frequency of enacted support or the size of social networks (Lakey and Drew, 1997). Perceived social support is however, consistently linked to better mental health outcomes whereas received support and social integration are not (Barrera, 1986; Uchino, 2009).

Sources of social support can be formal as in the case of social service providers or informal from family and friends as well as people in the community. Pets can also be a source of social support and although considered to be working animals, guide dogs can facilitate increased mobility, confidence and independence as well as companionship support for their visually impaired owners (Whitmarsh, 2005). Increasingly social support is available through online media forums which can provide the various components of social support. Cantor (1979) has suggested that individuals have a preferred hierarchy of care giving in which family members are usually the preferred source of social support over formal givers. The source of social support can however have varying impacts on its effectiveness as a coping strategy. For example, informational social support can be viewed as unhelpful when provided by a loved one, but helpful when provided by a professional. Similarly, emotional support may be viewed as beneficial when offered by a loved one, but negatively when offered by a professional (Shin et al., 1984). The effectiveness of social support has also been found to be related to developmental stages. Whilst parents are an important source of support during childhood, support from friends become more important during adolescence (Stice et al, 2004). An American study (Segrin, 2003) which investigated factors associated with social support found that the need for it diminished as people aged. The study found that older people are therefore less dependent than younger people on receiving social support in order to maintain a sense of well-being' (2003: page1) Segrin's study suggests that people may require different levels of social support at various life stages and may have different expectations for support depending on age or life situation. It is also possible that some people for will have less support but not be concerned about it. Others will also have different attitudes to help seeking. It has been argued that self-perceptions of social support are more indicative of personality than the environment in which individuals finds themselves in (Sarason et al, 1986). That is to say, some individuals will not welcome or value social support.

6.3 The link between resilience and social support models

In chapter 3, I described the models of resilience which explain how promotive factors such as social support counteract the negative effects of stress. Outside of the resilience studies and within the social support field, researchers have described the operation of social support in very similar ways. Two primary theories have been posited to explain how social support works (Uchino, 1996). The main effect model suggests that the accumulation of the benefits of social support over time provides individuals with a positive context to live their lives, irrespective of whether they are experiencing stress. In other words the receipt of regular positive encouragement such as urging a person to recognise their self-worth or reinforcing their feelings of competence can promote positive feelings. This provides individuals with stability and enables them to develop the belief that they can cope with stress thereby reducing the likelihood of the occurrence of stress. Social networks may also influenced individuals to undertake positive behaviours such as healthy lifestyles or not taking illicit drugs. Social support under this model works in periods of low stress.

The stress buffering model on the other hand, relates to the impact of social support on coping during periods of high stress unlike the main effect model which is beneficial even in the absence of stress (Cohen and Wills, 1985). In this model, social support interacts with the immediate impact of stressful events and alters or mediates the stress reaction experienced. These models are often presented as competing but there is evidence that both may operation at different times or simultaneously (Cohen and Wills, 1985; Thoits, 1995; Uchino, 2004). It should also be noted however that not all social support is beneficial. Excessive levels of social support or social support that is inappropriately provided can exacerbate the effect of the stressful situation rather than reduce it (Viswesvaran et al., 1999). An example of this is overprotection discussed in the earlier review, a form of negative support often experienced by visually impaired people. Overprotection can actually have a reverse moderating effect. This may be harmful to a person's mental health as well as threaten independence. As such, the type of support must match the need. Further, social support which is unable to be reciprocated can damage a person's self-esteem and confidence.

6.4 Statement of the problem

In order to understand resilience must be understood within the context of the adversities vulnerable people encounter. An understanding of risk means that risks means that…

Isolation is a key risk to social participation, in fact the opposite. Low levels of social support are associated with increased levels of participation. Given its potential to facilitate social participation, social support, may provide clues as to how included or not they are in the lives others. Further, perceived social support, the subjective view that individuals have people around them, whether they can call on people. How good they feel about themselves wellbeing. Whether they have the support from others whether instrumental or emotional support to deal with adversities when they occur. All of these can be linked to social participation.

6.5 The aims of the current study are to:

The aim of this study is to assess the extent to which visually impaired people have access to this valuable resource and the factors that are associated with an increase or decrease its availability.

RQ1 Identify impaired subgroups who are most vulnerable to an increased risk isolation?

To address RQ1 the overall perceived levels of social support experienced by registered blind and partially sighted people and compare this with the general population who are the reference group. Additional groups are included in the analysis as a means of establishing how visually impaired people rank in terms of social support levels.

6.6 Analysis

In this section of the study I describe the preparation and process of analysis which employs logistic regression analysis incorporating three datasets. Details of the characteristics of the datasets used in the analysis are discussed, in addition to details of the measure of social support used and the technical issues related to comparing across studies.

Network 1000

The current analysis is focussed on data from the Network 1000 study (Douglas et al, 2008). Network 1000 is a longitudinal survey set up to provide information on the needs, circumstances and opinions of registered visually impaired people in the UK. Participants were aged 18 years and were registered sight impaired or severely sight impaired. As noted earlier in the thesis, people who are eligible for registration have lower levels of visual function than those who do not meet the legal criteria. The network 1000 population are therefore at the more severe end of the visual impairment continuum. The study was conducted by the Visual Impairment Centre for Teaching and Research (VICTAR) at University of Birmingham and commissioned by key organisations operating within the visual impairment sector. The first Network 1000 report was published in 2006 with data being collected during the spring of 2005 and 2006. This first survey included the views of 1007 visually impaired people on a wide range of areas of social life such as employment, education, mobility and finances. The current study is based on the responses of participants in the second wave of interviews collected between 2006 and 2007. In addition to the original questions asked in survey 1, this second survey also included a battery of questions on the respondent's perceived levels of social support. This study is the first time that data from these questions have been analysed in any detail.

RNIB Needs survey

The second data set used in the analysis was taken from the RNIB survey of needs and lifestyles of blind and partially sighted people and was conducted in 2001, 2003 and 2005. Before the Network 1000 survey, RNIB's Needs Survey was the largest collection of data on visually impaired people. The data used in this analysis RNIB survey includes over 900 people who self-reported as having low vision. Respondents were drawn from a larger government national study on disability in the UK (Grundy et al, 1999). Respondents who in the government survey had identified as having 'sight problems' were re-contacted by ONS researchers to take part in the RNIB study. Interviews too place in the home using face to face interview methods. In addition, ONS interviewers performed visual acuity assessments on each respondent using portable testing equipment. Given the nature of the sample recruitment process, the RNIB sample population is likely to include less severely impaired individuals. The results of the questions on social support were reported by Bruce and Obolenskaya (2007) in which the construct social support was used to indicate levels of inclusion amongst visually impaired adults.

Health Survey England

To establish a normative baseline measure, data from the registered and self-reported visually impaired populations were compared with the general population. Data on the general population was taken from the Health Survey England (HSE), a national survey of adults aged over 16 years and over living in private households. Commissioned by the Health and Social Care Information Centre, the annual survey collects data factors affecting health and lifestyle. The HSE survey also provided information on a subpopulation of people who report living with a long term disability or illness. Data for both of these populations were analysed separately. The analysis for the current study uses data taken from the 1998 published data. For the purposes of this analysis both the general population and people who self-report as having a long term disability are reported.

Table 3: Populations included in the analysis

Population Characteristics	Survey	Sample number
Registered sight impaired	Network 1000	(n=830)
Self -reported sight impaired	RNIB	(n=904)
General population without disabilities	HSE	(n=15099)
Longstanding illness or disability	HSE	(n=6565)

Measurement instrument

Despite the abundance of literature across a range of disciplines, comparisons of social support across studies are complicated by the use of differing conceptualisations and measures of the construct (Tardy, 1985). Studies have focussed on different aspects of the construct making it difficult to establish which type and source of social support is most beneficial in particular situations. In addition, the development measurement tools designed specifically for individual studies has resulted in a lack of empirically tested measures and correspondingly few have established validity and reliability (Langford et al, 1997). To overcome these issues the decision was taken to use a measure that has been used in a number of previous studies. All three datasets used the same seven item measurement scale of perceived social support. The scale was used in HSE surveys in all years except 1996 and 1997 and the Health and lifestyle survey. Bruce and Obolenskaya (2007) note that a key benefit of using this scale is that it enables visually impaired people to appraise their own levels of social support rather than have the objective view of professionals imposed on them.

The scale focusses on perceived social support which has proven to be a good indicator of wellbeing which help self-esteem and consequently the ability to evaluate stressful factors and choose effective coping strategies. The measure includes statements on perceived access to support from family and friends and focuses on the *emotional* aspects of social support. The Items statements are listed below:

1. Do things to make me feel happy
2. *Make me feel loved.*
3. *Can be relied upon always no matter what happens*
4. *Would see that I am taken care of if needed to be*
5. *Accept me as I am*
6. *Make me feel an important part of their lives*
7. *Give me support an encouragement*

Three possible responses of 'not true', 'partly true' or 'certainly true' were available to respondents in relation to each statement. A score of 1 equated to 'not true', 2 equated to 'partly true' and those who were responded 'certainly true' were assigned a score of 3. A respondent's combined score therefore, could range from a minimum of 7 (indicating a severe lack of social support) to 21 (no lack of social support).

Variables included in analysis of Network 1000 data

Variables selected for inclusion in the Network 1000 analysis were age, gender, marital status, whether an individual lives alone and whether they have a long term health problem or disability. Before undertaking the analysis, the distribution of the key variable social support was checked and found to be unevenly distributed. The pattern of social support scores was highly skewed toward the upper end of the scale (coefficient -2.085) resulting in a positive outcome for the majority of individuals involved in the study (Table 4). This does suggest that the scale has a ceiling effect. This may have been reduced had a greater number of possible responses for each item been included and illustrates some of the limitations working with secondary data. From a statistical viewpoint, it would be preferable to have a measure with a normal distribution (currently the median represents the highest possible score). Since the data did not meet the assumptions of parametric tests which rely on data which is normally distributed (Pratt and Gibbons, 1981), nonparametric or distribution free tests were employed throughout. Non-parametric tests though less powerful, provide more reliable estimates as they make fewer assumptions about the distribution of the data. Mann Whitney U tests were conducted to test for significant differences between two groups and Kruskal Wallace tests were used to detect significant differences between three or more groups.

Weighting

To adjust for the fact that sight loss is strongly correlated with age (Douglas et al, 2007, Tate et al, 2005) age quotas were set in the sampling of participants of Network 1000. This was to ensure that sufficient numbers of respondents from younger age cohorts were included in the survey (Douglas et al, 2006). Weights were applied to data comparing the overall social support scores of Network 1000 respondents with those in the HSE survey and RNIB data (2007). Unweighted data on the other hand was used in the presentation of data which explores demographic differences within Network 1000 survey alone.

6.7 Results

This section of the study presents the results of the secondary data analysis which aimed to identify those at greatest risk of isolation using social support levels as an indicator. The summary findings of the network 1000 as compared to the other sample populations. The section then explores characteristics of the network 1000 which are associated with an increased vulnerability to social isolation.

6.7.1 Overall levels of Social Support

A total of 802 registered visually impaired people in the Network 1000 survey responded to the series of statements on social support. Table 4 shows that the median perceived social support score is 21. Given that 21 is the maximum score, the results suggest that generally the visually impaired registered population do not perceive themselves to be lacking in social support.

Table 4: Descriptive statistics for overall perceived social support score

Statistics	Statistic	Std. Error
Number of cases	802	
Median	21	
Std. Deviation	2.336	
Variance	5.456	
Skewness	-2.085	0.086
Kurtosis	4.479	0.172

6.7.2 Re-grouping social support scores

Replicating the design of the previous studies using the measurement scale, the continuous variable social support was regrouped into three mutually exclusive categories. This enabled comparisons across surveys. Respondents scoring up to and including 17 were considered to be 'severely' lacking in social support; those scoring 18-20 were considered to be experiencing 'some' lack of social support and those who score a maximum of 21 had 'no lack' of support.

Table 5 shows the proportion of Network 1000 respondents in each of the three social support categories. Whilst just over half of registered visually impaired respondents (53%) were not lacking in social support, a substantial proportion (47%) either perceived themselves as experiencing some lack (31%) or severely lacked (16%) social support. Re-grouping the social support scores therefore revealed some of the hidden differences between groups.

Table 5: Levels of perceived social support amongst the registered Network 1000 respondents

Level of Support	Frequency	Percent
No lack of social support	423	53%
Some lack of social support	252	31%
Severe lack of social support	127	16%
Total	802	100%

Unweighted data

6.7.3 Comparisons with HSE and RNIB surveys

Table 6, shows that people without disabilities are considerably younger. The average age of the non-disabled population is 44 years in contrast to an average age of 57 years for the disabled HSE population. Considerably older are the respondents within the registered Network 1000 population with an average age of 80. Although the average of the RNIB survey was not reported in Bruce and colleagues published paper, they are most likely to be similar to the Network 1000 respondents in age.

Table 6. Average age of survey respondents

Survey	Average sample age
Network 1000 (registered)	80 years
RNIB (Self-reported VI)	Unknown
HSE (general population)	44 years
HSE longstanding illness	57 years

Table 7 shows that there are significant difference between the overall social support scores of the four survey populations (p≤0.01). The non-disabled, younger sighted population of the HSE survey are most likely to report no lack of social support (63%). This does however mean that inversely, just over a third of the general population feel they at least lack some social support.

Amongst respondents reporting a disability, the registered population of the Network 1000 survey respondents were most likely to believe they experienced some lack of social support (47%). This was greater than respondents with a longstanding disability or illness (41%) and those with self-reported visual impairments (41%). Respondents with self-reported visual impairments however, were most likely of all the groups to report experiencing a severe lack of social support (19%). This suggests that people who are visually impaired are more vulnerable to isolation than both the general population and other disabled groups but that there are differences between the two visually impaired groups. Whilst a greater proportion of registered visually impaired people perceive less than preferred levels of support from family and friends who can be counted on, visually impaired people who self-report visually people expressed a greater deficit of available support.

Table 7: Comparison of social support scores across all populations

	Severe Lack		Some Lack		No lack	
	n.	%	n.	%	n.	%
Registered VI (n=830)	127	16%	252	31%	423	53%
Self-reported VI (n=904)	145	19%	203	22%	556	60%
General Population (n=15099)	2050	13%	3974	24%	9075	63%
Longstanding illness or disability (n=6565)	1014	15%	1751	26%	3800	59%

P ≤ 0.01 Kruskal Wallace tests there are significant differences

6.7.4 Associations between perceived level of social support and demographic and lifestyle variables

Next, the analysis focussed on the perceived social support scores of registered visually impaired population of the Network 1000 only. A selection of demographic variables were selected for inclusion in the analysis based on their known association with the social support. The purpose of this analysis was to establish whether specific characteristics increased or decreased the likelihood of social support. The analysis was performed with the grouped data. The variables selected at this stage were: gender; age group (defined as working age and retired); whether a person lives alone or not; marital status and whether they have a longstanding health problem or disability.

Gender and age

Although females in the survey were more likely than males to report having 'no lack' of support (57% and 53% respectively), the difference between the groups was not statistically significant (p=0.138). Similarly no association between perceived social support and age (Table 8).

Table 8: Social Score by demographic variables

Variable	Severe Lack		Some Lack		No lack		Total	
	n.	**%**	**n.**	**%**	**n.**	**%**	**n.**	**%**
Gender p≤ **0.138**								
(z score -1.483)								
Male	61	16%	102	32%	193	53%	367	100%
Female	66	13%	136	29%	265	57%	463	100%
Total	127	15%	252	30%	127	55%	830	100%
Age p≤ 0.158								
Working age	61	13%	146	31%	272	57%	479	100%
Retired	59	17%	106	30%	186	53%	351	100%
Total	127	15%	252	30%	423	55%	830	100%
****Living alone?** p≤ 0.01								
(z score -2.760)								
Live alone	46	19%	80	33%	117	48%	243	100
Lives with at least one other person	74	13%	172	29%	341	58%	587	100
Total	120	15%	252	30%	458	55%	830	100
****Marital status p≤ 0**.007 (df=4)								
Single (never married)	27	14%	65	34%	99	52%	191	100%
Married or living together as a couple (but not married)	54	13%	117	28%	250	59%	421	100%
Widowed	21	16%	37	28%	73	56%	131	100%
Divorced	16	24%	28	41%	24	35%	68	100%
Separated	2	13%	3	19%	11	69%	16	100%
Total	120	15%	250	30%	457	55%	827	100%
****Long term health problems or disabilities p ≤ 0.00 z score -2.757**								
Yes	93	18%	145	29%	267	53%	505	100%
No	27	8%	107	33%	191	59%	325	100%
Total	120	15%	252	30%	458	55%	830	100%

* ≤ 0.05 significance level

** ≤ 0.01 significance level

Living alone

There were however, associations between the respondents social support status and whether a person lived alone or not (p≤0.01). Although social support and loneliness are different concepts (Rook, 1984), parallels have been drawn between the two (Newcomb and Bentler, 1986). It might therefore be expected that people who live alone will report a lower level of perceived social support (assuming that people who live alone are more likely to be lonely). Indeed, registered visually impaired people who lived alone were significantly more likely to perceive themselves as lacking in social support (19%) than those who lived with others (13%). The difference in social support between those who live alone and those who do not is even greater when observing the proportions of those who report that they do not lack social support. 58% of those who have other people in their household do not lack social support in contrast to less than half (48%) of people who live alone.

Marital status

A significant difference was found between the different marital statuses of respondents and their perceived levels of social support (p≤0.007, df= 4). Given that there was an association between perceived social support and whether a person lives alone, it might be expected that there would also be differences in social support and marital status (the assumption being that those who are married or living as married are living in the same household as their spouse or partner and therefore have an extended support network). However, the differences within marital status are interesting. Although cell numbers are low, respondents who describe themselves as separated are most likely to perceive themselves as not lacking in social support (69%). Separated respondents therefore are more likely to be satisfied with levels of social support than those who are married or living as married of people (59%) or people who are single (52%). These findings are also interesting in that they suggest over a third of married respondents within the visually impaired population report at least some lack of support. This indicates that having a partner does not preclude low levels of social support. Most likely however to report a lack of social support are people who describe themselves as divorced, of whom just under three quarters (65%) report either a severe or some lack of social support.

Long term health problems or disabilities

Although long term disabled people as a population were explored in the comparison of all studies, the variable was also available in the Network 1000 survey. The results in the analysis show data for registered visually impaired individuals who have an additional long term health condition or disability. The most marked difference in the variables tested was in the perceived levels of social support between those who reported having a long term health problem or disability and those who did not. The registered visually impaired population who reported having a long term health problem or disability were more than twice as likely to report a severe lack of social support than visually impaired who did not (18% and 8% respectively). Conversely, 59% of those who do not have a long term health problem or disability have no perceived lack of social support compared to 53% of those who do.

6.8 Discussion

Overview

The purpose of the current study was to address RQ1 as the basis for a deeper investigation of resilience amongst visually impaired people. This first question set the foundation for subsequent studies in that it explored the characteristics associated with greater risk of the negative outcome, a lack of social participation. The social support status of visually impaired people was compared to the wider UK population and people with long term disabilities or illnesses which provided useful benchmark data. Social support was selected as the focus of analysis because of its central role in social relationships as well as its role in helping recipients to cope with stress. Research also suggests that social support is an antecedent of social participation and can lead to increased social participation levels. Thus although the study cannot be said to establish the social participation levels of visually impaired people, it can be assumed that their social support status is an indicator of their inclusion in the lives of others. The perceived social support status of visually impaired people therefore provided a proximal indicator of levels of social participation amongst this population.

Groups most at risk of social isolation

The study findings showed that the social support is by no means a universal commodity. This was illustrated by the finding that almost a third of the general population reported at lack some of support from family and friends. The study also found that people who are registered visually impaired were more likely than any other group in the analysis to report experiencing some lack of social support. Thus, although in theory the registration process potentially opens up pathways of support, there remain visually impaired people who are registered but do not feel as though their support needs are being fully met. Statutory support may not be a substitute of support from loved ones especially in view of Cantor's finding of preferred sources of social support. Whilst the differences in levels of social support between the disabled and non-disabled respondents may have been expected, variations in the findings of the two visually impaired populations is perhaps less so. Differences may in part be due to the variations in survey methodology. First, the youngest age of participants in the Network 1000 respondents was 18 years and in the RNIB survey, 16 years. However this small difference is likely to have virtually no impact on the results given that visual impairment increases with age. Second, the RNIB survey included people who were just below the threshold for registration and therefore has a wider range of sight levels (Bruce et al, 2007). The Network 1000 survey on the other hand was exclusively comprised of registered blind and partially sighted people who as discussed earlier are more likely to be at the more severe end of the sight loss continuum. However, whether this difference alone accounts for the variations in outcomes is not clear, particularly as Bruce and colleagues (2007) themselves note that whilst the presence of a visual impairment was significantly associated with lower perceived levels of social support, "more severe visual impairment has no greater association than less severe visual impairment" (2007, p. 80). That said, the self-reported population were more likely to experience a severe lack of social support which is concerning given their distance from formal sources of support. In any case, formal sources of support are not the preferred source of social support since informal support from friends and family has been found to have a greater perceived valued (Cantor, 1979). Again it is difficult to know why this particular group of visually impaired people should feel less able to call on the support of others in times of need. There is some evidence in the literature to suggest that some people with invisible disabilities such as low vision are fearful of disclosing their condition to avoid being regarded as vulnerable. A lack of disclosure however, could preclude accessing help and support. How a lack of disclosure might translate into lower levels of help from support from friends and family is uncertain. Individuals reporting a lack of social support in this study which involved statement relating to the emotional component of social support, are actually articulating the belief that there are an inadequate number and quality of people in their lives who provide encouragement to try new experiences, can be relied on in tough time and make people feel good about themselves.

Considering the support status of registered population, the findings suggest that visually impaired people who are divorced are particularly vulnerable to the risk of isolation. The process and long term impact of divorce has been noted to be one of the most stressful and represent a significant event from which a person might require protective resources. However, even visually impaired people who are married report some lack of support which might be surprising given the expectation that individuals will reside with their spouses. There is the possibility that some married respondents were responding as a couple and therefore on behalf of their partners. This would suggest that both individuals were experiencing isolation. It is interesting therefore that well over two thirds of visually impaired people who are separated were not lacking in social support. Another vulnerable group are people with long term disabilities in addition to their visual impairment and people who live alone. There was no difference in gender or age, the latter finding being consistent with other studies reporting no association between social support and age. (Bruce et al, 2007; Calderwood and Tait, (2001).

Finally, the findings highlight the visually impaired people who have characteristics which increase their vulnerability, still report no lack of social support. Questions remain as to whether these people merely have supportive families who provide them with the empathy, love and support they need or whether there are other factors in operation.

Study limitations

There were some technical issues in that the secondary analysis was limited somewhat by the protocols of previous surveys which were used to generate comparisons (HSE and RNIB studies). This was evident during the analysis at which point a ceiling effect was identified. Although there are other measures of social support, comparisons of the nature presented in the current study may not have been possible. A direct measure of social participation would have been preferable to associated social support variable. However as discussed in the review measures of social participation are complicated by the lack of consensus on how the construct is conceptualised. What was clear from the review is that definitions of social participation are grounded in the experiences of visually impaired people.

In addition, the current study focussed on the emotional component of social support. Literature indicates that different types of social support are beneficial in different ways. Further research could be conducted to identify the ways in which different components of social support impact on the social participation levels of visually impaired individuals.

6.9 Conclusion

Study one indicates that visually impaired people have comparatively lower levels of social support than the general population or people with long term disabilities or illnesses. Since social support can provide encouragement to keep going in spite of challenge or information and advice it would seem that some visually impaired people are at a disadvantage. It was also evident that some visually impaired people are more likely to lack this resilience promoting resource more than others. The presence of these risk indicators do not necessarily mean a lack of social participation is inevitable It does however help with the early identification of visually impaired individuals who may require and want intervention. The identification of risk indicators also enable those involved in intervention programmes to work on reducing modifiable risk factors particularly for those impacting on the most vulnerable. The task of identification however, is made more difficult for people who are unregistered, this group of whom are more likely to experience more severe levels of a lack of social support. Interventions aiming to attract individuals would have to use methods other than the use of registration data.

Although the aim of RQ1 was only ever intended to establish level of risk, it was evident that qualitative approach was limited in its ability to reveal additional details about the operation of resilience. The analysis in the current study investigates one variable, social support and it is likely that the factors hindering social participation are multiple. The analysis may well have benefitted from the application of additional multivariate analysis techniques to reveal the combined effects of variables impacting on levels of social support. For example, variables such as age which had little or no effect when observed in the current analysis may, when combined with other factors, have a lesser or greater effect. The limitations described in the methodology are all too apparent. Yet, the variables included in any one survey cannot be exhaustive. Further, although the analysis provided a broad based insight into vulnerability, as is typical with quantitative methods the approach centralises research participants. In other words, it is the attributes of visually impaired people which are under scrutiny without taking into account the extrinsic variables which may explain variations in social support. A weakness of quantitative methods such as those in investigations of resilience is the propensity to decontextualise the very phenonomenon under study as noted by Weinreich (1996):

> '[Quantitative methods] …*decontextualises human behaviour in a way that removes the event from its real world setting and ignores the effects of variables that have not been included in the model' (p53)*

Weinreich suggests that the use of quantitative methods are useful for the purposes of needs assessments which indeed was the purpose of RQ1. However, Weinreich notes that the *'paradigm breaks down when the phenomenon under study is difficult to measure or quantify' (ibid)*.

The following study presents study two which incorporates learning from the above limitations by widening the scope of data included in the study. In this regard study two takes a level step down in data level terms. That is, rather than look at population level data, study two explores data at the community level. The method employed is the Delphi technique which has its groundings in the interpretive paradigm. Given the need for richer and detailed data, study two involves a community of experts with direct or indirect experience of the risks visually impaired people encounter and the protective factors and their understanding of social participation within this context. Details of the method of data collection are provided.

CHAPTER 7: Study 2 – Reaching consensus using the Delphi technique

The preceding chapter demonstrated that certain risk indicators increase the risk of a lack of social participation for an already vulnerable population. However, whilst the ability to generalise at a population level is a strength of study one, the lack of context limited opportunities to say much about resilience. In addition, the focus on social support though an important variable side-lined other factors which were not involved in the analysis and may impact social participation. This chapter presents the findings of study two, a two round Delph and in doing so addresses the issues described. The Delphi draws on the views of a community of experts to address RQ2 which sought to elucidate the concept of social participation as it relates to visually impaired people and sought to provide clarity on conceptualisations of social participation and RQ32) to identify cross systemic risk and protective factors in the search for those which are unique to people with visual impairment. The chapter describes the utility of the Delphi technique and provides the rationale for employing the method in this instance.

7.1 Gaining consensus on key resilience terms

Despite social participation being an integral part of human life and a main goal of rehabilitation, its definition and measurement remain unclear. According to WHO social participation can be defined by involvement in life situations. However, this definition has been criticised for being too vague. Levasseur's taxonomic categories define social participation as relating to interactions with others in society, whereas Hammel's taxonomy proposed a further distinction by emphasising the importance of the underlying values for participatory activities to be warranted as sufficiently meaningful. Others maintain that social participation can be defined by the roles individuals assume during their interactions with others (Fougeyrollas, 2010; Whiteneck and Dijkers, 2009; Piskur, 2014). The absence of agreement on a single definition of the construct has resulted in problems with operationalising the construct in studies. Questions also remain as to the breadth of life domain to be included in definitions and whether objective or subjective measures should be used. For the purposes of this thesis a clear definition of social participation is required to better understand what constitutes a positive outcome and therefore how to gauge whether a person is doing well.

A second aim of the thesis is to understand the risk and protective factors which make social participation more or less likely for individuals with a visual impairment. Although the risk and protective factors are well documented in the visual impairment literature, it cannot be assumed that these are the same across groups and that risk factors are the inverse of protective factors. Risk factors and protective are also key to understanding resilience processes.

The Delphi technique is an attractive method in the context of the current task as it provides not only a systematic mechanism for obtaining consensus from a group of experts but is also a means of measuring the degree to which consensus is achieved (Linstone and Turoff, 1975). The Delphi has been noted to be particularly useful for achieving the views of a group of knowledgeable experts where there is uncertainty or lack of empirical evidence (Delbecq et al, 1975, Dawson and Barker 1995, Murphy et al. 1998). As noted in earlier chapters there is a paucity of evidence on resilience within the context of visual impairment, necessitating a study. Often simply called 'The Delphi', the technique can be used for both normative and exploratory purposes. It is a dialectical communication technique based on the principle that collective wisdom is more valid than an individual one (Ludwig, 1997).

First developed in the 1950's by the RAND Corporation for work on a US military project, the Delphi method was designed to obtain consensus from experts on subjective forecasting matters and to overcome the difficulties associated with the dynamics of face-to-face or round table discussions.

The traditional or classic Delphi technique (Martino, 1983) involves a panel of pre-selected experts being sent a series of self-completion questionnaires over two or more sequential rounds which are interspersed with controlled feedback from a moderator. The questionnaires and feedback are sent to the expert panel members who are anonymous to each other. A feature of the Classic Delphi is the inductive nature of the first round in which panel members are usually sent an unstructured questionnaire that is designed to elicit information about the factors that are felt to be important within the context of the specified topic. Individual panel members return their responses to the moderator who then analyses the resulting qualitative data and synthesises them into a single set of factors.

The second round questionnaire is more structured and panel members are asked to rank or rate the importance of each factor, typically using a Likert or similar scaling method. The group median scores and individual scores for each factor are fed back to the panel members who are encouraged to adjust their scores in light of the group response. A predefined criterion of group consensus or stability between rounds, or a set number of rounds determines the end of Delphi process. The criterion for which consensus is achieved is often omitted in published studies using the Delphi method (Powell, 2003) although some have used 100% agreement (Williams and Webb, 1994) and others simply stating that 'most' panellists agreed (Butterworth and Bishop, 1995).

7.2 Statement of the problem

Several reasons necessitate the development of a set of working definitions within the context current study. The diverse range of topics areas covered in investigations of resilience has resulted in varied conceptualisations of resilience and its key terms. Definitions of positive outcomes are defined by normative cultural standards. The positive outcome within the context of this study is defined as social participation. However, the literature review indicates that there is considerable equivocality on the definition of social participation. The lack of international consensus on the definition of social participation (LeVasseur et al, 2010; Alma, 2011) suggests that it cannot be assumed social participation is experienced by people with disabilities. Studies examining social participation amongst visually impaired people have tended to focus on older populations (Amla, 2011). Few studies have consulted disabled people about their expectations of social participation.

Whilst correlates of resilience (protective factors) such as social support have been found to recur across studies (Luther et al, 2000), there is also a need to identify whether there are protective factors which are specific to the visually impaired population. Indeed the dearth of resilience studies in the visual impairment field means that it is not fully understood whether the known protective factors are also relevant to visually impaired people or whether there are features of a visually impaired persons experience that *'…transform the significance and operation of factors and processes universally identified as consistent with resilience' (Young et al, 2008)*

7.3 Aims and objectives

The aim of the current study therefore is identify the:

RQ2*: How is a successful outcome defined?*

Success outcome being social participation. In order to tease more detail sub-questions are ***a) What are the indicators of a successful outcome (social participation)? And b) What are the***

characteristics of someone 'doing well'?' that is to say, what might a person be doing if they are participating.

To identify the unique risk and protective factors experienced by visually impaired people ***RQ3: What are the risk and* protective *factors associated with social participation for individuals with a visual impairment?***

7.4 Method

7.4.1 Study design

The Delphi technique was employed over other methods because it held several advantages. Although the Delphi technique lends itself to a range of positivist methods in subsequent rounds, the first round is interpretive in nature and can be considered as constructionist in nature (Turoff, 1975; Rauch, 1979; Stewart 2001). Stewart (2001) notes the special nature of the technique:

> *'Epistemologically, the Delphi could be viewed as deriving from objectivism where the statements generated from the experts are considered as facts and objective truths, as in the case of a `classical Delphi'. But equally it could be derived from constructionism where the findings only represent a shared meaning, developed from an interactive process as in a `policy Delphi'.*

The introduction of contextual factors is important given the limitations of study one which focussed on a single variable, social support, when influencers of social participation are likely to be multifactorial. Although the Delphi is unlikely to uncover all of these factors it will provide more detail on the type and range of influences. Further, since the first round is inductive in nature, it facilitates for a range of perspectives from people who are close to the phenomenon under investigation. The Delphi technique enables the researcher to obtain the responses of large groups of people at a time, regardless of their geographic location. This meant that experts with the best knowledge were not restricted by their location. Technology has also meant that questionnaires can be returned expediently and at low cost to the moderator by email or web based systems. Perhaps as a consequence, the technique has now been used in a range of fields from ICT development, economics, health, education and social policy and is increasingly being used by policy makers as a participatory method for involving local communities in decision making. Another major benefit of the Classic Delphi is the anonymity of the process avoids some of the problems encountered in face-to-face methods (Boberg, 1992). These include the psychological distractions associated with panel member feedback being influenced by dominant individuals (Butterworth and Bishop, 1995) and those who may be regarded as being more authoritative than the rest of the group (Murphy et al, 1998). The anonymous nature of the Delphi also means that panel members are free to change their minds without embarrassment and the facilitator's limited interaction with panel members reduces the potential for researcher bias that may occur in face-to-face techniques (Boberg, 1992). The anonymity of the process also appeals to emancipatory principles of power reduction between disabled and non-disabled panel members and researcher and researched which was absent in study one.

Number of rounds

The current study initially set out to undertake a three round Delphi, the first round being exploratory, the second to obtain a group view on the importance of the indicators and the third to further refine the list of indicators. Although three rounds are typical of reported Delphi studies, the final number of rounds has been noted to be a matter of pragmatism (Jones et al. 1992).

The decision was taken to limit the Delphi to two rounds for two reasons. First, The analysis of round two data which resulted in a comprehensive list indicators. In addition by the end of round two experts expressed concerns about being able to articulate the complexities of social participation in a questionnaire. Further refinement in a third round was deemed unnecessary.

Figure 7: Diagram of original Delphi design

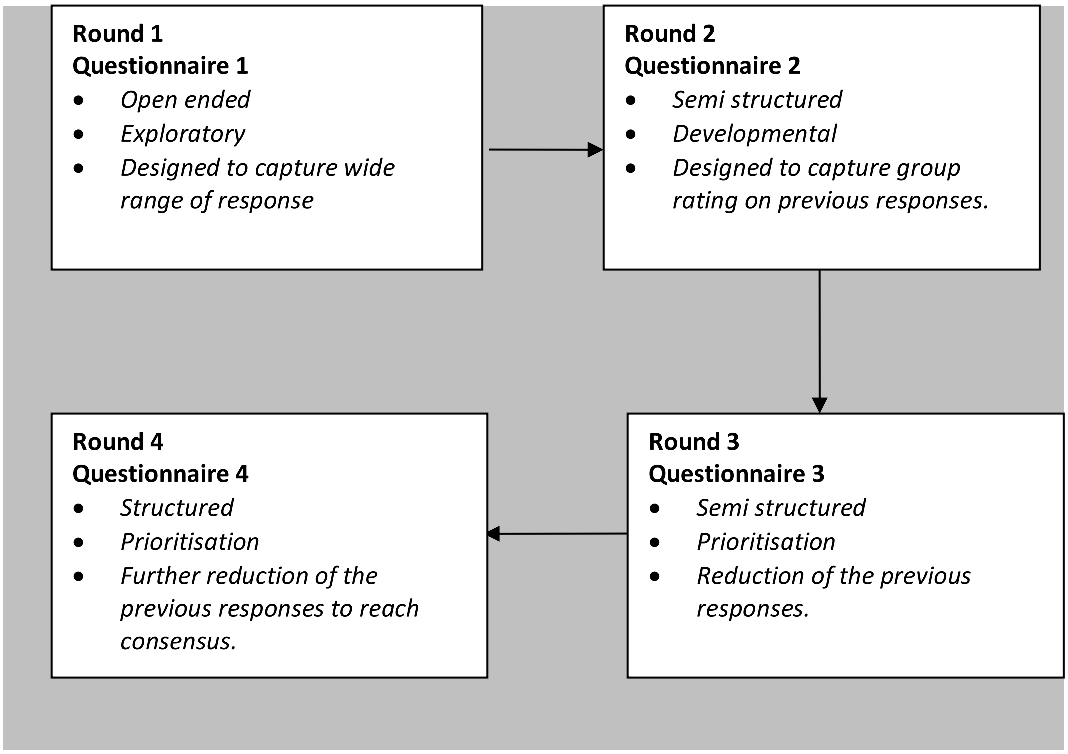
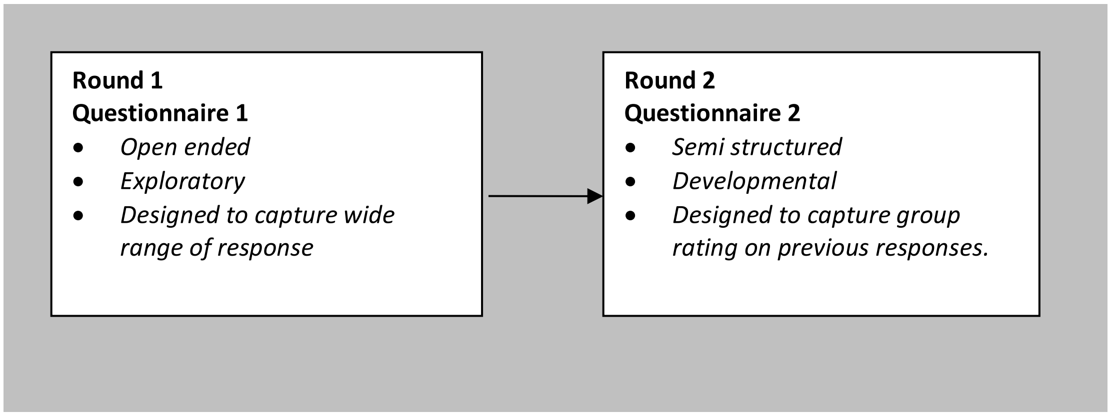


Figure 8: Diagram of final design of Delphi



Panel selection and defining expertise

Careful consideration was paid to ensure the right people were invited to take part in the panel which is recognised to be the most important aspect of the process (Campbell, 2004; Day and Bobeva, 2005). Given that the quality of the panel is linked to the quality of the resulting data, panellists were required to have a wide range of understanding of both visual impairment and the factors that facilitate social participation for this population. Yet the difficulty of defining exactly what constitutes expertise is acknowledged by Delphi originator Olaf Helmer:

> *"...it is far from obvious what we mean – or should mean – when we say that somebody is an expert; and even given reasonable criteria of expertness it may not be easy to obtain adequate data for determining a person´s degree of expertise."* Helmer 1967).

Implicit in Helmer's quote is that the definition of an expert will vary according to the particular field under study and that the researcher has to make pragmatic decisions about how this is achieved. For the current study therefore, experts were defined as professionals working in the field of visual impairment sector and/or individuals who were visually impaired themselves. Including professionals and people who experience living with a visual impairment was a deliberate strategy. A panel comprising of solely professionals could result in the emergence of issues that were pertinent to or witnessed by them (Sinha et al, 2011). The inclusion of visually impaired experts as well as professionals provides a blend of perspectives. The inclusion of heterogeneous panel members in Delphi studies has also been found to produce higher quality results than homogenous groups (Delbecq et al. 1975, Murphy et al., 1998; Rowe, 1994). For example, Kennedy's (2000) study of models of midwifery care noted that the inclusion of midwifery clients in addition to midwives provided insightful results. In another study both professionals and patients worked together collaboratively to define health outcome measures which was noted to produce high quality results (see Stewart, 2011)

A selection criteria was devised to ensure that both professionals and visually impaired experts, the latter of whom are referred to as experience experts for the remainder of this study, were sufficiently qualified with knowledge and experience to participate (Akins, 2005; Singh and Kasavana; 2005). The criteria also demonstrate that objectivity in the selection process was considered in an effort to increase transparency and reduce bias (de Merick, 2002).

Table 9: Selection criteria for Experience and Professional experts

Type of expert	Inclusion criteria
Experience	*10 or more years living sight loss* *Aged 18-64 years*
Professional	*Based in the UK* *Involved in the care, education or habilitation of people with visual impairment.* *10 years' experience*

Perceptions and expectations of what it means to socially participate have been found to vary with age (Lavasseur et al, 2010). It was considered that the perceptions of what constitutes 'doing well' in terms of participation might also vary as a result. Taking this into account, two specifications were set for experience experts. The first that they should be aged between 18 and 64 years and secondly that they should have lived with their sight condition for over 10 years to account for the length of time taken to adjust.

Professional experts were required to be actively involved in the care, education or habilitation of people with visual impairment. To ensure that opinions of professional experts reflected a view of social participation that is relevant to the experiences of visually impaired people in the UK, they were also required to have 10 years or more work experience in a UK context. Although the extent to which the number of years equates to greater expertise has been called into question (Tetlock 2005), this was considered to be an important prerequisite given the complexities of disability.

Recruitment strategy - Professional experts

As a researcher working within the visual impairment sector I was on first name terms with a number for professionals who would potentially meet the criteria of professional expert and therefore eligible to inclusion in the study. However, researching in familiar settings presents disadvantages and disadvantages. One particular disadvantage is that the selection of participants who are known to the investigator is the risk of researcher bias entering into the study (Murphy et al, 1998). Participants may have the desire to provide responses that are in line with the organisation I was working for or feel that services may be dependent on the responses. As a preventative measure colleagues with whom I was familiar were excluded from the selection process and instead steps were made to create a list of new contacts. Since a list of professionals working within the field of visual impairment had not been identified, a modified snowballing technique was used. During informal interviews, colleagues were asked to suggest the names of professionals outside of the organisation who had direct work responsibilities or interests in social inclusion and participation. In this regard colleagues acted as key informants by providing details of job roles and contact addresses. Discussions with the key informants resulted in the development of a list of the names and professional job roles of potential panellists (Table 10). In a few instances it was necessary for the referrer to seek permission from the expert before passing on their contact details although in most cases details were publicly available. In each of the roles professionals came into contact with visually impaired people at various stages of the sight loss journey. These included rehabilitation officers, eye clinic liaison officers (ECLOs) and counsellors. The list also included ophthalmic staff whose role tended to be focussed on the medical aspects of visual impairment. However, discussions with colleagues identified individuals within this group with an interest in the social implications of living with a visual impairment and in particular social participation. An ‘Other’ category was included in recognition that this did not represent an inclusive list of job roles which might be included.

Table 10: Work roles of potential professional panel members

Job role
Rehabilitation officers
Employment officers
Eye Clinic Liaison Officers
Independent living co-ordinators
Counsellors specialising in visual impairment
Qualified teachers of the visually impaired (QTVI's)
Ophthalmologists and Optometrists
Other

Professionals were sent an expert referral form (Appendix A) which included details of the study, the selection criteria and the work roles listed above. A space was provided within each job role for key informants to include the names and contact details of professionals who both fulfilled the selection criteria and who in their opinion, could provide the level of expertise required for the Delphi study.

Recruitment strategy - Experience experts

Experience experts were recruited into the study through an existing consultation panel of visually impaired persons which had been set up by RNIB. The consultation panel had been created for the purposes of soliciting the views and experiences of visually impaired people loss on a wide range of issues impacting on their lives. Members of the consultation groups were geographically spread across the UK and had previous contact with RNIB either as members of the organisation or through their use of products or services.

In order to recruit consultation panel members into the Delphi, information on the aim and purpose of the study was provided to the group moderator from whom permission was required before contact could be made. After obtaining authorisation from the moderator, who personally contacted panel members to seek their permission to be contacted, individuals who fell within the Delphi selection criteria were contacted by the researcher.

Panel size

The recruitment strategy resulted in the identification of 26 experience experts and 20 professional experts. It was felt that the similar numbers of expert included would reduce the risk that the views of one expert group outweighing the other. The general consensus amongst reviews of studies using the Delphi is that 'representativeness 'is assessed on the qualities of the expert panel rather than its numbers’ (Powell, 2003, Sinha et al, 2011). There is however no agreement on the optimal size of Delphi panels (Akins et al, 2005; Nelms and Porter, Powell, 2003). Reid (1988) observed that studies usually reported panel sizes of between 10 and 1685 experts. Akins (2005) noted that studies with panel sizes of less than 5 members are rarely reported and Czinkota and Ronkainen (1997) that panels of more than 30 rarely yield a greater range of items than smaller ones. Although Murphy et al (1998) suggest that the more experts involved in a Delphi the better, they also acknowledge that there is no empirical grounding for this assertion:

> *"There is very little actual empirical evidence on the effect of the number of participants on*

> *the reliability or validity of consensus processes." (p. 37).*

The total of 46 experts to be invited to take part in the Delphi was therefore judged to be an adequate number given the efforts to ensure the quality of expertise. Efforts were also made to reduce attrition which can result in the overstatement of the degree to which agreement was achieved (Sinha et al, 2011). An information sheet was designed to explain the various stages of the Delphi and the required input from panellists (Appendix B). Since willingness and sufficient time can impact on attrition (Skolmoski et al, 2007) the information sheet stressed the need for experts to complete the questionnaires for all rounds. Experts were requested not to take part if the necessary commitment could not be provided. The benefits of taking part were stated and as an added incentive were informed that only experts who took part in the final round would be listed in the final report.

7.4.2 Round One Methods

This section describes the questionnaire design and piloting

Questionnaire

Round one questionnaire (Appendix one) used an inductive approach and therefore was designed to be as open ended as possible. This was to ensure that the resulting responses were generated by the experts themselves rather than being imposed on by the moderator. Based on the literature relating to resilience, questionnaire 1 was organised around five main areas prompts:

1. Demographic information
2. Main activities that would indicate an adult with sight loss was successfully engaging in everyday life
3. Characteristics of a person doing well
4. Barriers or challenges to social participation for adults with sight loss
5. Enablers of social participation for adults with sight loss

Since panel members require effective communication skills to take part (Skolmoski et al, 2007) care was taken to ensure that the questionnaire terminology was jargon free. Key terms such as resilience and protective were omitted from the questionnaire for this reason. The ability of experience experts to both access the online questionnaires and to communicate their responses was also considered in the choice of survey tool to be utilised. A common complaint amongst internet users is the poor design of websites and inaccessibility with screen reading equipment (Edwards, 2012, Ofcom, 2008). Bristol Online Surveys was used as the survey platform since it is stated by developers to be accessible for respondents with sight loss who use screen readers. The software was tested in the pilot stage and was found to be functional.

Pilot

Questionnaire 1 was piloted with the aim of testing the validity of the questions and importantly its online accessibility for experience experts. Six participants took part in the first round pilot. Participants were asked to complete the questionnaire in full as well as provide written feedback on the layout, grammar, time taken to complete and accessibility, both in terms of comprehension and compatibility with screen reading equipment. The feedback from the pilot was that the questionnaire was too long, taking approximately 30 minutes to complete. Participants also felt there were too many questions per page which resulted in having to scroll too far down which was found to be off-putting. As a result the questionnaire was modified by grouping questions into section headings which reflect the ecological framework, 'individual', 'home life', 'community' and 'wider society'. This also served to encourage experts to think about barriers and enablers in all areas of an individual’s life. The modified questionnaire section headings are shown below:

1. Demographic information of experts
2. Main activities that would indicate an adult with sight loss was successfully engaging in everyday life
3. Characteristics of a person doing well
4. Barriers or challenges to social participation for adults with sight loss (individual, home life, community, wider society)
5. Enablers of social participation for adults with sight loss (individual, home life, community, wider society)

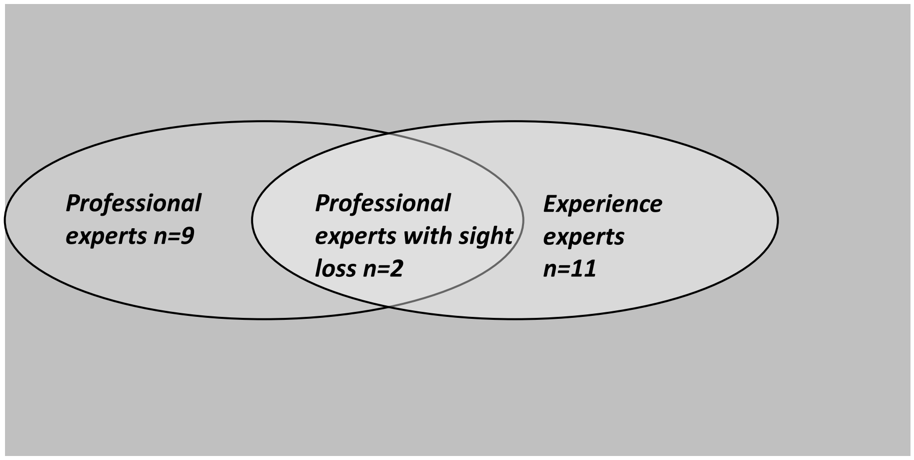
Administration

Round 1 commenced on December 17th 2011. Emails were sent to all 46 people identified as potential experts (Appendix C) inviting them to take part in the study. The email provided brief details of the study and the closing date for submission of the completed questionnaire which was February 9th 2012. A more detailed information sheet and consent form were also attached (Appendix D). An offline version of the questionnaire was also available for experts who requested it. A link to the questionnaire was embedded within the email which in some cases resulted in experts returning their completed questionnaires in advance of their consent forms. Those individuals were however pursued until consent forms were returned. The initial closing date for return of completed questionnaires was extended for a further three weeks (February 26th 2012) to provide experts with more time.

7.4.3 Panel characteristics

Of the forty six invitations sent, twenty two experts completed questionnaire one which resulted in a response rate of 48%. Eight males and thirteen females. Eleven experts reported having a visual impairment and the remaining eleven sighted. Although for the purposes of recruitment, experts are defined as 'experience' and 'professional' experts, the Venn diagram below (Figure 9) illustrates that there was considerable overlap between the two groups. Just under a third of the professionals also reported having a visual impairment.

Figure 9: Overlap between professionals and experience experts in Round 1



Fourteen of the twenty two round one experts completed the round 2 questionnaire of the Delphi providing a response rate of 30%.

Analysis

A content analysis, largely considered to be the most objective method for analysing qualitative text (Seale, 2012) was used to process the considerable data emerging from Round one responses. Treating each question in turn, the grouped responses were coded into broad themes. Within each theme subcategories were created by grouping similar responses together. In all cases responses were unambiguous and clarification from individual experts was not required. Pragmatism was however required during this process. For example, the words 'confidence' and 'assertiveness' were combined because it was judged that the experts were referring to the same concept.

The second stage of the content analysis involved counting the themes under each category and producing percentages for each. The categorised data was organised into tabular formats which formed the basis of the expert feedback document (appendix 3) and questionnaire 2. (Appendix 4).

7.4.4 Round Two Methods

Questionnaire

The aim of round two was to obtain the panel view on the level of impact each of the categories identified in round one had on a visually impaired person’s ability to participate in social life. To this end, the themes and sub-categories were organised into Likert scale questions. In most cases a 7 item Likert scale was used where 1 = Weak indicator through to 7 = Strong. In some instances it was necessary to present the indicators as statements whereby experts were asked to say how much they disagreed or agreed which resulted in data along a 5 point scale.

Pilot

Questionnaire 2 was sent to three people who had taken part in the piloting of questionnaire 1. As with the piloting of the previous questionnaire, the participants were asked to complete the questionnaire in full and feedback was sought on the length, structure and accessibility.

Administration

In October 2012 questionnaire 2 was sent to experts who had completed the first round. The questionnaire was accompanied by feedback from the first round which experts were asked to consider before completing the questionnaire.

Analysis

To facilitate analysis, both the 7 and 5 point Likert scales were transformed into a common 3 point scale by collapsing the positive and negative options into two respective options. The neutral options on the both scales remained as they were (Table 11).

Table 11: Transformed response scale

Original scale	Transformed scale
7 item scale	
1 (low) , 2 3, 4 5, 6, 7 (high)	*1, 2, 3 = Weak = 1*
	4 = Neutral = 2
	5, 6 and 7 = Strong = 3
5 item scale	
Strongly Disagree	*Strongly Disagree and Disagree Weak) = 1*
Disagree	*Neither (Neutral) = 2*
Neither	*Strongly Agree or Agree (Strong) = 3*
Agree	
Strongly Agree	

Percentages were generated for each of the transformed response options and items for which less than two thirds (66%) of the panel indicated as strong were rejected from the final list of indicators.

7.5 Round one findings

The section of the study presents the themes generated by the panel. Experts were asked to both consider the main activities indicating an adult with a visual impairment was successfully engaging in everyday life. In addition they were asked to, using their own experiences or someone they know, describe a person with sight loss who was doing well in relation to social participation. Experts were also asked to consider factors that posed barriers and enablers to participation.

7.5.1 Doing well

The themes which emerged begin to develop a picture of the types of activities a person participating in social life is likely to be undertaking. Table 12 indicates that ‘doing well’ could be conceptualised by

1) the types of activities (both inside and outside of the home), 2) relationships with other people, 3) Psychological attributes and 3) a loose 'other' category. A total of 22 individual indicators were proposed that might indicate a person is doing well.

The most commonly reported indicator of successful participation was independently taking part in activities outside of the home (n=18). A wide range of activities undertaken outside of the home were mentioned such as participating in leisure activities, shopping, attending a place of worship if the individual so wished. Activities inside the home were less likely to be reported and related to managing the household (n=2) and being able to make meals (n=2). The majority of the experts (n=15) also suggested that being in paid employment would indicate a person was doing well. One expert however, felt that the type and quality of the job role was an important consideration and suggested that being *'Employed full time in a non-menial job'.* Was a important consideration. Volunteering was also mentioned by two experts although it was not clear whether experts felt that the unpaid nature of volunteering was considered to be on a par with paid employment.

Table 12: Types of activities and characteristics of someone doing well, N=22

Item number		Frequency	% of experts
Activities (inside and outside of the home)			
1.	Paid employment	15	68
2.	Volunteering	2	9
3.	Managing the household	2	9
4.	Is able to make meals	2	9
5.	Is independent (e.g. getting out into the community, using public transport)	18	82
Relationships			
6.	In a loving relationship	3	14
7.	Is a parent	1	5
8.	Has a good network of friends	7	32
9.	Has a mix of friends who are sighted and have sight loss	8	36
Personality attributes			
10.	Is able to access information	4	18
11.	Accepts own sight loss	5	23
12.	Feels ok around sighted people	3	14
13.	Is happy and has fun	4	18
14.		4	18
15.	Keen to try new things	2	9
16.	Self-assertive in a nice way	3	14
17.	Relaxed in social settings	2	9
Skills (Social and technological)			
18.	Able to use computer	3	14
19.	Able to use Internet	2	9
20.	Able to use TV	2	9
21.	Social skills	10	45
22.	Able to use assistive technology	2	9

Skills

Technological

Experts regarded competency in particular types of skills as an indicator of doing well. These were categorised as technical and social skills. Use of computers (n=3), accessing the internet (n=2) and the ability to use assistive technologies (n=1), were felt to be indicative of participation. The ability to control a radio or TV (n=2), suggested by experts was perhaps a surprising addition, but may reflect the experts consideration of the variations in expected outcomes depending on factors such as visual function, age or health status indicators.

Social skills

Having good social skills (n=10) related to how easy a person is in the company of others, a characteristic as noted by the one expert, that is relevant to all individuals, regardless of whether they are visually impaired or not. Social skills included being *'fun'*, possessing an awareness of '*when to listen and when to talk*', being *'relaxed in social settings'*, *'keen to try new things'* and feeling *'…okay with sighted and non-sighted people'*. Conversely, poor social skills included having a *'Lack of understanding of social etiquette', how they are perceived in a social context' and a 'Lack of awareness of social topics and related inability to join in conversation in an effective manner.'*

Psychological attributes

The psychological attributes identified by experts which might indicate a person is doing well were numerous. Just under a quarter (23%) of experts suggested that a person doing well in relation to social participation would be likely to have an *'acceptance of sight loss'* (n=5). Experts provided scenarios of individuals which were indicative of poor acceptance.

> '[Playing]*…the sight loss card every time something is not working…'*
>
> *'If you don't accept help when you clearly need it that could be one, because if a person can see your struggling and you still insist on not taking the help even though you know you need it, the person could think you're stubborn and could even mistake it for arrogance.'*
>
> *'Not acknowledging that the limitations imposed by sight loss prevents you from overcoming the limitations.'*

Conversely, positive psychological attributes which suggested a person had accepted their sight loss and had progressed to educating others:

> *'Someone who understands their visual impairment'*

> *‘Able to embrace their sight loss so it doesn't impact adversely on them and impede their enjoyment of life’*

> *‘I feel as blind people, it's important to educate these [sighted] people and make them feel that they're able to approach and ask questions.’*

Relationships with others

The responses of experts suggest that in identifying a person doing well, the nature and type of relationships with others should be considered. Not only was having a good network of friends (n=7) mentioned but the composition of the network was also felt to be important. Some experts (n=8) specified that the social networks of visually impaired people should include sighted friends as well as friends with sight loss:

> ’*Have a mixture of blind and sighted friends’*

> *‘Having friends including probably some sighted friends’*

Being in a relationship with a significant other (n=3) and being a parent (n=1) were also suggested.

7.5.2 Risk and protective factors to social participation

The further sections of Round 1 questionnaire were concerned with identifying the main risks and enablers to successful social participation. Experts were prompted to think about the risk and enablers found at various systemic levels of the lives of visually impaired people, namely individual, family, community and wider society. This resulted in some duplication of responses with questions 1 and 2 of the questionnaire. Some experts also felt that enablers or protective factors were merely the opposite of the risk factors they had identified earlier:

> *‘Well a lot is the same as the last answer really’*

> *‘Same issues as already stated’*

This reflects the bi-directional nature of risk and protective factors, factors identified by the experts appeared at multiple levels of people lives. Further, when asked to report enabling factors which facilitated social participation, respondents often provided the semantic opposite to the risk factors they had previously stated. In such cases, only the positive or negative aspect of the factor is presented and its opposite can be read within the same statistic. For example, confidence was reported as a risk factor whilst the opposite, a lack of confidence was regarded as a protective factor. The results are discussed below.

7.5.3 Individual level risk and protective factors

The main risk and protective factors found the individual level suggested by experts were grouped into three themes, 'Psychological attributes', 'Physical' attributes and an ‘Other’ category. As noted above, some of the characteristics featured in the first section of the questionnaire were repeated such as the psychological attributes of confidence and independence, acceptance of sight loss, worries about the perceptions of sighted people. Other psychological attributes such as ‘Coping strategies’ (n=4) and determination (n=4) make a first appearance.

Table 13: Individual risk and protective factors

Item number		No. of experts	%
Individual: Psychological attributes			
23.	Confidence	10	45
24.	Fear of trying something new	3	14
25.	Coping strategies	5	23
26.	Worries about the perceptions of sighted people	3	14
27.	Determination	4	18
28.	Well being	2	9
29.	Self-belief	2	9
30.	Sense of belonging	1	5
31.	Awareness of surroundings	2	9
32.	Independence	12	55
Individual: Physical attributes			
33.	No sight	2	9
34.	Physical health	2	9
35.	Being young (positive) enabler	2	9
36.	Sight loss from birth or at an early age (Enabler)	3	14
37.	Being from a particular ethnic group (Enabler)	1	5
38.	Being from a particular ethnic group (Barrier)	3	14
Individual: Other			
39.	Educational attainment	2	9
40.	Adequate personal finances	3	14
41.	Loss of the ability to drive / no access to private transport	2	9
42.	Poor self-care (e.g. dressing inappropriately)	4	18
43.	Body rocking or swaying	1	5
44.	Poor English language skills	1	5

Physical attributes

Physical attributes are those which are assumed to be immutable or fixed characteristics making individuals vulnerable. Poor health (n=2) and not having sight (n2) was identified as being a risk to participation:

> *"Not being able to recognise friends and colleagues in casual acquaintance"*

The level of sight was also felt to impact on risk:

> *'Level of visual impairment. Those with more severe visual impairments will obviously find some tasks more difficult to do independently (e.g. using buses or trains).'*
>
> *'Simple household tasks become major challenges when they have to be done without sight'*

Age was mentioned in slightly different contexts, the first referring to the age at which a person loses (or never having had) sight and the second relating to the idea that being a younger visually impaired person is presents advantages over being older such increased opportunities for social support:

> *'[The] Arrogance of youth'*
>
> *'Age - Children/young teenagers can often rely on parental support for travel etc., whereas adults don't always have this available.'*

Ethnicity was suggested in both protective (n=1) and risk contexts (n=3) depending on an individual's environment. One expert felt that coming from a particular ethnic groups could mean those individuals were at a higher risk *'because cultural issues maybe affecting the way disability is perceived'*. However, the same expert also believed that cultural values could also be a protective factor since some cultures place an emphasis on maintaining family:

> "….cultural values may be a bonus because that culture may place a high regard on social contact, if not social independence".

Other individual risk and protective factors

The 'other' risk and protective factors found at an individual level included poor educational attainment (n=2), lacking in English language skills (n=2) and the loss of the ability to drive (n=2). Transport received the greatest number of responses. Physical appearance were also felt to impact on participation reflecting how individuals are likely to be perceived by others.

7.5.4 Home life level

Just two themes emerged from the home life level which were categorised as ‘Attitudes and behaviours of others’ and ‘Other’.

Attitudes and behaviours of others

Risks and enablers relating to attitudes and behaviours related to the type and quality of support provided by people closest to the person with a visual impairment. Over protection by family members was the most commonly identified risk to social participation identified in this domain of (n=10). Experts provided a range of examples of how over protective behaviours had the potential to inhibit participation in a number of ways. One expert noted that ‘over support’ could hinder independence if family members did not allow individuals to *'get on with their lives'.* Taking part in household chores was regarded as promoting independence. Over protection was felt to adversely impact on opportunities to interact with people outside of the home:

> *"If a parent/carer does everything then it's very difficult to break that e.g. if they are used to getting lifts everywhere, then they may not be able to use public transport confidently."*
>
> *‘Adults who are in close contact with well minded people, such as immediate family and loved ones, can sometimes "cotton wool" those with sight loss causing them to become reliant on them for support rather than learning to become independently socially active.’*
>
> *‘If relationships at home are disempowering and foster dependency, then this can set a pattern for social interaction in the world. Home life should be a stepping stone for other social participation.’*
>
> *"This [overprotection] is a barrier because if a person who is sighted saw a family member with me they'd probably not bother to come up and chat to me because they can see I'm with someone.*"

A number of experts noted that those closest to the visually impaired people can lack an understanding of the condition and consequently their needs. This may also be linked to the other negative behaviours expressed by family and friends such as having *‘low expectations about what* *people with sight loss can do'* (n=4) and *'not including them in activities'* (n=3).

Table 14: Home life barriers and enablers

Item number		No. of experts	%
Home life: Attitudes and behaviours			
45.	Individuals in a person's life who are over protective	10	45
46.	Individuals in a person's life who have low expectations about what people with sight loss can and cannot do	4	18
47.	People in a person's life who are embarrassed about their family or friends sight loss	1	5
48.	A change in power balance that may occur between a person with sight loss and their family and friends	2	9
49.	People in a person's life who do not understand the impact of sight loss	4	18
50.	People in a person's life who do not include them in activities	3	14
51.	People in a person's life who do not have time to provide support practical and emotional support	4	18
Home life: Other			
52.	Living far away from family and friends	1	5
53.	Living in a rural area	2	9
54.	Limited household finances (e.g. to fund social activities or purchasing assistive technologies)	3	14
55.	Having support from different people to avoid '''reliance''' on any one person	1	5
56.	''Balanced support''' i.e. practical and emotional support that is provided when necessary but which encourages '''independence'''	3	14
57.	No available support at all	3	14

One expert noted that some people could be embarrassed about their family member's visual impairment (n=4) and others that "pressures on time" limited opportunities for family members to provide practical support such as providing 'lifts in the car' which could lead to participation '.

> *'Lack of understanding family and friends of the impact of the individual's sight loss on their ability to participate socially and how they can facilitate continued social interaction.'*
>
> *'Their friends and family can unwittingly isolate them by bringing that social interaction to them in their home'.*

‘Balanced support’, was described as the ‘provision of practical and emotional support provided when necessary but which encourages independence’ and was felt to enable social participation. This was therefore the opposite of overprotective behaviours. Support obtained from a range of sources was felt by one expert to avoid the risk of over reliance on any one individual. A further risk noted by an expert was the change in power balance which could occur within the relationships experienced by a person with sight loss:

> *‘Change in status / role within family – breadwinner, father / mother to dependent children, role model etc.’*

Other home life barriers

Other risk factors located within the home domain related to the practicalities of getting out of the home. These included ‘a lack of transportation’, ‘living far away from friends and family’ (n=1) and ‘insufficient household finances which can make social participation difficult to happen’. Reflecting the findings of Study 1, experts felt that having ‘no support at all’ (n=3) when individuals lived alone was also a factor influencing low levels of social participation:

> *‘Many of those diagnosed with sight loss are older people many of whom live alone. This makes it harder to socially participate in local activities.’*

7.5.5 Community domain

Risks and protective factors to social participation at a community level were grouped into 4 themes: Attitudes and behaviours, Mainstream services, Services specifically for people with visual impairments and 'Other'.

Table 15: Community barriers and enablers

Item number		No. of experts	%
Community: Attitudes and behaviours			
58.	A good understanding about sight loss amongst members of the community	8	36
59.	Discrimination from people in the community	2	9
60.	Bullying from people in the community	2	9
61.	People in the community who look out for each other	2	9
62.	Cultural beliefs about sight loss that stigmatise sight loss	4	18
63.	Opportunities for sighted people in the community to meet community members with sight loss	2	9
Community: Services			
64.	Mainstream services that are inaccessible to people with sight loss	6	27
65.	A lack of information about local events and services provided in formats people with sight loss can read	2	9
66.	A lack of funding for local Visual Impairment Services	5	23
67.	Good customer service	1	5
68.	The availability of a wide range of '''local services''' so that people have choice	3	14
69.	Individualised rehabilitation programmes with assessments of needs for every person with sight loss	2	9
70.	The availability of emotional support or Counselling as part of a person's 'eye care journey'	1	5
71.	Visual awareness training for staff in local services	2	9
Community: Other			
72.	Poor physical environment (such as poor street lighting, high crime, unsafe street crossings)	4	18
73.	Public transport issues (poor links, inaccessible, cost)	7	32
74.	Limited local employment opportunities		0
75.	Information provided to people with sight loss (through accessible formats and the internet advertising, word of mouth, letting people know	2	9
76.	Poor understanding of the English language amongst members of the local community	1	5

Attitudes and behaviours of people in the community

Most of the responses related to a lack of understanding about visual impairment (n=8) Risks to social participation in this regard included discriminatory behaviour (n=2) as a result of misconceptions about the needs of people with sight loss. Verbal or physical bullying from neighbours (n=2) was also identified as a risk:

> *"… if you apply to join something and the people find out you have a visual problem they may automatically dismiss you for safety reasons or because they don't know how to handle you."*
>
> *'Attitudes of general public to VI person - inability to appreciate the concept of 'low vision' between 'blind' and partially sighted.'*
>
> *'Individuals in the community that do not understand VI e.g. those with a white stick are not necessarily completely blind.'*
>
> *'Cultural issues maybe affecting the way disability is perceived'*

Opportunities for people in the community to meet and get to know visually impaired people and with sight loss (n=2) and living in cohesive communities where community members look out for each other were regarded as factors which fostered a greater understanding of the needs of visually impaired people and facilitated social participation:

> *'Community cohesion: In a close-knit community, more people are likely to be aware of the individual's needs and may be more willing to provide support.'*
>
> *'People also being willing to go that extra mile to help you out if you need it and just being willing to try and listen and understand your needs and judge you on your ability not your disability'*

Services

Despite being places which provide opportunities for people to meet and interact with others, mainstream services such as banks, shops or leisure facilities were noted to inhibit participation. One expert noted that a lack of access to: *'social activities such as the theatre, cinema, libraries, banking [and] facilities'* posed a barrier to this happening:

> *'Rural locations without support groups and accessible centres for activities can be a barrier to social participation'*

Visual impairment services

Risk factors related to visual impairment services related poor funding or in some cases the closure of local provision:

> *'Lack of access to new opportunities, e.g. closure of day centres'*

> *'Voluntary aided activities for the visually impaired are struggling with increased transport costs and rent for venues.'*

A lack of services designed to provide the resources which aid participation such as emotional support, counselling services and mobility were regarded as risks. In addition, it was also felt that existing visual impairment services tended to be geared towards the interests of older visually impaired people. Also felt to present risks to social participation was the lack of gender and culturally specific visual impairment organisations:

> *'Blind organisations when they exist tend to support mostly elderly individuals."*

> *'Lack of adequate local authority services, such as volunteers to befriend and take people out.'*

Other

The issue of mobility features as a risk to participation at a community level and was mentioned by almost a third of the experts in the panel). Local transport services were noted to be inaccessible, non-existent in some rural locations, sporadic, costly and yet necessary for people to get out of their homes and into their communities:

> *'Public transport - inconsistent - local rail network is good, but bus travel is difficult - need to plan a long way in advance - hard to be spontaneous.'*

Poor urban design and unsafe environments were identified as risks to visually impaired people with sight loss participating in their local communities.

> *'An environment that prevents social participation e.g. lack of traffic light crossings in some town centers'*

7.5.6 Wider society

Four themes emerged from the experts responses on the risk and protective factors located within the wider society domain. These were 'Attitudes and behaviours of others', 'Technology', 'Government policy' and 'other'.

Table 16: Wider society barriers and enablers

Item number		No. of experts	%
Wider society: Attitudes and behaviours			
77.	Negative attitudes towards people with disabilities / sight loss	5	23
80.	Discriminatory behaviour towards people with sight loss	9	41
79.	A lack of understanding about sight loss amongst the general public	3	14
Wider society: Technology			
78.	Inbuilt accessibility in everyday technologies (e.g. audio description on TV, Ebook readers with inbuilt speech)	1	5
81.	Satellite navigation systems (GPS) that work indoors	1	5
86.	Cost of Assistive Technology	2	9
82.	Social values where self-interest is key	1	5
Wider society: Government policy			
83.	Abolition of Disability Living Allowance (DLA)	2	9
84.	Legislation such as DDA and Equalities Act not being enforced	1	5
Wider society: Other			
85.	Economic climate	1	5
87.	Financial entitlements	3	14
88.	Living in the UK	1	5

Attitudes and behaviours

As in other domains lack of awareness of visual impairment and its nuances posed risks to successful participation. Negative attitudes about people with disabilities were felt to be in part due to the political rhetoric of policy makers and their focus on addressing benefit fraud within the current UK context of austerity measures:

> *'A more recent occurrence is the fact that communities can target the visually impaired as scroungers and spongers. This is due to the mis-information put out by the media and to a*

> *certain extent the government'*

> *"Labelling of disabled people as scroungers, that is creating the biggest barrier."*

Employers were included in explanations of the ways in which the attitudes of the general public could disregard the potential for people with sight loss to make meaningful contributions to society.

> *"People being prejudiced can also be an issue as there are some people who would think a blind person worthless which does create problems as then the person is misjudged and not looked at for what they can do."*

> *"Assumptions about blind and partially sighted people's potential"*

> *'General lack of more detailed understanding of the nuances of visual impairment. Many people hold archetypes of blindness or out-dated images of 'the blind person' in their minds. There is not enough social awareness of the causes and actual lived experience.'*

Understandings about sight loss amongst people in the wider society were felt to be poor and contributing to the exclusion of people with sight loss:

> *'Lack of awareness - particularly of things that can help in the workplace e.g. specialist software'.*

> *'Assumptions* [of others]*, i.e. 'can't come to the event because there are stairs!'*

> *'Health and safety concerns; embarrassment and ignorance of people generally, i.e. people would rather leave you out than risk getting you involved.'*

Technology

The costs of assistive technology devices and software are significant and are often beyond the means of many individual without some form of grant also noted by two experts as a barrier to participation. Access to Work (ATW) the scheme which provides workplace support such as access technology, support workers and covers travel costs was mentioned by experts (n=2) in the context of providing opportunities for visually impaired people to compete in the labour market. These experts also felt that ATW or similar scheme should be extended to provide similar support in non-employment settings to aid participatory activities. Increasing the extent to which accessibility is built into everyday technology items such as in some phones and e-readers, was also noted to facilitate inclusion. One expert also recommended a refinement of GPS navigation systems which might work indoors.

Government policy

Allowances

Although the impact of government policy in shaping the attitudes to people on with sight loss was implicit in the experts comments, current government policies were felt to directly impact on social participation of people with sight loss through its failure to take into account the associated financial costs (Chou et al, 2006). The replacement of the Disability Living Allowance (DLA) with the new benefit Personal individualised Payments was felt to be a risk to social participation. The changes were regarded by some experts as representing a further reduction to the incomes available to make social participation happen.

Poor enforcement of the disability legislation

The government was also criticised by experts for failing to sufficiently enforce the Equalities Acts and previous Disability Discrimination Act (DDA) which effectively enables employers and service providers to continue with discriminatory practices which exclude people with sight loss:

> *'Requirements on employers and business: Although most employers and business pay lip-service to the Equalities act,'*

Economic climate

Perhaps related to all the risks located in the wider society domain of an individual's lives is the economic climate identified (n=1). The recession was felt to pose a risk to social participation due to its impact across all environments within which visually impaired people are active players. The financial constraints experienced at a national level were noted to result in reduced personal and household finances, local authority cuts to the funding of mainstream and visual impairment services and further reduced employment opportunities for people with sight loss.

‘"Lack of funds allocated to improving services for those with VI’"

"Inadequate benefits to help people to interact with the community."

‘Financial resources - lack of resources to provide the support to enable adults with sight loss participate in society - benefits system.’

‘Premium house prices and rents and yet people with sight loss need to be situated near train stations.’

However, one expert felt that living with a visual impairment in the UK was preferable to living in other parts of the world:

‘I think that there are challenges but living in the UK is probably a good thing

7.5.7 Overall round 1 comments

The final section of the round 1 questionnaire provided a space for experts to comment on any aspect of the study if they so wished. In some cases experts used the space to articulate in their own words, their thoughts on social participation. The views of the experts suggest that social participation is not unidirectional. That is to say it is not just a matter of individuals undertaking activities but that there is also a responsibility of others to enable this to happen:

‘The world is set up for people with sight, so adjustments always need to be made. Example, print on notices, signposts, etc. But the biggest barrier is how blind people are perceived, i.e. they're different.’

‘Social participation is in my eye's is all about instilling confidence, giving respect and being empathic to a sight impaired persons needs and worries. Not being patronising to them or making them feel like a second rate citizen’.

> *'I think it is crucial to look at social participation due to the impact it has on people's quality of life - too often everything seems a lot of effort for people with a visual impairment and some may end up taking the easy option and give up.'*

Others commented about the questionnaire design and the difficulties they encountered with attempting to encapsulate their views on social participation through the survey:

> *'I ran out of steam a little. It is easier to comment on more specific issues. I am not sure how much of this relates to me personally, rather than others with sight loss.'*
>
> *'It strikes me that social participation is a very individual thing so very hard to make general statements.'*

7.6 Round two findings

The following section of this chapter presents the findings of round two of the Delphi study. This round was concerned with measuring opinion by establishing the emerging patterns of concerns identified in the previous round. This was achieved by the experts ratings of the items in the round two questionnaire which was developed from the data gathered in questionnaire one. As noted above the consensus was that two thirds of the panel should agree with the importance of a particular item. In summary, fifteen of the twenty one characteristics and activities identified in round one achieved over 66% agreement amongst experts.

Of the 63 risk and protective factors identified in round one, 48 achieved the required level of agreement amongst experts. The results are provided below.

7.6.1 Doing well

The first task of the questionnaire 2 was to rank the level of importance attached to items indicative of a person doing well with regards to social participation. The indicators 'independence outside the home', 'feeling ok around sighted people' and 'being relaxed in social settings' achieved 100% consensus. That independence outside of the home achieved universal agreement amongst panellists and activities undertaken inside the home such as making meals and managing the household were rejected from the final lists suggests that experts regard social participation as being conceptualised as an external phenomenon. Being in employment and having a good network of friends also achieved high levels of agreement (93% respectively).

Table 17: indicators that a person is doing well in relation to social participation

		No. of experts		
Item number	Indicator	Weak (%)	Neutral (%)	Strong (%)
1	Independent (outside)	-	-	100
2	Feels ok around sighted people	-	-	100
3	Relaxed in social settings	-	-	100
4	Paid employment	7.1	-	93
5	Good network of friends	7.1	-	93
6	Good social skills		7.1	93
7	Computer use	7.1	-	93
8	Internet use	7.1	-	93
9	Mix of friends	14.3	-	85.7
10	Able to obtain information	-	14.3	85.7
11	Is happy and has fun	-	14.3	85.7
12	Assertive in a nice way	-	14.3	85.7
13	Accepting of own sight loss	-	21.4	78.6
14	Keen to try new things	-	28.6	71
15	TV / Radio	7.1	21.4	71
16	Able to managing household	21.4	14.3	63
17	Can making meals	21.4	14.3	63
18	Is aware of surroundings	-	42.9	57
19	Volunteering	14.3	28.6	57
20	In a loving relationship	14.3	35.7	50
21	Is a parent	50	28.6	21.4

Consensus at 66% level.

Taking part in volunteering activities and being a parent in a relationship with a significant other were not felt to be strong markers of some who is doing well with regards to social participation.

7.6.2 Round two risks and enablers

Experts were next asked to rate the risk and protective factors which were identified in round one which are presented below.

Individual risk and protective factors

All of the factors identified as personality attributes in round 1 achieved agreement by the panellists. Experts universally agreed that ‘determination’ was a protective factor. Other personal attributes included confidence, good coping skills and awareness of surroundings. The sole factor under the physical attributes theme to achieve consensus was the attribute of having ‘no sight’ which was felt to be a barrier to participation by well of three quarters of the experts (78.5%).

Table 18: Individual risk and enablers

Items	**Rating**		
	Weak (%)	**Neutral (%)**	**Strong (%)**
Individual: Personality attributes			
Determination	-	-	100
Depressed / low well being	-	7.7	92.3
Confidence/ assertiveness	-	14.3	85.7
High self-belief	7.1	7.1	85.7
Good coping strategies	21.4	14.3	78.6
Sense of belonging	7.1	14.3	78.6
Fear of trying something new	7.1	21.4	71.4
Worries about the perceptions of sighted people	14.3	14.3	71.4
Awareness of surrounding	-	28.6	71.4
Individual: Physical attributes			
No sight	14.3	7.1	78.5
Physical health	7.1	42.9	50
Ethnic	7.1	50	42.8
Ethnic	7.1	64.3	28.5
From birth or early age	21.4	50	21.4
Young	42.9	50	-
Individual Other			
Poor self-care	-	21.4	78.6
Personal finances	14.3	14.3	71.4
Poor English	-	28.6	71.4
Education	21.4	14.3	64.3
Being able to drive	21.4	14.3	64.3
Rocking	-	42.9	57.1

Other personal attributes influencing participation levels for visually impaired people related to poor self-care, personal finances and having a poor grasp of the English language. Both Education and the ability to drive (64.3% respectively) were not felt to be sufficient barriers or enablers to social participation and did not achieve the required agreement level.

Home life risk and protective factors

The two themes ‘Attitudes and behaviours of others’ and ‘Other’ were once again presented to the panel for the consideration. Both overprotection and low expectations achieved 100% agreement. In contrast people within the home life context who do not understand the needs of the person with a visual impairment and the change in power balance which might occur after the onset of the visual impairment were not regarded as the most important barriers to social participation.

Amongst the ‘other’ theme mainly related to the logistics of getting to and from sites where social activities take place. These included living far away from family and friends, residing in a rural location and the financial resources to fund activities. Just ‘support from a range of sources’ as opposed to relying on just one person did not achieve agreement one item did not achieve agreement.

Table 19: Round 2 agreement home life risk and enablers to successful social participation.

Home life: Attitudes and behaviours	Weak (%)	Neutral (%)	Strong (%)
Over protective	-	-	100
Low expectations of what person without sight can do	-	-	100
Embarrassment about sight loss	-	7.1	92.9
People who don’t include	-	7.1	92.9
No available support all	-	7.1	92.9
No time to provide support	7.1	14.3	78.6
Don’t understand needs of person with sight loss	-	35.7	64.3
Change in power balance	7.1	35.7	57.1
Home life: Other			
Live far from friends and family	-	14.3	85.7
Living in a rural area	-	14.3	85.7
Balanced support	-	21.4	78.6
Limited household finances	-	28.6	71.4
Support from a range of sources to prevent over reliance one individual	-	38.5	61.5

Community risk and enablers

Under the ‘Attitudes and behaviours of other people’, the experts responses illustrate the types of community that would be prohibitive or promote social participation for visually impaired people. It was unanimously agreed that ‘Discrimination’ and ‘bullying’ were barriers whereas living in a community where people members look out for each other was overwhelmingly regarded as a protective factor. Cultural beliefs were regarded as both a risk and protective factor and also reached agreement. Opportunities for people in the community to meet people with sight loss did not however, achieved the required level of consensus. Community services

Table 20: Community barriers and enablers

Community: Attitudes and behaviours	**Weak (%)**	**Neutral (%)**	**Strong (%)**
Discrimination	-	-	100
Bullying from members of neighbours / members of the community	-	-	100
A community where people look out for each other	-	-	100
Good understanding of sight loss	-	7.1	92.9
Cultural beliefs	-	7.1	92.9
Opportunities to meet people with sight loss	7.1	28.6	64.3
Community services			
Accessible services	-	-	100
Information about what's on	-	7.1	92.9
Good customer service	-	15.4	84.6
Funding for vi services	7.1	14.3	78.6
Wide range of services to facilitate choice	-	21.4	78.6
Emotional support and counselling	-	21.4	78.6
Visual awareness focus on older people	14.3	14.3	71.4
Individualised rehabilitation	7.1	28.6	64.3
Community Other			
Poor physical environment	-	-	100
Poor transport / cost	-	-	100
Information what's on in the community	-	14.3	85.7
Limited employment opportunities to meet people with sight loss	-	21.4	78.6

All factors under community services achieved consensus with the exception of individualised rehabilitation. Amongst the community 'other' theme, all factors achieved agreement.

Wide society risks and enablers

All three of the original items under the theme 'Attitudes and behaviours' of others achieved consensus from the panel. Under technology, inbuilt accessibility in everyday items was felt to enable social participation whereas the cost of specialised technologies was felt to be prohibitive. The facility of GPS which might enable individuals to navigate their surroundings was not felt to be a sufficiently important influence on social participation. The two factors from the miscellaneous ‘other’ theme economic climate and financial entitlements were however were deemed to be influential. Social values and living in the UK were not.

Table 21: Wider society

	Weak (%)	Neutral (%)	Strong (%)
Wider society: Attitudes and behaviours			
Negative attitudes	-	-	100
Discriminatory behaviour	-	-	100
Public lack understanding		7.1	92.9
Wider society: Technology			
Inbuilt accessibility	-	-	100
Cost assist	-	7.1	92.9
GPS indoors	35.7	35.7	28.6
Wider society: Government policy			
Legislation such as DDA not being enforced	-	7.1	92.9
Abolition of DLA	7.1	21.4	71.4
Wider society: Other			
Economic climate	-	21.4	78.6
Financial entitlements	-	28.6	71.4
Social values	7.1	35.7	57
Living in the UK	14.3	42.9	42.9

7.6.3 Overall Round 2 comments

As in questionnaire one, a free response question enabled experts to comment on aspects of the study. Again comments focussed on the experts views on definitions of social participation as well as the problems of distilling the complexities of the phenomenon within the confines of a questionnaire. The expert’s responses suggest that social participation is highly contextual and individual in that what may be considered to be an indicator of social participation for one person such as computer usage may have no bearing on the participation of another:

‘Some of the concepts are very hard to disentangle. Indicators around ethnicity will vary with what a person wants. Not speaking English may be a very real barrier but older generation, foreign language speakers may prefer community engagement with their own community. It may well depend on the size of the BME community and how that community sees itself in the wider community. Computer technology may have little or no bearing on engagement for some people, but for others it will be what they and their peers use.’

‘I found this very difficult to complete and found myself feeling that most things have significant impact one way or another.’

‘On the surface of it I am successful as I am in work and appear successful and happy. However, since I lost my sight I get very tired. Working so that I do not rely on benefits takes everything out of me, limiting my ability to get out in the evenings. The result is that I am socially very isolated - a massive risk factor for emotional well-being. Also I still have limited resources to buy enabling support e.g. taxis, sighted support to help me socialise where I choose.'

7.7 Discussion

7.7.1 Definitions of social participation

A goal of the Delphi was to identify the characteristics of individuals with sight loss who in spite of the various challenges were routinely taking part in participatory activities. The study is the first of its type to organise a group of experts within the field of sight loss to discuss definitions of social participation as well as the factors posing a risk or promoting social participation.

The responses of experts suggest that social participation is a bi-directional construct involving agency and power. That is to say engaging in social activities is not just a matter of individuals simply making the decision to take part and executing that choice, but that engagement relies on the interactions between a wide range of risk and protective factors which are located across life domains. The expert's responses characterisations of a person who is doing well also suggests that social participation is a phenomenon that takes place in environments outside of the home setting rather than within it. This is a narrower definition of that provided by the ICF which describes participation as 'involvement in life situations'.

Characterisations of a person doing well indicated that they will engage in a wide range of activities with varying levels of involvement with other people. Using Levasseur and colleagues (2010) six proximal to distal levels of involvement, the experts examples of activities indicated that social participation was likely to involve level 1, '*doing an activity in preparation for connecting with others'* such as accessing information and internet usage; levels 2 *'being with others'* where examples provided by experts included socialising with friends and going on holiday and attending places of worship; level 3, *'interacting with others without doing a specific activity with them'* such as shopping and travelling independently; level 4, '*doing an activity with others*' such as sporting activities, membership of clubs and level 5, '*helping others'* in visually impaired people were educating others about sight loss. There were less examples of level 6 *'contributing to society'* which Levasseur and colleagues describe as participation in civic activities such as being involved in political parties and organisations. However, the broad nature of the topic and consequently the expert's responses means that this cannot be excluded.

The experts placed great emphasis on visually impaired people performing these activities with a reasonable degree of autonomy and independence which was indicative of someone doing well.

Individuals doing well were also likely to welcome the idea of trying new things, possess good social skills and be comfortable in a range of social setting. The expert's descriptions are perhaps the profile of an individual with whom most people would wish to spend time with irrespective of level of sight. The characteristics and activities undertaken by a person doing well therefore, are as one expert commented, no different to that of '*anyone else'.* In the words of another, social participation can be defined as '…*accessing a range of activities that fully sighted people take for granted*.' The experts have therefore identified the potential for resilience as with other grand theories to polarise discussion. In other words, in defining those who demonstrate a positive outcome, it is necessary to define those who do not. Yet it is likely that most individuals occupy the middle ground, occupying the positive and negative ends of the pole at different times and contexts in their lives. This illustrates the unevenness of resilience, this point was expressed by one visually impaired Delphi expert. The expert explained that in spite of doing well in labour market participation terms, they were experiencing isolation and loneliness in their social lives.

The term 'doing well' which at a fundamental level implies an individual has achieved the desired outcome, also implies something over and above what is expected (Young et al, 2008). The desired outcome, in this case social participation, should be regarded as the default position *'…i.e. that which happens in the absence of specific pathogenic factors*' (Shalev and Errera, 2008). Visually impaired people who are getting out of their homes and into their communities independently are not dynamic or extraordinary, but merely undertaking the right of every individual in society. Viewing social participation as the default position can contribute to reversing the low expectations expressed through the disabling attitudes and behaviours of friends, family and people in the wider community as described by the experts in the study. Acceptance of sight loss also emerged as a process which facilitates social participation.

7.7.2 Factors specific to visual impairment

The experts identified a wide range of factors which could inhibit or promote a visually impaired person's ability to achieve the default position. The use of a triadic ecological framework to guide the expert's responses enabled these factors to be identified at each systemic level of an individual's environment. Although many of the risk and protective factors were reflected in the earlier literature review, a key benefit of the study was its ability to combine these under the rubric of visual impairment. In addition, whilst many of the personal characteristics identified in the current study such as determination, confidence, and high self-esteem are generally found in the wider resilience field (Masten, Werner,) and visual impairment research (Griffin-Shirley and Nes, 2005; Huurre and Aro, 2000), the findings suggest that there are factors which are specific to visual impairment. *Poor acceptance of visual impairment*, *worries about sighted people* and the physical condition of *having no sight* were regarded by experts as risk factors to social participation. The inclusion of sight loss as a risk factor to social participation by experts warrants a return to the discussion on whether visual impairment is a vulnerability or a risk factor. Experts did not define visual impairment as a vulnerability although this may be due to the complexities of doing so within the confines of a questionnaire format. It does however, suggest that visual impairment is regarded by professionals and visually impaired people alike as presenting its challenges independent of interactions with others. In other words, difficulties such as those which might be experienced with self-care (Beer et al., 2006; Douglas, 2006) are not easily explained by the interaction of others and may well be regarded as directly occurring as a result of having no sight.

7.7.3 Attitudes and behaviours of others

Attitudes of other people was a common feature across the domains of an individual’s life. For example, the context of the family is widely regarded as an important domain in resilience terms and is the source of both risk and protective resources. (Werner and Smith, 1992, Yates and Masten, 2004). Attitudes and behaviours exhibited by individuals closest to a visually impaired person accounted for over half of the factors impacting on the potential to participate in social activities. Overprotection by carers of visually impaired people achieved 100% consensus amongst Delphi experts and indicates the belief of experts on its strong role in influencing participation. Over protection, embarrassment and a lack of inclusion by family members, categorised as negative support has been noted to have a detrimental impact on a person’s ability to be independent (Cimarolli and Boerner, 2005). Experts also noted that some cultural groups place emphasis on looking after family even though independence is stifled by overprotection or embarrassment of their loved ones condition. Balanced or positive support on the other hand as noted by experts, can foster independence and high self-esteem and validates the focus on social support in study one. The responses of the experts also reflect the finding in study one that some visually impaired people have no support at all and the ways this can be detrimental to social participation. Given that factors within the home life domain are most likely to influence the outcomes developmental outcomes, the findings suggest that resources which enable independence such as the nature of social support as well as acceptance of visual impairment must be considered in the design of interventions supporting visually impaired people.

The community environment is where people interact, transact, use transport and are consumers. The expert's descriptions of protective factors found at the community level characterise communities which are cohesive. A picture was painted of a utopian ideal (UPIAS, 1976; Ratzka, 1998) in which neighbours welcome the presence of visually impaired people, provide appropriate levels of practical support and regard the participation of visually impaired people as the default position. In such a community mainstream services would be varied and accessible and staff both inclusive and understanding of the needs of people with a visual impairment. However, a community such as this relies on the awareness of local people on the nuances of visual impairment. Yet poor awareness of the needs of visually impaired people is regarded as the most influential barrier to the participation of disabled people in mainstream society. Whilst it is likely that the presence of visually impaired people engaging in community life will contribute to a sense normalcy by virtue of familiarity they must first endure the pre-cursory in which a visual impairment is regarded as the 'unsual'. The causality dilemma also illustrates the bi-directional nature of social participation. Disability theorists such as Finklestein however argue that this cannot be achieved under the current capitalist economic system which he argues maintains existing social relationships.

It is at the community level that visual impaired people and their families' access information and support through services designed to meet the needs of people with sight loss. Community resources which promote social participation require a commitment to funding, such as emotional support and counselling services to assist with the adjustment process. However, factors located at the wider society level such as the economic climate and the government's programme of austerity cuts have reduced available funding. Thus participation is about power. The lack of organisation around the provision of information at the early stages of sight loss (Douglas, Corcoran and Pavey, 2008) and limited health and social care provision for people with visual impairments which if accessed could support healthy and more expedient adaptation to sight loss has been noted elsewhere (SSMR, 2009; Douglas et al, 2008; Nzegwu, 2008).

Location

The importance of where visually impaired people reside, particularly those living in rural areas was noted by experts. Areas with well served, affordable transportation and living near family were regarded as a resources which promote participation in social activities. Conversely, poor environmental design were found to be risk factors.

Technology

The growing importance of technology as a facilitator to social participation was recognised by experts in the study. Technology solutions built into everyday items such as mobile phones can increase independence. However, the costs of obtaining these items were felt to be prohibitive for some. It was also suggested that technology may not necessarily be a protective factor for some visually impaired people who will participate regardless depending on the presence of other promotive factors.

Government policy

The failure of government departments to enforce disability discrimination legislation which might otherwise protect visually impaired people in some environments was regarded as a risk factor to social participation. Similarly the decision to replace the Disability Discrimination Act and Disability Living Allowance are regarded as risk factors to social participation.

Finances

The availability of personal finances pervades across domains. Additional finances to support the extra costs of living with a visual impairment.

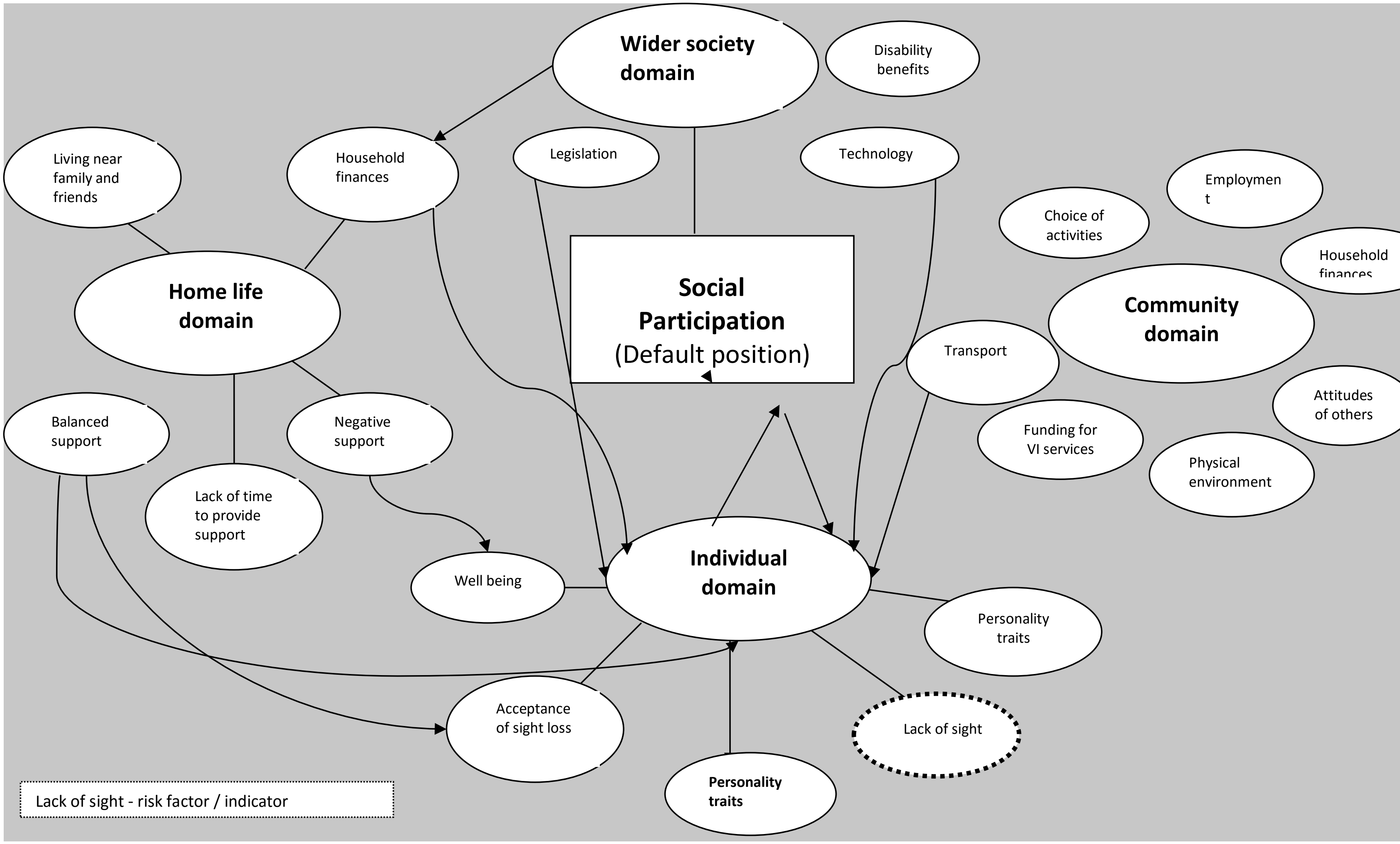
This issues of whether risk and risk factors are merely the opposite ends of the same pole (Shaikh and Kauppi, 2010) are reflected the discussions on resilience. Rutter (1990) suggests that even when the two factors are seemingly dichotomous they should be treated as separate variables. However, Masten (2001) suggests that it is possible to treat them as the same variable and describes them as bipolar predictors. For example 'poorly designed environment' is a risk factor whilst a 'well-designed environment' is a protective factor but refer to opposite ends of the same phenomena. Masten does recognise that there are some factors which can only be regarded as risk. Glantz and Sloboda (1999) also suggest that a variable can be a mixture of the two in the case of social support which can be both helpful and detrimental to participation. Ethnicity which experts suggested could be both a risk indicator and a protective factor further supports the idea that the same risk factor can increase the chances of risk in one context and decrease it in another (Little, Axeford and Morpeth, 2004).

7.7.4 The emergence of risk and protective processes

An unexpected outcome of the Delphi was the emergence of data which begins to illustrate how risk and protective mechanisms operate. For example, particular factors were found to pervade across systemic levels. Finances, and the attitudes and behaviours of people toward sight loss were recurring themes which create a chain of events. For example, the economic climate impacts on local authority funding for services in the community, which ultimately impact on the individual's choice of activities. The impact of finances may be just one particular process, which exerts pressure on visually impaired individuals. On the positive end of the risk-resilience continuum, acceptance of visual impairment and overcoming anxiety about the perceptions of others are part of the process of adjustment (Tuttle, online) and therefore represent a process within the resilience process. Such processes are referred to in resilience terms as underlying component processes (Hauser et al, 2006). Figure 10 (below) attempts to show some of the linkages between the risk and protective factors and how they relate to a visually impaired person achieving the end goal of social participation.

The figure below shows connections between factors and the individuals various ecological domains according to the experts.

Figure 10: Emergence of risk processes



7.7.5 Study limitations

The Delphi illustrated that participating in social life involves taking part in activities outside of the home and has a wide social network and provided a good indicator of individuals who fit this description which opens up the possibility of identifying potential participants for further studies on resilience. However, difficulties capturing the complexities of the linkages between social participation and the risk and protective factors within the confines of a questionnaire were apparent from the comments of the experts. The resulting list of characteristics, protective and risk factors as noted by experts are highly dependent on factors such as culture, gender, geographic location and historical context. That so few of the indicators were considered weak in round two indicates that all factors will have merit to different degrees at some point in the lives of people with visual impairments. That physical characteristics other than sight loss made it through to the final set of indicators suggests the resulting list can only ever be generic in nature. This illustrates the dynamic nature of resilience (Masten; Cardenas and Lopez, 2010) and it is only through the unique stories of individuals with sight loss can the processes involved in resilience be elucidated.

The Delphi was terminated in the second round since it was felt that proceeding to a further round would adversely impact on the response rates and enthusiasm amongst experts who had already expressed their difficulty with rating indicators at the first round. The propensity of the Delphi to force experts to agree with the majority view has been noted elsewhere (Goodman, 1987, Sackman, 1975). Sinha et al, (2011). Nelms and Porter (1985) suggest that rather than using criteria based on consensus, stability of agreement on responses between rounds is often preferable to pressurising experts into agreeing. Stability and uncertainty can be measured by the standard deviation, range, and inter-quartile range of the answers' (Nelms and Porter, 1985: page 50).

7.8 Conclusion

The application of the language of resilience on visual impairment reflects findings of past resilience research that risk and resilience factors are not static but are a dynamic phenomenon. Factors which promote and hinder the development of a positive outcome are found at various systemic levels of a person's environment (Cardenas and Lopez, 2010; Shalev and Errera, 2008). The study has also emergence of factors their interrelationships which contribute to enabling or disabling processes. Similarly the intended outcome social participation is not a static, unidimensional construct but one that relies on agency and power exerted by those very same factors. There was also evident that some factors operate as both risk and protective factors depending on the individual's context and environment.

The Delphi has provided a description of the types of activities that would be expected of a person with a visual impairment and indeed any other, regardless of presence of the presence of the condition or not. In combination with the results of study one, the description can be used to identify participants for participation in intervention programs aimed at facilitating greater inclusion. However, even though the Delphi included an iterative first round, the resulting data was still restricted by the confines of the questionnaire format. Although to a lesser extent, the Delphi study exhibited some of the limitations apparent in study one despite efforts to reduce them. The concept of resilience it would seem can only be examined effectively using the most qualitative of methods.

The following chapter discusses the subsequent and final study (study 3) which employs a narrative approach as a means of obtaining unrestricted personal accounts of social participation. This chapter discusses justifications for the use of narrate approach in greater detail in addition to the research findings and their implications.

CHAPTER 8: Study 3 – Getting out and about with sight loss

In the previous chapter, the Delphi technique was used to obtain the views of a group of experts on the risks and protective factors involved in social participation. The experts did provide contextualised examples which saw the emergence resilience processes such as acceptance of visual impairment. Although the approach was selected for its iterative first round which facilitated the participation of people with experience of visual impairment, it became apparent that a deep understanding of resilience required a method free of constraints. It was apparent that without context, the risk and protective factors on their own are abstract constructs. This chapter presents study three which advances the early emergence of processes by examining resilience in action using data collected by visually impaired people as they engage in social activities. The data inherently includes personalised descriptions of the ways in which participants navigate daily challenges which both present threats to social participation and trigger a mediating response. The strategies individuals employ to cope with potential challenges and how they recover from setbacks are also described. The chapter also describes the way in which the processes operate.

8.1. Meaning from narratives

In earlier chapters I discussed that individuals cannot be considered as entities independent of their social surroundings but as part of a complex and interdependent structure (Ungar, 2003). Discussions throughout this thesis have centered on the argument that investigating social outcomes cannot be attributed to solely individual or social factors. Rather social things are embedded in the unique contexts in which people are situated. The previous studies illustrate well the difficulties of researching complexed social phenomenon such as resilience. Whilst the Delphi study was able to get closer to revealing the underlying processes involved in resilience, it is clear that researching this complex social phenomenon requires unorthodox methods to obtain data generated by the through the accounts of individuals experiencing them. This is because context is all important in resilience. Qualitative research recognises the complexities of social life by allowing for the whole person in their environment to be examined. Qualitative research also recognises that there are multiple realities which are inherently subjective. Ungar (2003) in has paper on contributions of qualitative research to resilience notes that:

> *"Qualitative methods: are well suited to the discovery of the unnamed protective processes relevant to the lived experience of research participants; provide thick description of phenomenon in very specific contexts; elicit and add power to minority 'voices' which account for unique localized definitions of positive outcomes; promote tolerance for these localized constructions by avoiding generalization but facilitating transferability of results; and, require researchers to account for their biased standpoints." (2003, page 85)*

One particular qualitative method - narrative inquiry, presents opportunities for accessing the unique views and experiences of individuals with a visual impairment on social participation. Conceptualized by Connelly and Clandinin (1990) as *'a way of characterising the phenomena of human experience'* (p. 2), narrative inquiry is based on the premise that humans are predisposed to narratising their experiences through the telling of stories (Andrews, Squire and Tambokou, 2008). Narrative approaches therefore emphasise the lives of individuals as told through stories to understand the learned significance of those experiences. Far from being a childish endeavor, telling stories is a universal competence regardless of education and language – humans are as suggested by Connolly and Clandinin (1990), 'story-telling organisms'. Along similar lines Barthes observes that: '...the history of narrative begins with the history of (hu)mankind; there does not exist, and has never existed, a people without narratives' (1966: 14). Throughout our lives we encounter a multitude of experiences and dialogic interactions, both with our surrounding world and ourselves. To order and structure these experiences, events are organised into meaningful units often through telling stories or narratives. People create narrative descriptions for themselves and others (Moen, 2006). A person recounting a train journey into work or the reason for a phobia of spiders are examples of narratives which are transformed, shared and compared with those of others (Rosen, 1987; Plummer, 1995). Narratives are also created to explain the behaviours of others (Zellermayer, 1997). One such narrative to describe the behavior of others was demonstrated by the female research participant in Butler and Bowlby's investigation of visually impaired people who described sighted people in which regarding her as must have regarded as 'normal' (Chapter 4). In addition, as well as constantly producing narratives we are also bombarded by narratives from the social world around us (Moen, 2006) an example which was described by Crow (Chapter 4). Narratives are therefore not just chronicles of events and experiences but are more about the meanings this events have. They are reconstructed accounts of the persons experience rather than not the actual event.

> *"Making stories from one's lived history is a process by which ordinarily we revise the past retroactively, and when we do we are engaged in processes of languaging and describing that modify the past. What we see as true today may not have been true at the time the actions we are describing were performed. Thus we need to resist the temptation to attribute intentions and meanings to events that they did not have at the time they were experienced" (Bochner, 2007)*

8.1.2 Narrative research in resilience

The term 'narrative turn' has been used to describe the increasing interest amongst social scientists across disciplines in storytelling as a means of understanding human development. The approach is grounded in the post modernism tradition of rejecting assumptions of rationality and universal truth. In contrast, knowledge is regarded as co-constructed and grounded in the everyday experiences of individuals experiencing the phenomenon under study. Narratives also challenge the idea that life events have a linear trajectory through its ability to capture the messiness of social life. Narrative researchers gather data from written or spoken words in the form of autobiographies, interviews, journals, letters and other textual data. Trahar (2009) notes that narrative inquiry is not just about collecting stories but that researchers should observe the meaning behind the text being conveyed:

> *‘…strive to attend to the ways in which a story is constructed for whom and why as well as the cultural discourses that it draws from’ (about the examining the meaning individuals in relation to the social context of in which they occur and how.*

Narrative approaches are being increasingly adopted in resilience studies perhaps as Ungar suggests, because the approach fits with the resilience researcher’s interest in agency and context. This is particularly interesting in view of the earlier discussion on the values placed on participating in social activities. Hauser also notes the sensitivity of narrative approaches

> *'…both to the individual and to his or her surround (x)'. Narratives enable researchers to explore the personal and contextual forces that influence human behaviours, what caused them to make certain choices within system level constraints and resilience as the individual understands it.’ (Hauser, 2006, p207)*.

Riessman (2002) suggests that narratives ‘illuminates the intersection of biography, history, and society’ (p. 697) which implies narrative approaches can be used within an ecological framework. Others have used semi structured interviewing techniques to enable participants to tell their life stories. Narrative research is also participatory in nature and the research subject is the collaborator (Altork 1998, Moen 2006; Didkowsky et al, 2010). Since the approach therefore democratises the research process, narrative inquiry is viewed within a participatory framework.

8.1.3 Audio diaries

In the current study the decision was taken to use solicited diaries (referred to as solicited because they are created for the purpose of research), as the source of data for two principle reasons. Firstly, researchers working on the national resilience project (NRP) had reported success with using participant self-collected data. NRP researchers noted that the photo diaries and videotapes kept by young people at risk revealed the emergence of processes that may have gone unnoticed through the use of traditional methods. This feature of personal diaries has been noted in other studies (Almeida, 2005; Ong and Bergeman, 2004; Didowsky et al, 2010). Secondly, personal diaries provide a 'window' into people's lives and provide an innovative means of obtaining personal accounts of events as in real time. Allport (1942) describes the diary as the document '*par excellence*', because of the diarist's chronicling of the 'ebb and flow' of public and private events.

In spite of these advantages, few studies have employed the use of solicited audio diaries with some notable exceptions (Dale, 2010; Monrouxe, 2009; Milligan et al., 2005; Worth, 2009). The method provides an alternative and arguably superior approach to visual methods because of its accessibility for visually impaired participants. Almeida (2005) notes that the method increases ecological validity as well as reducing memory distortion.

8.1.4 Narrative interviews

The intention was for the audio diaries to be supplemented with data obtained through narrative interviews to reveal explore how the presence of resilience processes developed given that resilience is not a static trait but a phenomenon that grows and develops over time. Hauser notes that using life history interviews in the study Resilience researchers have indicated human development has to be understood over the life course that *'…stories can trigger new perspectives about relationships, situations, goals, and all the other facts and forces that play decisive roles in individual's lives'* (Hauser, 2006, page 205). The ways in which is resilience developed and shaped by their life experiences is an important concern in terms of understanding resilience.

8.2 Statement of the problem and study aim

RQ4 set out to identify the resilience processes involved social participation within the context of visual impairment. Previously, studies one and two have examined vulnerability to risk and the discrete risk and protective factors associated with social participation. Both were limited in their ability to fully reveal resilience processes. An approach that taps in to the personal accounts of visually impaired people who regularly take part in social life is needed to understand the daily context in which positive adaptation occurs. The use of narrative methods resonates with the requirements of the current study as it facilitates the capturing of detail on individual experience and cultural context.

The purpose of the study is therefore is to understand in contextual detail the nature of the challenges which pose risks to successful participation for people visually impaired people and how these risks are mediated to result in positive outcomes. The study aims to develop theory on the processes involved in successful participation for visually impaired people.

8.3 Method

Having established the potential for narrative enquiry to capture detail on resilience processes this section describes the use of a case study design to frame data from six research participants. This section describes the range of data included in the analysis which included audio diary data, narrative interviews and a biographical account of living with a visual impairment. The use of the case study design is also described.

8.3.1 Case study design to frame narratives

The case study design was adopted as the mode of investigation to frame the data provided by six participants. A research strategy rather than a method, case study the represents a framework for organising one or more methods from a variety of sources, planning data collection, analysis and theory building (Parahoo, 1997). This was particularly necessary given the range of data collected during the course of the current study. The case study design also fits well with narrative methods as both emphasise the link between the phenomenon under study and its context. The case study approach facilitated a sharpened focus on the interactions between participants and their environment. In addition, the use of the case study enabled the positioning of resilience processes at the centre of the study rather than focusing on research participants (Liebenberg and Ungar, 2009). Locating resilience processes rather than participants at the centre of the study is an important consideration. Thomas (2011) notes that case studies are comprised of two parts - a subject (the theoretical focus) and an analytical frame (object). Within the current study, a researcher might instinctively believe visually impaired individuals who regularly engage in social life should be the subject of the case study. However, this would be an incorrect approach for two important reasons. Firstly, the focus of a case study is driven by the research question which in this case, is to elucidate the processes involved in achieving positive outcomes vis a vis social participation. Since resilience is understood to be a process, the subject is the process or processes which trigger positive outcomes (social participation).This approach concurs with Thomas (2011) who refers to the subject as:

> *'As objects which is the theoretical focus of the case study and is the sets of events reported by each case and its related variables. It is the object which forms the analytical framework.' (p512)*

Secondly, Liebenberg and Ungar (2009) reminds us that placing individuals at the centre of the case study design once again focusses on the individual as the locus of change rather than identifying the external factors which promote resilience:

> *'…by taking this [centering of participants] approach we once again put individuals at the centre of the analysis and indirectly reinforce the sense that resilience is about personal qualities and actions.' (p.115)*

Resilience processes as subject therefore, decentres the participant as the source of resilience and 'avoids defining them as resilient or not since all individuals at the focus of the study will encounter adversities on their path to health development' (Liebenberg and Ungar, 2009).

8.3.2 Stages of the case study

The case study was designed in six stages. The following section describes of the various stages which includes details of participant recruitment through to the data analysis.

Stage 1 – Participant recruitment

Events, incidents and experiences, not people per se, are typically the objects of purposeful sampling (Miles and Huberman 1994; Strauss and Corbin, 1990). Visually impaired people who are able to buck the general trend of isolation in spite of their increased risk of social isolation are in fact outlier cases. As such they are likely to hold useful information about the development of resilient processes. An aim of the earlier Delphi study was to identify characteristics held by visually impaired adults who are likely to be doing well and consequently were best able to inform further investigations on mechanisms of resilient processes. The experts identified prioritised three characteristics which would indicate that a visually impaired individual was participating in social life – 1) travelling independently, 2) having a mixed circle of friends and 3) being in paid employment. This criteria was initially used as the basis for selecting potential participants. To maximise the variation within cases, levels of sight, age and type of locality (rural vs. city dwellers) were also considered as factors which were likely to have a strong influence on the experience of participation. The sampling strategy therefore can be considered to be information oriented sampling, or selection of participants on the basis of knowledge held.

In November 2013 Action for Blind People who run a service user consultation panel were contacted and asked if they could assist with the recruitment of participants to take part in the current study. The researcher was asked to write a short synopsis of the aim and purpose of the study as well as the participant requirements and the researcher contact details (Appendix B). The researcher returned this information to the moderator who once satisfied with the aims and protocols, forwarded details of the study to members of panel expressing an interest in taking part in research activities.

In total nine individuals contacted the researcher by phone or email to learn more about the study. Each of the nine individuals were contacted initially by email or phone and a short interview took place both to thank potential participants for the interest and to explain their requirements and provide consent forms. Despite their initial enthusiasm only 5 individuals from the consultation panel returned their consent forms. A sixth participant was recruited directly through a referral from a rehabilitation officer known to the researcher. The details of the final six participants are shown below.

Table 22: Participant involved in the diary keeping

Name of Participant	Audio dairy
Carrie	Audio diary and narrative interview
Tom	Audio diary
Brian	Summarised autobiography
Amanda	Audio diary and narrative interview
Lisa	Audio diary and narrative interview
Denise	Audio diary

Stage 2 introductory interviews

After the initial contact from potential participants, the researcher arranged an informal interview / discussion to both obtain demographic details and to provide them with information about the study. Using an introductory interview schedule as a guide, the discussion covered the aims of the study, details of the diary keeping method, consent protocols, determining current activity levels for the week that data is collected and their involvement in a lengthier, in-depth interview. The interview schedule (Appendix E) was organised into five sections:

- Introduction – introducing myself and thanking the person for their taking part in the study. Explaining research aim and purpose
- Explain informed consent and establish preferred formats
- Equipment - establish whether participants have their own recording devices or require the loan of an MP3 Note taker (Olympus DP20 due to its ease of use, portability and relatively low cost). Short discussion to establish what does resilience mean to participant
- Discuss timing of week of data collection - discuss forthcoming events

During the interview details of the study were explained in greater depth and the researcher was able to obtain the participants thoughts on the research study. Participants were encouraged to think ahead to their forthcoming schedules and participants would describe events they were attending which might be useful to include in their diaries. Participants spoke enthusiastically about taking part and their belief that the topic of social participation amongst visually impaired people required greater attention. Participants stated the week in which they planned to collect data and how data would be returned to the researcher. It was anticipated that recording equipment would have to be supplied to participants either by post or in person. However, all except one participant had stated that their smart phone would be their recording device of choice.

After participants had verbally agreed to be involved in the study, an instruction sheet (Appendix F) describing the requirements for recording diary data was sent to each participant by email. Participants were asked to record describe their emotions, mood, thoughts and decision making related to the preparation leading to participatory event and the event itself. Mindful that researcher input should be kept to minimum the diary keeping instructions asks participants to include detail of four aspects of the participatory activity:

1) Nature of the event - type of event - planned or spontaneous
2) Getting there - how, with whom, when
3) Being there - how was it?
4) Getting home - how, with whom, when

Stage 3: Audio diary fieldwork

Diary keeping activities took place during the Christmas period of 2013. As well as recording the usual day to day activities, the festive season provided increased opportunities for participants to engage in additional events such as Christmas parties and shopping for gifts. For the researcher, the field work stage represented a quiet but nervous time as the arrival of audio diary recordings was awaited. In some cases diaries were returned on the same day they had taken place. In most cases however, the whole weeks’ worth of recordings were returned. The diaries were retuned in mp3 or mp4 files by email. And were easily downloadable directly to the researcher's computer. In instances where the recordings were sent early the researcher was able to listen and become familiar with the events that had taken place in the daily lives of the participants which were captured in sound.

The ability of the recordings to put the listener closer to the experience of the diary keeper was apparent. This was also noted by Dale (2010) who used audio diaries in her counselling research commented that audio diaries can make the 'strange' of living with a visual impairment familiar.

Stage 3: Audio diary transcription

The final six participants resulted in a somewhat mixed bag of data, detailed diaries, interviews, a biographical account and online audio blog of a holiday in South America. The deviation of the type of data illustrates the uncertainty of ethnographic methods and the requirement of the researcher to exercise flexibility and pragmatism.

To deal with the large amount of data (each days recording was approximately 20 minutes in length), the audio files were uploaded into the voice-to-text software program Dragon. It was anticipated that this would reduce the typing time. However, the software struggled to decipher the range of different voices across and within recordings. This was exacerbated when the sound quality was poor due to background noise. Whilst Dragon was able to convert some of the narrator's voice, a considerable amount of manual editing was required. Once transcribed further listening and manual editing was undertaken. Manual editing facilitated greater familiarity with the recordings and an appreciation of the subtle intonations and emphasis of words and sentences which themselves convey meaning. This would have gone unnoticed using text to speech software alone.

Stage 4: Audio diary analysis

The transcripts resulted in word files which were then uploaded into the qualitative analysis software QSR Nvivo. This enabled the coding of whole sections of text within and across transcripts. All paragraphs were coded into themes and sub-themes.

Stage 5: Narrative interview field work and transcription

It was only possible to conduct interviews with 3 participants to obtain storied accounts of how some of their ability to participate independently as evidenced in their week long diary keeping had developed over time. This was due to time constraints. Narrative interview were conducted with two participants – one over the telephone and one in person. Rather than asking participants to recount the story of their whole lives, the narrative interview was designed to obtain episodic stories, in other words, stories which were specific to the resilience processes identified in the diaries. Based on the diary data provided by participants the narrative interview schedule was guided by Wengraf's (2001) the BNIM interview procedure which is structured into the following three sub-sessions:

- Sub-session one - participants were asked a single question which is designed to initiate a story (SQUIN) around the topic under study. To initiate the participant's story of resilience each will be asked the following SQUIN: 'So many visually impaired people are, for one reason or other, unable to go out on their own. Using examples from your own life, can you tell me how you have been able to do this? Without interruption or prompting, notes were taken whilst listening attentively. This session one ended when the participant indicates that there is nothing more to add.

- Sub session two – this session allows the research some directionality by asking 'narrative pointed questions' in other words, questions designed to initiate more stories from the topics raised by participants but only in the order that they initially raised. Wengraf (2011) suggests that sub-session two should take place after a break to enable the interviewer to collect their thoughts and to consider the phrasing of the narrative pointed questions to be asked. Wengraf does however note that Fischer and Rosenthal (2004) advise against a break to maintain participant co-operation and trust of the interviewer.

- Sub-session three is an optional third session which may or may not be used to elicit further information arising from the preliminary analysis of sub-sessions 1 and 2 and as such, is required to be held on a separate day. The interviewer's questions need not be related to the topics discussed in previous sessions.

Stage 6: Biographical narrative

Stage 7: Analysis combining stage 1, 2 and 3 data using narrative analysis techniques

The biographical data provided by one participant was coded for evidence of resilience processes and was entered into QSR NVivo.

8.4 Study findings

This section describes findings from the activities undertaken during the participant's week of diary keeping. Rather than focus on the challenges which are well known from the literature review as well as studies one and two, this section describes the protective factors as and when they interact with potential risks. In other words, when challenges occur, they are discussed in relation to the strategies used to overcome them.

8.4.1 The positive outcomes: Social participation

In operational terms, a positive outcome is regarded as social participation. In study two this was defined as the independent travel of visually impaired people who engage in 'normal' expected activities in their communities. The participants in the study were indeed engaging independently in their communities, and beyond during their week of diary keeping. The more mundane activities described involved shopping for groceries and travelling to and from work. However, the diary entries also included a solo trip abroad, participation in regular sports activities and visiting friends out of town. Participants usually had a specific reason to leave their homes, for example attending a college course or meeting friends.

However, in Lisa's case there wasn't always a tangible reason to go out except the desire and determination to be part of the community and live a normal, ordinary life. Lisa described making a conscious effort to leave her home on a daily basis, reflecting that a failure to do so could result in a loss of confidence:

> *'I decided to go out. I didn't really need to go out today. I'm usually doing something on a Saturday, quite often tandem riding. It's not often at all nowadays that I've got nowhere to go and nothing to do on a Saturday. I spent most the day just catching up on housework. And I decided I would like to go out for a while. I always try to get out of the house every day because a) it makes me feel better and b) I don't want to get into a rut of not wanting to go out on my own. I don't think that would ever happen but I just make sure it doesn't.'*

Implicit in the Lisa's comment is that social participation takes confidence and that it would be very easy to slip into a life of isolation if opportunities to leave the home were not available. The reason for losing her confidence was not made explicit in Lisa's recording but recognising the potential for this to happen, she makes her own opportunities. There is also an indication that participating contributes to Lisa's sense of wellbeing as she says going out makes her '*feel good'*. Amanda regards getting out of the home as an adventure:

> *'It's always a bit I'm of a mission, an adventure to go out and do all these crossing roads and things.'*

Amanda does note however, that in the past as a cane user she lacked confident with getting around. It was only when she secured the support of a guide dog that she obtained freedom:

> *'So yeah, I was remembering when I was young and I didn't have the confidence to go with the cane cos the cane doesn't give you so much security. You're alone. Yeah, it tells you which obstacles are there, but if you really want to feel free and walk fast,*

> *for me, a guide dog is much better. I do know people who are really confident with it but I'm not and I remember when I used to use the cane I didn't feel confident at all. If I went out it was always with somebody.'*

Generally however, participants had a specified reason to get out and about. Participants would often state their reasons for going out, often starting the day's entry with the phrase *'Today is day x, and I'm getting ready to go to…'* Consistent with the format of storytelling which usually has a beginning, middle and an end, the research participants described in three distinct sections which can be defined as *'Getting there'*, *'Being there'* and *'Getting home'*. This structure was helpful in analysis terms since participants naturally provided detail on each of the three stages involved in their participatory activities. These three categories can also be used to illustrate the overall process involved in participation. In other words these three stages are usually undertaken after a positive outcome.

Figure 11: Stages of the social participation process

8.4.2 Getting there

Planning ahead

From listening to the recordings it was evident that few aspects of getting there were left to chance. The degree of planning would vary depending on the nature of the activity being undertaken. But at the very least participants gave themselves sufficient time to prevent having to rush. Denise describes her use of technology to set her mobile phone alarm.

> *Today, this is Friday 13th. I had to set my alarm on my phone. I use Siri to ask him to wake me up in the morning which he always does. I always allow plenty of time to get ready. I have to get my clothes all ready as you would if you were sighted, but I have to make sure that what I pick is will match. I don't want to go out looking like a clown, I take longer in the bathroom because I have make sure when I wash I am clean. I have to make sure I have washed all the soap off my body and all the shampoo from my hair. It takes me a longer time to do my hair because I can't see what I am doing. Having breakfast, getting ready, making sure I've got my handbag ready and then getting out of the house and navigating my way to the bus stop.*

From Denise's narrative it was evident that her self-presentation was important aspect of her self-identity and that she took time in the mornings to get this right. Amanda's narrative also indicates that her sense of self was associated with her sense of wellbeing:

> *'Its nice today – it's not cold, I'm wearing my purple jumper, my purple jeans and my purple boots and my purple earrings - I feel purple today.'*

With regards to planning, Tom had organised a trip abroad which meant arranging a taxi driver to transfer him to his hotel as well as a person to assist with filling out immigration forms. Tom's first recording begins at the airport in Costa Rica where he waits for his planning to come to fruition:

> *'First of all to get somebody to help me complete the immigration card. Obviously it's not going to be accessible in any way, so I'm hoping that whoever meets me is sufficiently literate to be able to help me do that. Secondly, when I'm in arrivals the challenge will be to find the driver. Now, I've mentioned to the hotel that I'm a visually impaired person, I therefore hope that the driver has the wit to look out for me but that may not happen.' (Tom)*

Tom continues to record as he waits for his driver although a short while after we hear him being greeted by Uri the driver:

> *'I'm now just arriving in arrivals actually, with Francisco and I'm hoping to meet somebody called Uri the driver. I've told him that I have a white cane so with any luck he'll find me.*
>
> *Tom: Uri?*
>
> *Uri: Hi yes*
>
> *Tom: Uri, mucho gracias, nice to meet you. Esto es Francisco. Tom yes. Excellent. Really nice to meet you, mucho gracia, mucho gracia. [Tom continues to converse in Spanish]*
>
> *[Tom] So there we go. Everything seems to have worked. A bit of a stress finding the rucksack but we got there in the end so FANTASTIC!'*

Carrie's business trip which meant travelling to another county involved organising travel assistance and colleagues to meet her at the alighting station. On the morning of her trip Carrie describes her nervousness about both traveling to an unfamiliar area and concerns about whether the rail staff will fulfil their promise to meet her at the connecting station.

> *'I have asked for assistance before and it hasn't always turned up, so I have my slight apprehensions about that, but hopefully it will be okay.'*

In Carrie's evening recording, she reflects on her day's travels and speaks with both relief and pleasure that all had gone as planned:

> *'…I think today went quite well. Luckily there was actually nothing really to be worried. The day in terms of travel went quite smoothly and also in terms of work as well. ..They took me down to the platform and radioed ahead to Paddington and luckily there was somebody there to meet me at the platform, they were there waiting when I got there. They took me to the passenger assistance room. Then once my train was actually in, because I got there quite early, I was worried about being late in case anything went wrong with the passenger assistance. When I should got the room they took me to my train and put me on and put me into the right seat and then they radioed ahead to Bristol to make sure that somebody was going to be there. The only slight worry that I had was when I actually got to Bristol they said that I should sit on the train and wait to somebody to come and collect me but after everyone had got off I was on there for a few minutes and nobody had come. Luckily Bristol was the end of the line so it wasn't going any further but I did start to wonder where the assistance was, so I managed to get myself off the train and I stood and waited on the platform and then there was a member of staff who I asked where the passenger assistance was and luckily just as I was asking the person will likely come along the platform so that was okay he then took me on to where everybody else was meeting at the main entrance to the train station and then we all just went into taxis to the venue…. [Going home] The only thing was, when I got to London Bridge because it was quite late at night I don't know that I don't usually travel to London Bridge at that time of day, when I got to the mainline train station I had to ask somebody on the ticket gate to let me know which platform my train was due on so that was fine and then I got home*

Implicit in Carries narrative of the day was that her positive outcome included good planning, service providers who mostly did what they promised to do, Carries own wit to get off the train when staff had not arrived and helpful others.

Familiar ground

Mostly however, the participant’s activities were centered in their local areas. Once outside of their homes, existing knowledge of routes to the intended destination or the local bus stop was called upon. There was a sense that this familiarity provided the confidence to propel participants forward. Participants could be heard travelling along at a steady pace, while describing upcoming turns and bumps in the road which signaled their exact location. Even though the participants travelled with confidence it was apparent that safety was always top of mind. Prior knowledge of the road layout and the position of pedestrian crossings were often described by participants who would name busy junctions and where danger hazards could potentiate.

> *‘I always use crossings to cross the road even if I have to walk out of my way. It’s not safe for me to just cross a road without the aid of a crossing or a sighted person with me*

The cones on pedestrian crossings were often lauded as a welcomed safety feature.

> *I’m sure you know about the cones on the pelican crossing for people who can’t see or hear very well or when pelicans don’t have an audio signal. I think they’re wonderful but these two pelicans that I’m about to cross do both have audio signals as well.*

Lisa comments that is actually the quieter roads in which she has to be careful:

> *‘It's the small roads and the driveways you have to watch out for cos you know to be careful on the main roads, and these little entrances, so few things come out of them, that when it does it surprises you. I did realise just before I got there so that was ok.’*

Tom, in new territory in South America and unable to rely on familiarity, Tom uses his existing sight and instinct to cross the busy Argentinian sprawling roads:

> *‘Ok, were gonna cross. Here we go. I think there’s one to go. The traffic has started so*

> *I will stop. Not long to go now. But this is a truly mad road in terms of size. As I say the one good thing about Argentina is that the traffic is generally quite well behaved. They do tend to stop when they are supposed to and they do avoid you if you're in the road. I once got caught in the middle of an extremely busy road near the river and the cars were just literally just whizzing around me. It was a little bit scary. But this shows what can happen when you make a major misjudgement. The cars are whizzing by. I'm hoping they're gonna stop soon. I've got two areas of road that I'm gonna cross. The cars are stopping now so I can go. I don't think any cars are going to turn in to here even though we're crossing on a junction. Nearly there - oh no, there's more. This is absolutely bonkers! I'd forgotten just how wide this road is. There you go, no wonder I couldn't see the other side. We're there now.'*

The participant's ability to take note of everything around them was evident. Having some residual sight was useful for those who have it. Lisa describes the lollipop shaped trees at the tail end of her journey which signaled that her alighting bus stop was next. However, having some sight wasn't always helpful particularly at night. More commonly, participants described what was going on by feeling changes under foot or changes in the atmosphere. Sounds and smells to identify what was happening around them were also navigational tools for getting around:

> *'Ok, I'm getting close to it [shop] now and what I generally do is get close to the wall and in Lidl there's a massive noise, I don't know if it comes from the ventilation or somewhere but when I hear that it means that I've arrived. [Amanda]*

Amanda also described her use of echo location, the use of sounds and reverberations to identify the objects to sense depth:

> *"I can feel the bus stop. I have got a bit of what you call echo location, where you can feel when things are near you, like a wall or a lamp post or a person. It's not vision, it's*

> *like a feeling thing."*

Denise also has a sense of when she is in a large open space. She describes the way in which she slowly navigates her way to the information desk. Denise's transcripts are characterised by the calm and considered approach to navigation without sight:

> *"Then I'm in the big hospital entrance atrium and its very echoey and noisy lots of footsteps, people talking, trolley's rapidly, babies crying. So I make my way very slowly over the other side of the atrium because I remember that there is an information desk there."*

The mobile phone was used as part of the planning of journeys. A mobile phone bus app was used by at least three of the participants to alert them of the arrival of buses. Once at the bus stop the app was used to establish the order in which the desired bus would arrive. This reduced the risk of getting on to the wrong bus.

Familiarity with the local area meant that participants tended to visit the same shops. It was clear that they knew the location of the local shops and services, and often the staff who worked there. Consequently, the staff were aware of the participant's and their needs. Carrie was a familiar face at her local train station which she used to travel to work. Being known to station staff resulted in special privileges such as having the barrier opened for her or allowing her travel before her free travel pass was permitted. It also meant that staff alerted her of platform changes which could otherwise confusion.

> *'The staff know me there as well so when I go to the ticket office to buy my ticket, they'll usually call to me to let me know that there's a window free so that if I can't see when there is a window free, I know when to go there. And I don't need to show my disabled Person's Railcard because they know me so well. So having a good relationship with the members of staff, this is quite helpful.'*

8.4.3 Being there

Asking for help

As noted earlier, being there involved a wide range of environments and contexts. Once there, participants would sometimes turn off their recordings depending on the purpose of the trip and mainly because it was not possible to continue recording. One of Carries recorded events involved a restaurant visit and trip to a comedy show with a group of friends. Once back at home Carrie describes the challenge of not being able to read the menu unless she took out her cumbersome reader. Since she was with friends Carrie asked them to read the food listed on her behalf. Toms numerous holiday recordings involved sight-seeing and visiting a karaoke club. There was no sense that Tom met any major challenges other than ensuring he crossed the busy roads safely. Amanda however, describes how she used her visit to the job centre to ask her employment officer to read letters which had arrived earlier that day:

> *'So the girl in the job centre said 'you can't afford to have any secrets can you?', and I guess to other people it would make them feel bad 'oh my privacy' but I'm very much an open person so I really don't mind. I guess I could have asked my dad whose coming tonight or my friends to do this, but I'm impatient and I don't mind, it's no big deal.'*

There was a sense that openness about having a visual impairment made life easier for participants as opposed to being embarrassed to ask for help.

Having company on shopping trips increases enjoyment for people regardless of whether they have sight. However, Carrie described the challenges which could make this experience less than enjoyable. Finding the till points in the first instance and then knowing when to approach any one of a number of till assistants was noted to be problematic. However, Carrie had the support of a companion on her days recording which took away some of the anxiety she described experiencing. Denise on the other hand did not have a friend on the days she recorded her shopping trips. To select an item of clothing for herself Denise used touch and feel to assess the quality of the materials used. She also ensured that the returns policy of the shop enabled her to return items, since her intention was to try them on at home and ask her husband or friends to comment on their suitability.

> *"I usually if I shop, I have to take things home to show a friend or show my husband and they double check whether it does suit me or not because it's very hard to choose clothes for yourself when you can't see in the mirror. I also get a feel for clothes. A lot of clothes I choose now I think I choose because of how they feel the fabrics and how they feel when I got them on, so that's my first thing now rather than 'wow that looks nice' its wow that feels nice' but of course it might not look a good on."*

Lisa had also commented that when buying clothes it was preferable to have someone with her.

> *'Would like to have company for clothes shopping if can't find something.'*

Denise also described buying a gift for a family member. Having already decided what she wanted to buy (some toiletries) Denise navigated her way into a store which she was familiar with. Once in store she navigated her way to the area she knew these items were usually displayed. Denise recounted knocking over a few displayed items but *calmly* navigated her way to the tills after making her selection. On reaching the till point Denise asked the shop assistant to confirm that she had indeed picked up the correct items. She noted that she would *take her time* and to put away her receipt and payment card and purse safely into her bag

When shopping for food, participants tended to shop in the same local stores for a number of reasons. Not only were staff familiar, but participants knew the shop layout and therefore where items are located. Amanda's strategy for conducting her main food shopping visit was to, once in the store wait for a member of staff to approach her. Amanda can be heard saying 'I wonder if they see me?' as she waits. As predicted, within seconds a member of staff asks if she needs any help. The two can be heard discussing Amanda's requirements and the section of the recording is paused as the assistant accompanies Amanda around the store to locate her items:

> *Amanda: 'And what I do is I stand near the tills and generally the security guy who's really nice comes and asks me if I need help. And then I go and do my shopping with him. He knows already what kind of stuff I like so that's what I'm gonna do now. Can you hear the ventilation that means were at Lidl's? Smells nice in here. Let's see if they see me.'*
> *(Silence)*
> *Amanda: 'It kinda take a while.'*
> *(Silence as waiting)*
> *Amanda: Cos they are busy with people*
> *Shop assistant: 'Can I help you?'*
> *Amanda: Yeah, I just need some help with the shopping, can you help me*
> *Shop assistant: Yes, course I can. So what are we doing today?*
> *Amanda: I just need some milk and eggs and bread from the bakery, a nice one*
> *Shop assistant: What kind of bread do you want?*
> *Amanda: You know the multigrain, the seedy one. …*

Positive outlook when things go wrong

Thankfully, the diaries didn't provide many extreme examples of adversities or challenges although Lisa did record her brush with a lamp post. Whilst this could have been much worse, the absence of major setbacks could be because participants were seemingly so competent or simply that the likes of the challenges that occur are modest annoyances such as refuse bins left on pavements or parked cars protruding onto pavements:

> *'The other day I had my blind friend was with me and he was using his cane and I was with Tamara but he was holding on to me so I kept bumping him into all of the bins. It's terrible how people just leave them in the middle of the way but its ok.' [Amanda]*

> *'Just walked into a lamp post. It catches me out sometimes. It does jut out rather, on my left. It did give me a black eye once, when I first didn't have a guide dog, but it's never happened again. It literally did just brush my arm. So no injuries at all. I do have to remember to be careful and remember where that one is.'*

In one of Lisa's recordings she describes asking a person she knew to walk with her to the bus stop. Lisa reflected that the person walked too slowly, presumably for Lisa's benefit. Lisa also suspected that the person did not actually want to walk with her. However, Lisa later reflects that she was grateful for her guide's assistance irrespectively. Having a positive outlook on life and individual events seemed to help participants when things didn't always go to plan or when people didn't always behave as they should. Rather than dwelling or ruminating on events, participants often completed their narrative of an annoying incident with a positive comment, as if to end on a positive note:

> *'Luckily a very helpful passenger who was also waiting caught hold of my arm and said this is the bus you want and because he obviously hadn't had training in guiding a visually impaired person, he grabbed my arm and pulled me along. I don't get offended by this because the man is being very helpful and I am grateful but I don't think it looks very dignified. Anyway, never mind.' [Denise]*

Coming to terms with sight loss

Certain personality attributes were evident amongst participants such as not being embarrassed to ask for help, being polite and courteous when doing so and very often doing this with humor. The participants in the study were all likeable individuals and seemed fun to be around. Tom on his holiday can be heard initiating conversations with strangers he meets along the way and asking them for their stories. There is a sense from listening to the recordings that participants have a joy of life which comes from being at ease with who they are. This is exemplified by Brian's comment after describing his life before and after the onset of his visual impairment:

> *'So that's all of the best years of my life & if I am honest I don't know what I have done to deserve a life as good as I have had for the last 53 years & long may it continue.'*

There was also a sense that participants had full social lives and strong friendships which they themselves had cultivated over the years. These friendships were important in the sense that they provided opportunities to participate with friends. It is impossible to say whether all of those involved in the study had completely adjusted to their loss of sight but there was a sense that they were all getting on with the business of living regardless. However, the attitude of two of the participant's was that their visual impairment had enriched their lives. For Brian having a family meant that his sight loss took a back seat to being a devoted dad and husband. Amanda noted that before she had counselling she worried about people in her local community viewing her as the *'blind girl'*. Now she is happy to be known as the blind girl and feels this adds something special to her personality and makes her different to everyone else:

> *"So sometimes I think my blindness is like this… it's something that makes me different and makes me special it's got good sides and back sides. Cos it does have really good sides, like now I just went to the shop and the guy in the Woolworths said 'you know Amanda, everyone here knows you'. For some people that might mean 'oh they know me because I'm blind, they know me because I'm different, they know me because I'm a burden, and I think 'ah that's great', everyone knows me because I'm special, because I'm different."*

Both Amanda and Tom reflected on the perceptions of people toward people with impairments and how this reflected on their own identities:

> *'… I was telling you about this time when we got in the bus and there was this woman coming with a wheel chair and there was no space for both of us. And at moments like this is when I am more aware that I am a disabled person that people look at me and you know, classify me as a disabled person because there were two of us and I felt 'wow', we have this in common that we need special requirements, we need special space and I had a mixture of feelings. Like on one side, I felt bad because you know, I need something special and I'm categorised as disabled, which I don't see myself as really a disabled person cos I can do loads of things, but then again in the eyes of people who know me I'm always going to be a disabled person.' [Amanda]*

> *'… three experiences today have highlighted the Argentinian attitude towards disabled/ visual impairment people and it's all a bit embarrassing but all kind of to my advantage. First of all I went in a bank to withdraw some money and was taken straight to the front of the queue. Then I found the tour bus and again there was an enormous queue and some employee just put me straight on the bus and then thirdly just going into the Boca juniors ground I was allowed to go in free of charge. It would be interesting to know what the sort of wider implications of these are for disabled people, visually impaired people in Buenos Aires and one occasionally runs into a wheelchair user. I saw a person in a wheelchair today and the odd visually impaired person here but not enough to draw any generalised conclusion. [Tom]*

For Brian, the suggestion that he may have been a candidate for pioneering treatment that could improve his sight result in a major setback when it was discovered that he not in fact suitable:

> *'Mr [names consultant], he gave my eye's a very good examination then he told me I might fit the criteria for a course of stem cell treatment however he told me not to build my hopes up, He made me an appointment to go to see the generics team at the [name of hospital] on the 20th of December 2012. When I look back to March I wish I had never even went to the eye infirmary. The last 10 months have been upside down.*

8.4.4 Getting home

Getting home from involved a reversal of the earlier getting there although friends and acquaintances who were already there would often walk with participants or provide car journeys home. There was a sense that having successfully achieved their intended outcome provided a great sense of satisfaction and achievement.

Lisa described how often after returning home after experiencing a challenge she felt could have been avoided, she would complain to the those who had the authority to improve matters. These included bus drivers who did not stop despite observing her at the bus stop with her cane or local authority to report over hanging branches in front gardens.

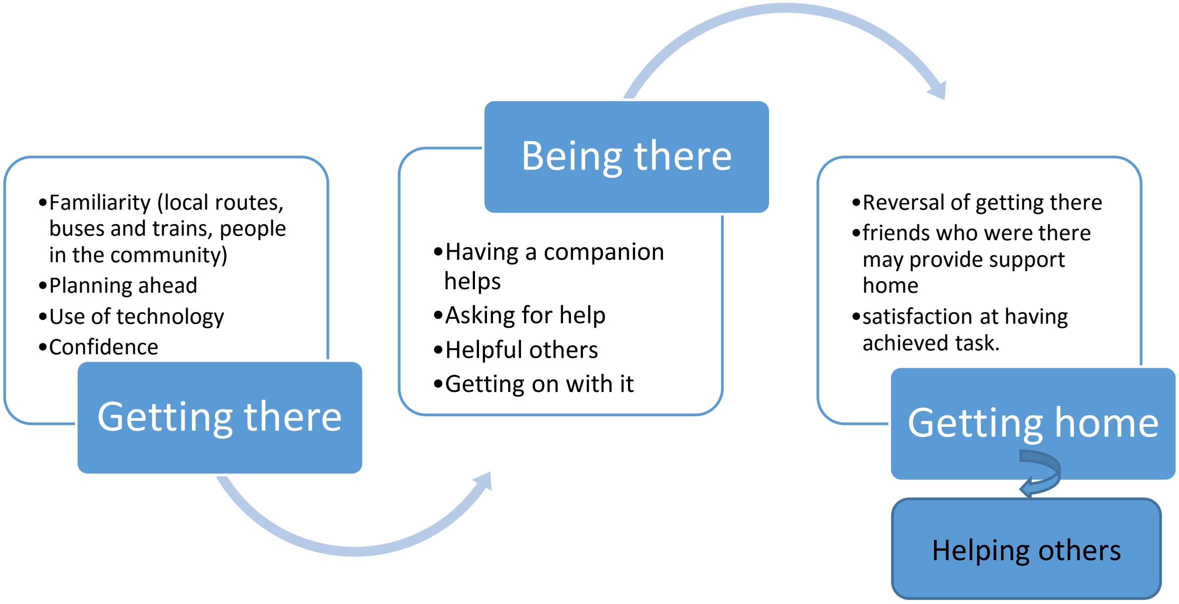
Helping others

Coming to terms with their own condition appeared to the desire to assist others with sight loss so that they can share the skills and experiences that they had acquired and had helped them. Brian described introducing other visually impaired people with IT as did Amanda. In many ways Lisa's complaining to services can be also considered as a way of helping other visually impaired people.

8.5 Discussion

Familiarity was a key feature in the narratives of participants. Familiarity with their local area and its services meant that participants were able to move around their communities with considerable confidence. Of course being familiar with an area must be built over time and at some point the familiar was unfamiliar to those included in the study. Confidence seems to have developed with successive independent trips out of the home. However, being known to local shop staff meant that once there, assistance with identifying and selecting items was likely to be available. Getting there was a matter of safety. Being familiar with dangerous crossings enabled participants to get to their destinations with relative safety. Once there, participants were happy to accept help although there was a sense that they did not rely on it. Planning in advance also meant that assistance was available at the intersections of getting there, being there and getting home. There is also a sense that over time, the confidence which enabled participants to independently take part in their communities led to the desire to help others with a visual impairment, thus extending the type of social participation according to Levasseur’s taxonomy of social participation.

Figure 12: Resilience process involved in social participation



8.6 Conclusion

The aim of the study was to identify the resilience processes underlying the social participation of visually impaired people in the UK. The study found that three distinct phases of participation getting there, being there and getting there which are underscored by safety concerns.

The narrative method utilised in this study was ideally suited to exploring resilience. The narrative data provided access to the unique experiences of visually impaired people while facilitating the identification of emerging themes across cases.

The following chapter concludes the thesis by reviewing the findings of the three studies included in this thesis, assessing the merits of the three studies and their ability to elucidate the pathways leading to resilience. The conclusion also makes recommendations for future research.

CHAPTER 9: Thesis Conclusion

This thesis has been concerned with understanding the factors enabling some visually impaired people to participate in their communities in spite of encountering many obstacles. The review of the literature has indicated that the theory of resilience evolved around similar concerns. In other words, understanding the factors enabling individuals who are considered to be ‘at risk’ which enables them to have positive outcomes. The literature revealed that it is not discrete factors which result in resilience, but the interaction of risk and protective factors which underlie a positive outcome. It is the combination of these elements which is regarded as defining resilience.

The three studies contained within this thesis therefore were conducted with the ambition of understanding these elements of resilience within the context of visual impairment. The stages of the empirical studies being to establish risk, identify risk and protective factors and the interactive processes thereof. This final short chapter will reflect on the extent to which the studies have been able to address my inquiry aims and the utility of the findings.

9.1 Study One

Study One can be considered in risk assessment terms. It was conducted to identify the individuals most vulnerable to a lack of social participation. The study used the perceptions of visually impaired people’s access to social support as an indicator of a lack of social participation. The premise being that those lacking social support were less likely to have access to a resource which promotes social participation. Although the literature indicates that isolation is a problem for visually impaired people it cannot be assumed that all people are at risk by virtue of having the condition. An exploration of characteristics which increase risk would provide a more nuanced look at the population.

Registered visually impaired people were indeed found to be more vulnerable to the risk of social isolation by virtue of lower levels of social support. This was lower than the general public and people with other types of impairment or long term illness. However, as suspected, risk was not equal and there were differences within the visually impaired population. When unregistered people reported a lack of social support, they were more likely to be ‘severely lacking’. Translated into the language of ‘participation’, this group is articulating that they have a lack of people in their lives who can provide advice, encourage information to promote social participation. It would not be hard to fathom how participation might be compromised in such circumstances. Of the registered population, perhaps unsurprisingly, people who were living alone and those with the additional disabilities and divorced were most likely to report a lack of such support.

The Study One results indicate that there is also need amongst visually impaired people who are in the unregistered population; in part, and as discussed in the review, some people slip through the proverbial service support net since according the legal criteria of visual impairment they are ‘not quite visually impaired enough’. What is more, even people who are registered and require support are likely to experience long waits to be seen and reduced local resources limit the ability of rehabilitation officers to offer such support.

The findings of Study One also provided early evidence that there is merit in exploring participation amongst visually impaired people, an understanding of which can be used to help others develop their social networks given its links to wellbeing and participation. However, as Schoon (2006) notes, statistical risk is not the same as actual risk. Of interest were the visually impaired respondents in the analysis who were statistically located in the most vulnerable groups but reported no lack of social support. The perennial resilience question arose; what resources do these individuals have that their peers with the same statistical risk do not? The separation of person’s responses from their real world experiences means that study one was never going to achieve this but did show the importance of context.

9.2 Study Two

Having established that some visually impaired people are particularly at risk, Study 2 was concerned with two things: to shed more light on the construct of social participation, and understand a broader range of risk and protective factors. With regards to social participation, the review had suggested that the term lacked agreement on its conceptualisation even though it was understood to be an important aspect of healthy functioning. There was also concern in the resilience literature that healthy functioning which is conceptualised as social participation in this thesis, is defined by cultural and historical norms. It cannot be assumed that all groups will have the same expectations or desires of it. Since healthy functioning was effectively conceptualised as social participation, there was a need to explore this within the context of visual impairment. Social participation was considered as taking part in activities taking place outside of the home setting. This is a narrower conceptualisation of social participation which refers to the construct as involvement in life situations. The latter conceptualisation had been criticised since defining what should and should not be included in the remit of life situations is endless. As Dijkers (2010) notes '…being born and dying, and everything we do in between, involve being in a life situation'. The finding in study two substantiates the work which suggests that a narrowing was warranted and that not only does social participation have an interactive element but must take place outside of the participant's home.

What might visually impaired people be doing while participating? The Delphi experts suggest that they are pretty much doing what the expected norms would be for sighted people of their peer groups. Of course this does not quite address the impact of cultural nuances such as those relating to ethnicity, gender or class, and does tend to reflect the dominant view of what is defined as normal. For the experts however, social participation was the default position rather than anything over what was expected of the sighted population. In terms of identifying someone as well they would be independently travelling, mixing with both sighted and visually impaired friends, and fun to be with. So in the one hand, Study One had identified those who require intervention by way of support and encouragement from others. On the other hand, the social participation aspect identified in Study Two, described the type of person who has social participation sorted. Of course the resilience literature does caution that a person doing well in one aspect of their lives may be struggling to overcome adversities in another, and the review was a constant reminder of the dangers of polarising any kind of social debate involving human behaviour. However, the description does indicate the baseline expected level of participation which is no different to those of any other member of the population.

The second aspect of Study Two also aimed to identify the risk and protective factors. A wide range of factors were presented as involved in social participation, and many validate the factors also found in existing resilience literature. The presence of social support was one such feature vindicating its use in Study One. Other vision related protective factors were identified. The study also concurred with other studies of resilience which found that a single factor can operate as both a risk and protective factor depending on the context. Ethnicity was one such factor identified by experts as both facilitating social participation in some families and be a present a risk in others.

However the *raison d'etre* of this second aim of Study Two was to identify factors specific to living with a visual impairment. This facilitated the surprise emergence of the processes 'acceptance of sight loss'. A process in its own right because acceptance of the condition has been found to take time, years even to acquire. It was the iterative second round of the Delphi study which encouraged experts to provide contextually specific examples. This facilitated the introduction of context which was absent in top down, generalisable survey used in the risk assessment of study one. However, experts can only write so much within the boundaries of the questionnaire format before inevitably running out of steam. It was clear that the construct of resilience is so complex and multi-factored that it could not be contained within any method with strict parameters. Even large longitudinal studies which applied statistics could not account for this complexity; some have argued that that this makes resilience un-researchable. However, other qualitative investigators have reported good results with identifying what they call 'hidden processes' using innovative methods. So-called hidden because they are masked by traditional positivist methods which seek to recreate resilience in questionnaires or interviews rather than investigate it in the settings within which it naturally occurs.

9.3 Study Three

This understanding lead to the use of narrative inquiry methods in Study Three; the aim of which was to identify the processes involved in social participation amongst visually impaired people in a more direct and naturalistic way. The method selected involved visually impaired participants collecting their own data by keeping of an audio diary of their participatory activities. The method meant that the data was controlled by participants and took place during, just before or after the events took place. Importantly, the narratives of the participants conveyed the *meaning* participants attached to their experiences.

Although relatively small scale, the findings of Study Three suggest that achieving social participation can be thought of as involving three distinct stages: ‘Getting there’, ‘Being there’ and ‘Getting home’. ‘Getting there’ was characterised by the process of (physical and social) wayfinding in the safest manner possible. Participants described their familiarity with local routes and roads and knew where to roads where potential hazards existed. The process of planning was also important particularly when routes were unfamiliar. This might involve organising travel assistance to ensure support was available. This included underlying processes such as the planning process and the familiarisation processes.

‘Being there’ involved familiarity with surroundings and not being embarrassed to ask for help when needed such as with food shopping. This stage was in main characterised by getting on with the intended outcome, in other words the default position. Asking for help tended to occur at the intersection or point at which participants had encountered a barrier to moving forward. Once this gap had been bridged by the assistance of a helpful other, participants were able to continue as normal. For example, one participant described asking a friend to read out the food items on a restaurant menu. This brief moment of assistance enabled the participant to make their food choices and continue their conversations while their meal was prepared. This perhaps marks the difference between dependence and independence since the recordings suggested that participants asked for help when necessary, although there was never a sense that this was relied upon.

‘Getting home’ was very much a reversal of ‘Getting there’. Participants often used the same familiarisation and wayfinding techniques to get home safely. On occasions however, friends and acquaintances who were present at the participatory event would provide companionship along the way home or provide car journeys home. On arriving home, participants would often describe the relief, but also a sense of achievement which had the effect of reinforcing continued social participation and the desire to help others.

One issue stood out during the recordings – the apparent absence of ‘significant’ challenge or adversity. Regarding the apparent absence of adversity, the premise of resilience is that it is only present in relation to risk. This prompts some theoretical questions relating to the participant’s recordings. Was resilience in operation but that the strategies employed diverted the impact of risk? Was resilience simply not required in the instances the recordings took place. It is likely that the former is the case. There was evidence of the challenges in the recordings, the sounds of heavy traffic in the background. However, it was the manner in which participants had skilfully navigated their way to avoid them which characterises resilience. It may be that personal traits are important in as much as these factors enable individuals to reach out to access available resources in the first instance.

Given restriction in time available for this study, the intention was to explore some of these conceptual issues by linking discussion with the participant’s self-collected data and narrative interviews. However, the study does kick-start discussion of resilience in this field.

9.4 Key thesis conclusions

Resilience amongst visually impaired people as they participate in their communities can best be described by the term ‘ordinary magic’ (Masten, 2014). In other words, resilience occurs in the very normal, everyday activities involved in getting there, being there and getting home (physically and metaphorically). Resilience processes underlying participatory activities can go unnoticed simply because individuals are adept at both accessing external resources and navigating their way through risk. Understanding these processes requires research methodologies which harness the complex and context-specific nature of resilience in the environment in which it occurs.

9.5 Significance and relevance of the research

9.5.1 For research and theory

The thesis has significance in research terms because of its contribution to resilience theory. To the author's knowledge, only one other study has attempted to apply resilience theory, including the understanding of resilience processes, to the experiences of visually impaired people in the UK (the recent work by Thetford et al, 2015). Inversely, the application of key resilience concepts and language provides the opportunity to test the validity of existing theory on resilience and asks how well it stands up. For example, the identification of protective factors in Study Two, show considerable consistency with those identified in other populations. Further the use of audio diary methods, seldom used in research studies with visually impaired people, democratises the ways in which research knowledge is obtained.

9.5.2 For practice

Study One results show that it should not be assumed all visually impaired people are 'at risk' of isolation but that some life situations can make some individuals more vulnerable. As such, the study facilitates the identification of individuals who may be considered vulnerable and may require additional support. Similarly, people with visual impairments have skills and strengths which can be used to teach others

9.6 Limitations and Recommendations for future research

Time has been a challenge for completion of the project and given additional time the links between existing resilience theory and narrative data collected in Study Three would be used to further understandings of the phenomenon within the context of visual impairment. Following this, future work might usefully develop these methods and lines of enquiry further. Of central importance is understanding how resilient people become resilient. For example, participants in Study Three demonstrated considerable confidence and competence with getting around - an understanding how resilience develops over time is highly recommended.

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Appendix A: Delphi Round 1 Questionnaire

Identifying indicators of social participation, challenges and enablers.

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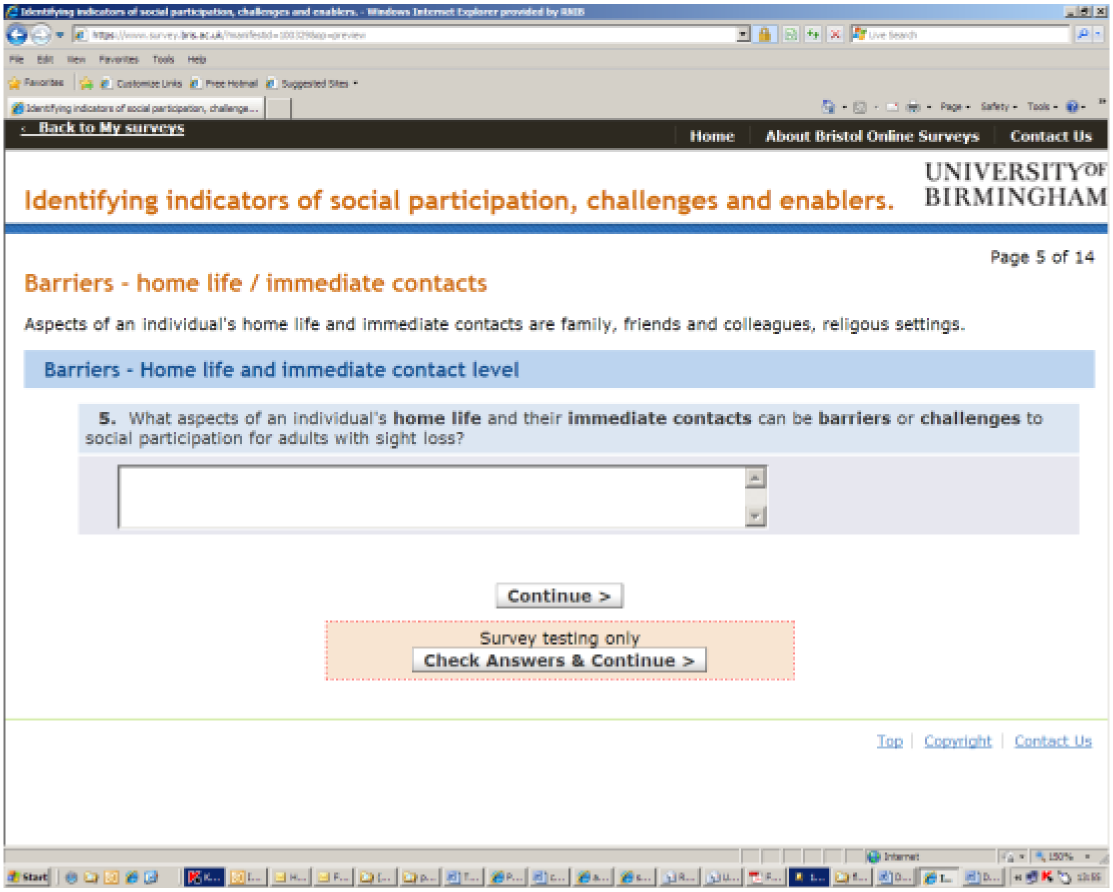
Barriers to Social participation

The following questions are designed to obtain your views on the barriers and challenges to social participation encountered by adults with sight loss. These barriers and challenges may be found in different areas of a person's life ranging from the individual level to barriers and challenges in wider society.

Barriers - Individual / personal level

Examples of individual level characteristics include age, gender, personality....

4. In your opinion what particular characteristics of the **individual** can be **barriers** or **challenges** to social participation for adults with sight loss?



Identifying indicators of social participation, challenges and enablers.

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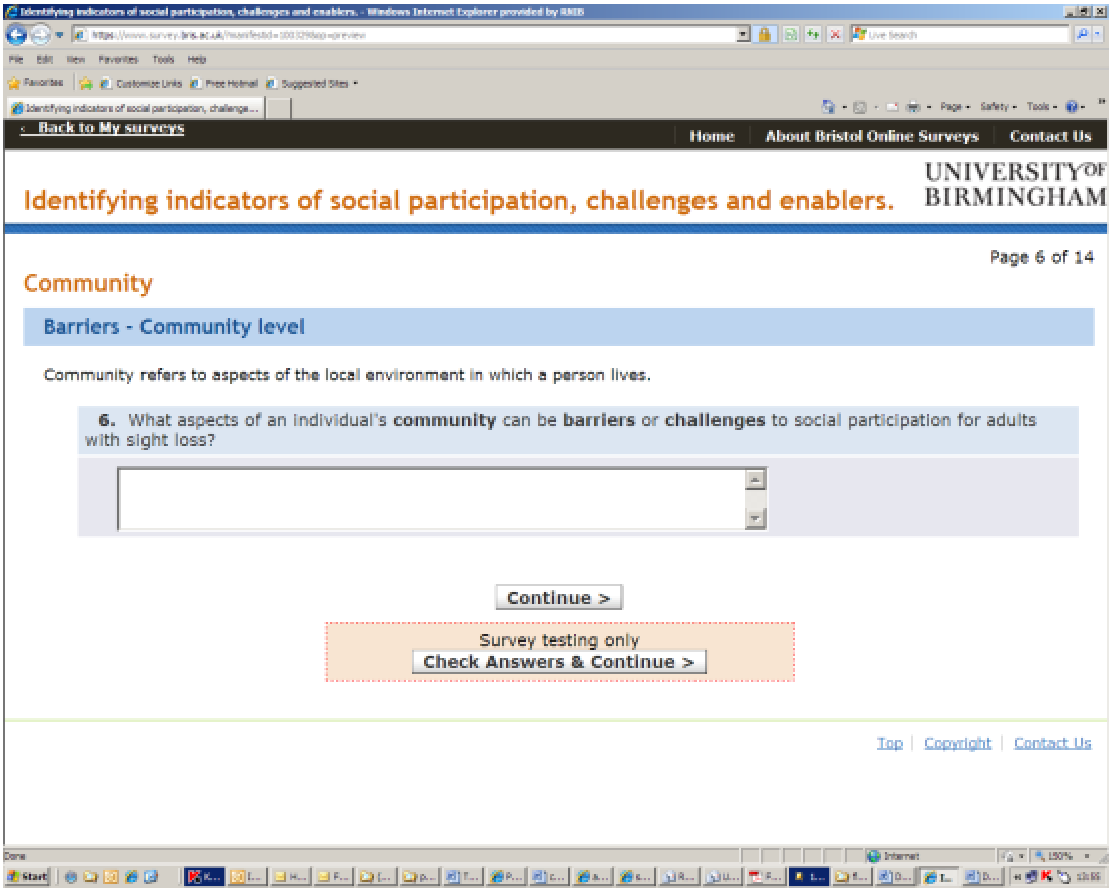
Barriers - home life / immediate contacts

Aspects of an individual's home life and immediate contacts are family, friends and colleagues, religous settings.

Barriers - Home life and immediate contact level

5. What aspects of an individual's **home life** and their **immediate contacts** can be **barriers** or **challenges** to social participation for adults with sight loss?



Identifying indicators of social participation, challenges and enablers.

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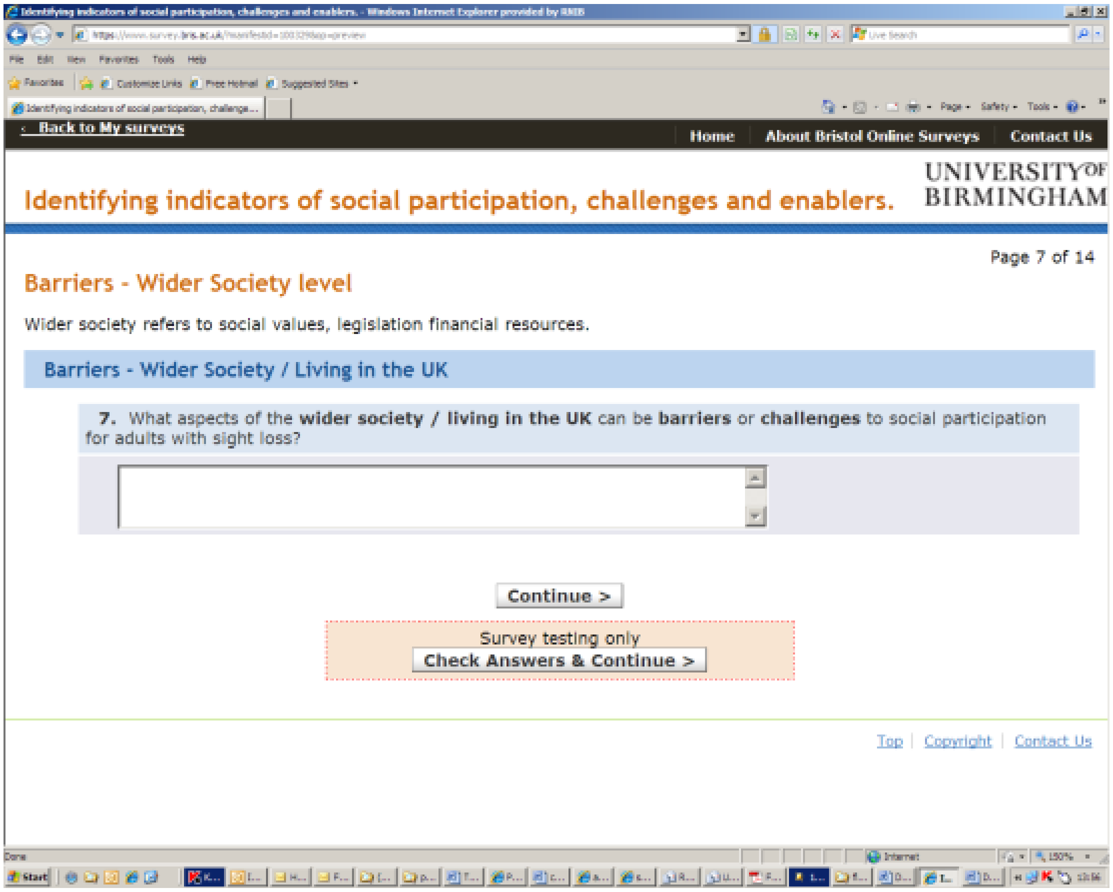
Community

Barriers - Community level

Community refers to aspects of the local environment in which a person lives.

6. What aspects of an individual's **community** can be **barriers** or **challenges** to social participation for adults with sight loss?



Identifying indicators of social participation, challenges and enablers.

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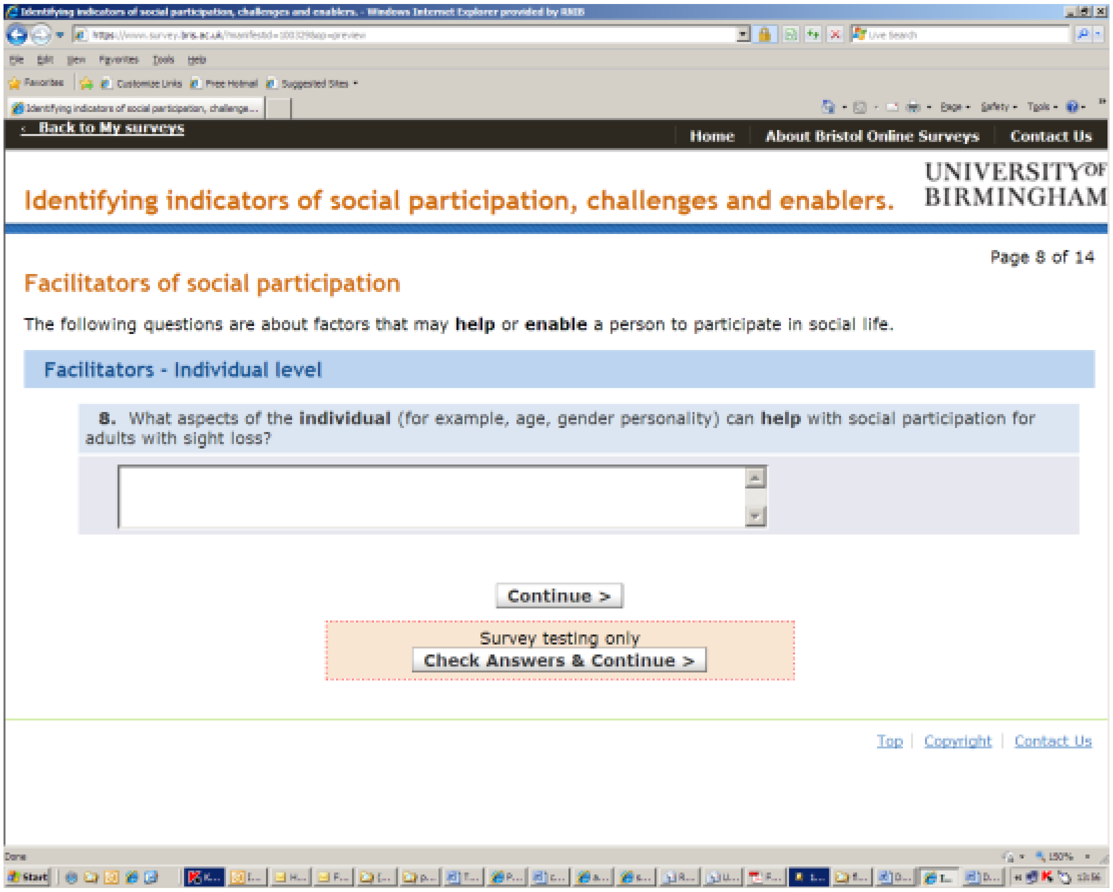
Barriers - Wider Society level

Wider society refers to social values, legislation financial resources.

Barriers - Wider Society / Living in the UK

7. What aspects of the **wider society / living in the UK** can be **barriers** or **challenges** to social participation for adults with sight loss?

Survey testing only



Identifying indicators of social participation, challenges and enablers.

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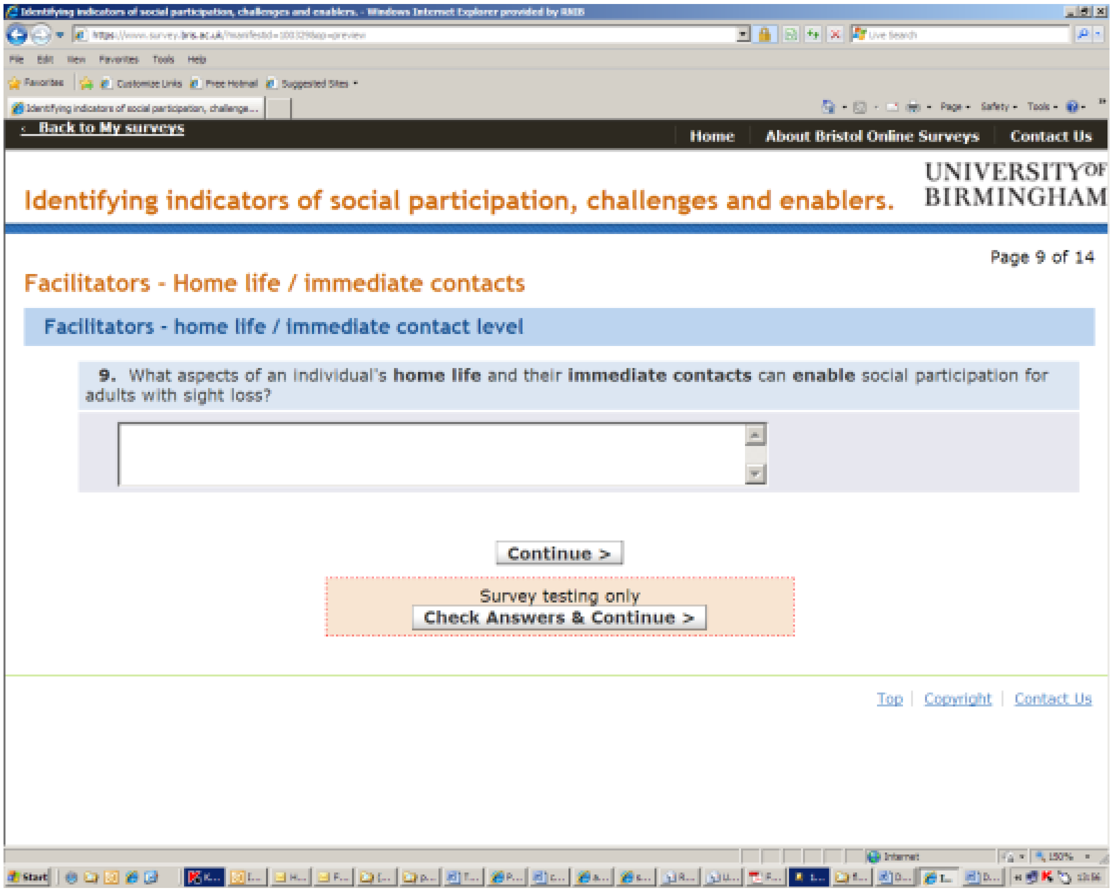
Facilitators of social participation

The following questions are about factors that may **help** or **enable** a person to participate in social life.

Facilitators - Individual level

8. What aspects of the **individual** (for example, age, gender personality) can **help** with social participation for adults with sight loss?



Identifying indicators of social participation, challenges and enablers.

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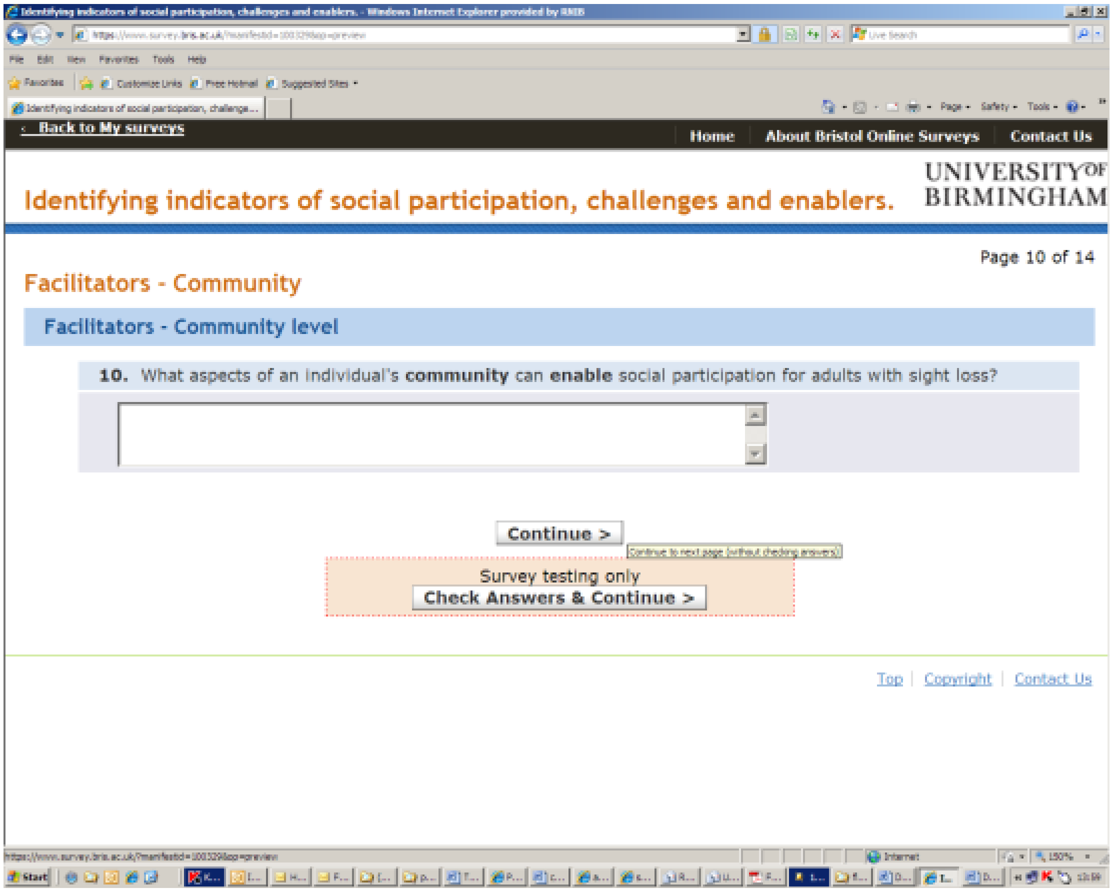
Facilitators - Home life / immediate contacts

Facilitators - home life / immediate contact level

9. What aspects of an individual's **home life** and their **immediate contacts** can **enable** social participation for adults with sight loss?



Identifying indicators of social participation, challenges and enablers.

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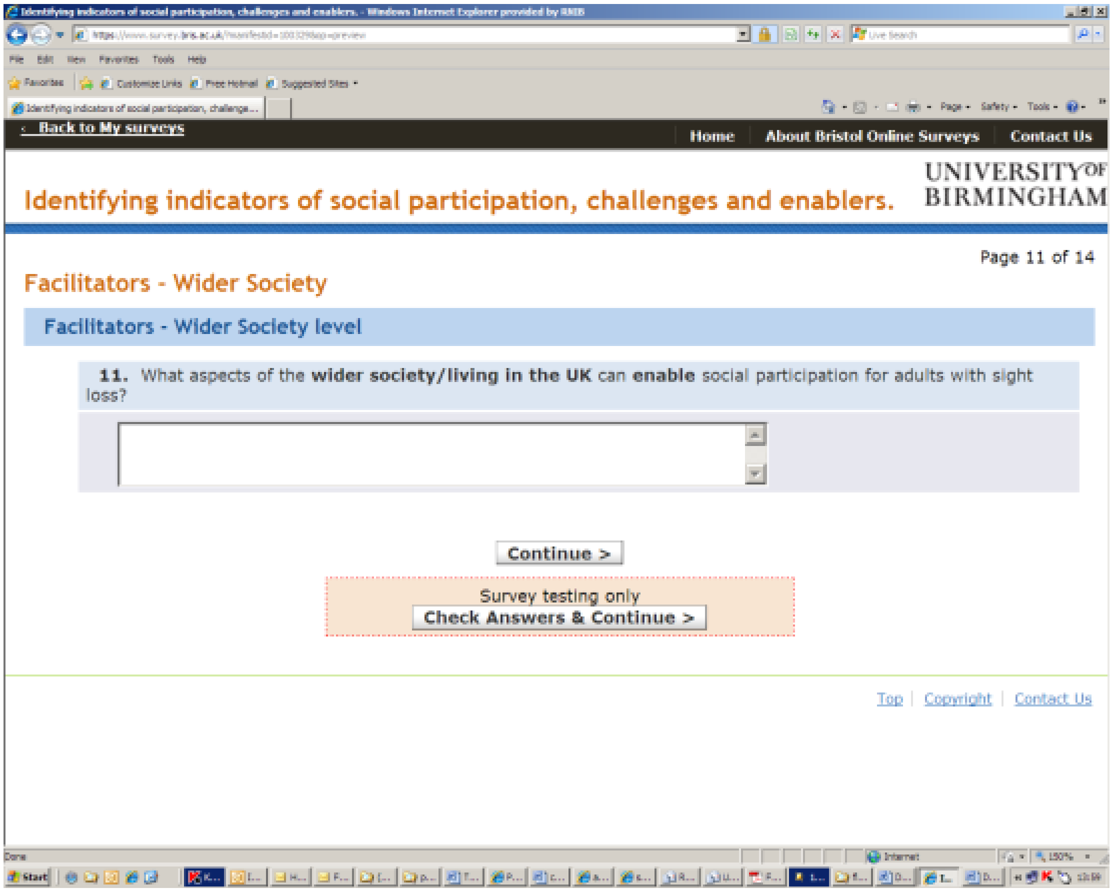
Facilitators - Community

Facilitators - Community level

10. What aspects of an individual's **community** can **enable** social participation for adults with sight loss?

Survey testing only



Identifying indicators of social participation, challenges and enablers.

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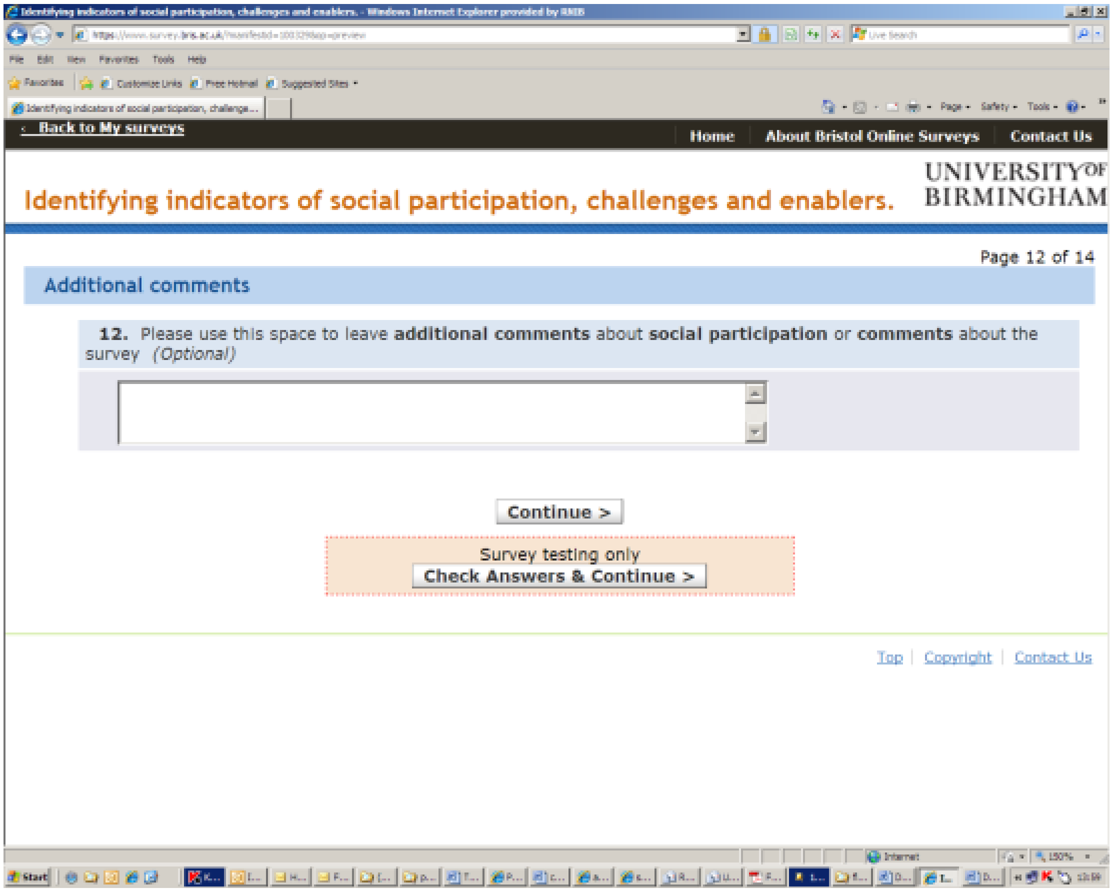
Facilitators - Wider Society

Facilitators - Wider Society level

11. What aspects of the **wider society/living in the UK** can **enable** social participation for adults with sight loss?



Identifying indicators of social participation, challenges and enablers.

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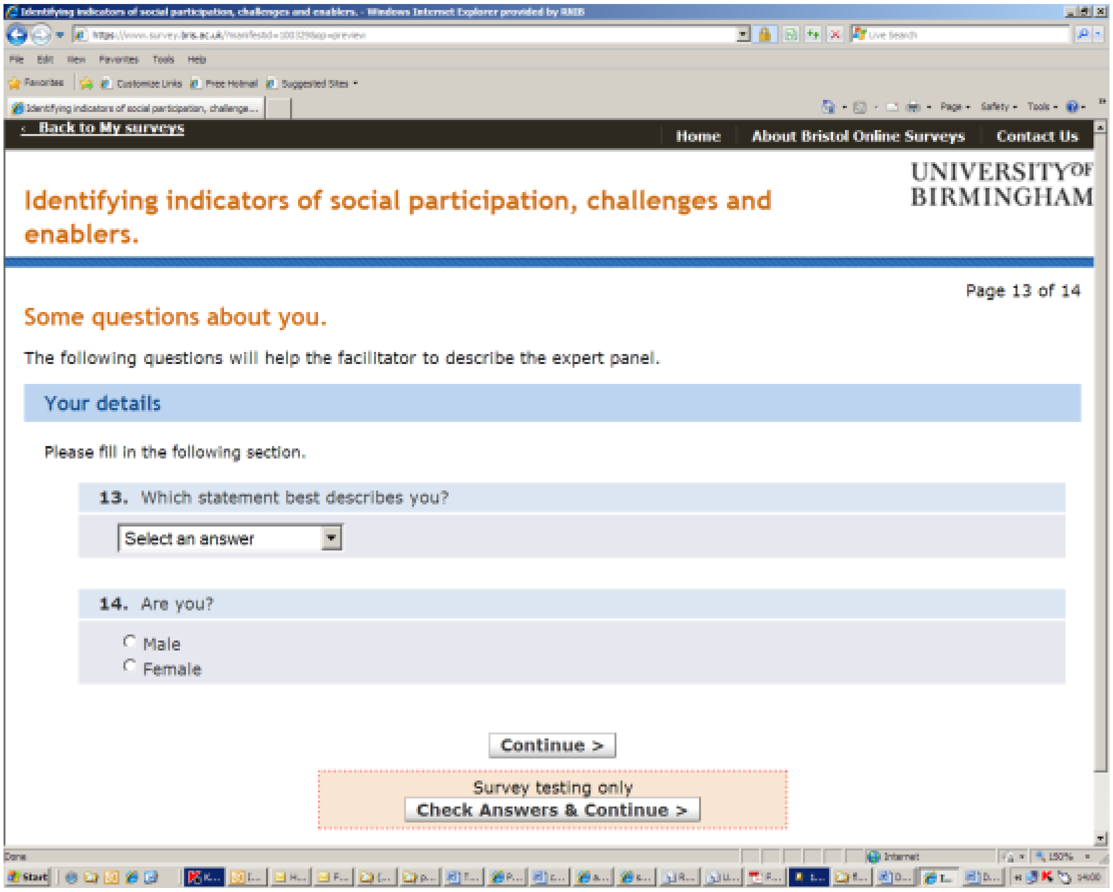
Additional comments

12. Please use this space to leave **additional comments** about **social participation** or **comments** about the survey *(Optional)*



Identifying indicators of social participation, challenges and enablers.

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Some questions about you.

The following questions will help the facilitator to describe the expert panel.

Your details

Please fill in the following section.

13. Which statement best describes you?

Select an answer ▾

14. Are you?

○ Male
○ Female

Identifying indicators of social participation, challenges and enablers.

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Thank you for completing this questionnaire.

You will recieve feedback and Questionnaire 2 within 2 weeks

Appendix B: Getting out and about – Introductory email

Dear [name of participant],
Thank you for expressing an interest in taking part in the research study called 'Getting out and about with sight loss'. For a week long period you will be required to record details of activities that involved you leaving your home. After completing your diary you will be asked to take part in a telephone interview where you will be asked to talk about how you developed the skills to overcome these obstacles over time.

The study is particularly interested in the following:

1. The things that get in the way of you getting outside of the home and meeting other people outside of the home. You will be asked to describe your thoughts and feelings and experiences in the run up to attending the event, your journey there, being there and getting home
2. The things that help you to overcome these challenges.
3. How you learnt developed the strategies to overcome those challenges over time.

To answer any questions you may have I have prepared an information sheet. I have also attached a consent form which you will need to complete and return to me before you start recording.

If you have any more questions please do not hesitate to contact me by telephone on 07795113383 or by email

Appendix C: Information sheet

Q. What is the purpose of the research?

A. The aim of the research to understand the ways in which living with sight loss impacts on your ability to socialise outside of the home and how you overcome potential challenges. The ultimate aim of the research is to share information on the things that have worked for you with other people with sight loss. The information we learn from you will also be helpful to families, carers and professionals to improve their understanding of the things people with sight loss need to enhance their social lives.

Q. Why have I been asked to take part?

A. You have been asked to take part in the study because you were identified by an RNIB professional as someone who is able to travel independently and frequently socialises outside of your home. You therefore hold important information.

Q. What information you like me to record?

A. Through your diary keeping you should record details of the events you attend throughout your week. This should include:

1) The types of challenges you encounter when attending an event outside of the home - this includes getting there, being there and getting home.
2) Descriptions of how you overcome these challenges.

You should record your experience of the event, your thoughts and feelings before, during and after the event. You can choose to record your diary in small chunks throughout the course of your day or at the end of the day.

Q. What equipment should I use to record my diary?

A. You may already use a tape or MP3 note taker or recorder to keep notes. If so and you would like to use your equipment for the diary keeping this will be okay. If you do not have a recorder one can be loaned to you for the period that you are keeping the diary.

Q. When should I start to keep the diary?

A. As soon as you have returned your consent form can begin recording your next event. If you already have recording equipment you can start recording the details the next time you are due to leave your home.

Q. What will happen to my recordings after the research?

The audio recordings and interview recordings will be held in a secure place.

Q. Will I be identified?

A. No. Your name will be changed in the report so that no one will know who you are. If you would like your real name to used in the thank you section of the report please indicate this in the consent form.

Q. What will be done with the research results?

A. The research results will be written into a final report.

Q. What are the benefits of taking part in the research?

People who have taken part in similar studies have described the diary keeping process as fun. Taking part also provides the opportunity for you to share your experiences with other people with sight loss who currently are quite isolated

Appendix D: Getting out and about - Consent form.

Consent form

Study title: Getting Out And About with Sight Loss

Researcher: Angela Edwards

University details: School of Education, University of Birmingham, Edgbaston, United Kingdom

Name of participant:

The information provided by you will remain confidential. Nobody except the researcher will have an access to it. Your name and identity will also not be disclosed at any time. However the data may be seen by Ethical review committee and may be published in journal and elsewhere without giving your name or disclosing your identity.

You also have the right to withdraw from the study at any time. Should you choose to withdraw from the study all information you provide will be destroyed and omitted from the final report

Direct quotes from you may be used in the report, your name and other identifying information will be kept anonymous.

By signing this consent form I certify that I,

(insert name here) ___________________________ agree to the terms of this agreement.

Date: _______________________________

Appendix E: Preliminary interview Guide

Section 1: Introduction

Thank you for agreeing to take part in the research study. In this interview which should last for about 20 minutes, I will talk through the:

1. Aims and objectives of the study
2. The stages that you will be involved with and
3. What will be done with the information on completion of the study
4. Your consent to take part

Please feel free to ask questions at any time during our interview or if you feel important aspects of getting out and about with sight loss have been missed – I value your feedback.

Section 2: Aim and purpose of the study

1. The overall aim of the research is to understand the types of challenges you might face when getting out and about with reduced vision and importantly, the things that help you to overcome these challenges.
2. It is anticipated that the diaries that you keep and the interview will reveal important information about those challenges and the things that participate in social settings.
3. The information that you and other participants provide will be used to assist other people with sight loss.

Stages of the research study

There are two main stages of the research that you will be involved with:

1. Keeping an audio diary for a week long period. In the diary you will record your thoughts, feeling and emotions, the things you do in the lead up to leaving your house; your experiences whilst out and a summary of your day when you return.
2. A telephone interview lasting between 1 – 2 hours to discuss how you developed the strategies you use to successfully get out and about.

Section 3: Equipment

Do you have your own recording device?

What type is it?

Getting data back to researcher

Response:

Section 4: - Forthcoming events
Thinking about the week that you plan to record your diary – do you have anything coming up over the next few days?
Response:

Section 5: What will be done with the information.
Your diary and interview data will be typed up and saved to a password protected file. Only I will have access to the password and the data. Your information along with those of the other participants will be analysed (I will be looking for similar themes as well as the differences between the experiences of participants).

The results will be written up into a report which will not use the real names of the participants. It is very likely that I will be asked to present the research findings at events. Again no names will be used but the use audio clips from diaries and interviews would bring the presentation to life. Would you allow clips from your diary to be used or would you prefer not to?
Response:

Section 6: Return of consent form
Before you begin recording I will need to please can you complete the consent form that I will email to you after this interview.
What is your preferred format? Font size
Response:

Section 7: Further information
That's almost it for this interview. I will send you an information sheet which covers some of the issues we have discussed. I will also send you a very brief guide to the type of information you should record in your diary. Do you have any further questions or comments?

Response:

Thank participant and close

Appendix F: Diary keeping Instruction sheet

You should record:

1) Nature of the event - type of event - planned or spontaneous
2) Getting there - how, with whom,
3) Being there - how was it?
4) Getting home - how, with whom, when
5) Summary

Appendix G: Narrative Interview Schedule

Sub-session One

SQIN: Many people with sight loss are for one reason or other, unable to go out on their own. Using examples from your own life, can you tell me how you have been able to do this? I won't interrupt you and will just take notes.

Interview notes

Sub-session two