EMOTIONAL SUPPORT AND INCLUSION FOR BLIND AND PARTIALLY SIGHTED PEOPLE IN THE UNITED KINGDOM: THE DEVELOPMENT OF COUNSELLING FOR SIGHT LOSS, A PLURALISTIC PRACTICE MODEL.

A thesis submitted for the degree of Doctor of Philosophy (PhD)

by

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June, 2016

Declaration

Candidate's declarations:

I, Mhairi Thurston, hereby certify that this thesis submitted in partial fulfilment of the requirements for the award of Doctor of Philosophy (PhD), Abertay University, is wholly my own work unless otherwise referenced or acknowledged. This work has not been submitted for any other qualification at any other academic institution.

Signed ....………………………………………….………
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Supervisor's declaration:

I, Geoff Dickens, hereby certify that the candidate has fulfilled the conditions of the Resolution and Regulations appropriate for the degree of Doctor of Philosophy (PhD) in Abertay University and that the candidate is qualified to submit this thesis in application for that degree.

Signed [Principal Supervisors signature]…………………………………...
Date…………………………………………………………………………..

Certificate of Approval

I certify that this is a true and accurate version of the thesis approved by the examiners, and that all relevant ordinance regulations have been fulfilled.

Supervisor…………………………………………………………….………
Date…………………………………………………………………………..

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List of Abbreviations

BACP   British Association for Counselling and Psychotherapy

CEO   Chief Executive Officer

CESS   VISION2020UK Counselling and Emotional Support Services Group

CVI   Certificate of Vision Impairment

ECLO   Eye Clinic Liaison Officer

ICMJE   International Committee of Medical Journal Editors

NICE   National Institute for Health and Care Excellence

REF   Research Excellence Framework

RNIB   Royal National Institute for Blind People

SVS   Scottish Vision Strategy

Acknowledgements

Abstract

This is a narrative account of a cohesive programme of research carried out between 2010 and 2016, which resulted in ten peer-reviewed, published papers that provide an empirical basis for my thesis. The impetus for this academic exploration was provided by my personal experience of acquired sight loss, where my medical and functional needs were prioritised but my emotional needs were overlooked. The first study I undertook confirmed that people experienced negative emotional effects attributable to acquired sight loss. Subsequent studies explored the experience of social exclusion in health and education for blind and partially sighted people. Difficulties were evident across the lifespan, starting with undiagnosed refractive errors in childhood, moving to perceptions of inclusion in high school and on to experiences of exclusion in health care and engagement with leisure activities in adulthood. These papers offer a context for understanding the social and emotional effects of sight loss. Two supporting papers examined how inclusion in healthcare might be increased through nurse education and how accessible games might aid inclusion in entertainment. The thesis as a whole focuses on the development of Counselling for Sight Loss, a pluralistic practice framework for responding holistically to the emotional effects of sight loss, which are compounded by social exclusion. My theoretical model explaining the transition from sight to blindness provided a theoretical context for the thesis, advocating that different people benefit from different types of emotional support at different times in their sight loss journey. This has implications for the nature and timing of emotional support offered to blind and partially sighted people. Counselling for Sight Loss is based around a menu of therapeutic tasks, identified from analysis of systematic case study data in which clients identified helpful aspects of their therapy. These tasks provide an empirical basis for working therapeutically with clients who have visual impairment and will act as a foundation for the development of training materials. The findings of my most recent study have highlighted the

need for a national framework for the provision of emotional support services for blind and partially sighted people within the United Kingdom. Currently, emotional support and counselling services are being delivered by staff with varying degrees of relevant training, including those with none. My research has contributed to the development of quality standards and training, based on my Counselling for Sight Loss data, to benefit UK service delivery. Thus my thesis represents a systematic commitment to using research to generate real-world solutions to a real-world problem: designing and delivering effective emotional support and counselling for adults with sight loss in the United Kingdom.

Chapter 1. Introduction and research contextualisation

The purpose of this chapter is to provide an overview and a contextualisation for the thesis. The chapter begins with an outline of the thesis and an explanation of the nature of sight loss. This is followed by a description of the policy context, including an overview of the UK Vision Strategy (2013), the Scottish Vision Strategy (2013), VISION2020UK Counselling and Emotional Support Services Group, the Adult UK Sight Loss Pathway (UK Vision Strategy 2013) and the process of Certification and Registration. This is followed by a presentation of the theoretical, research and methodological contexts, aimed at giving the reader a full contextual understanding of the body of work presented.

1.1 Outline of thesis

This a narrative account of a cohesive programme of research, grounded in the discipline of counselling, which resulted in ten papers, published in peer-reviewed journals between 2010 and 2016. My thesis represents an attempt to find a real-world solution to a real-world problem: how can we design and deliver effective emotional support and counselling for adults with sight loss in the United Kingdom? It was structured around a series of questions, which I identified and sought to answer during the course of my six-year program of research:

i. What are the social and emotional effects of sight loss?
In papers 1, 2, 5, 8 and 9, I investigated the social and emotional effects of sight loss across the lifespan. Findings showed that from childhood onwards, sight loss impacted negatively on quality of life and perceptions of inclusion.

ii. What are the sight loss sector aspirations for emotional support?
Over the past seven years there has been national recognition that emotional support is needed in sight loss (UK Vision Strategy, 2013; Scottish Vision Strategy, 2013). In addition, it has been recognised that emotional support needs to be embedded into sight loss pathways (UK

Vision Strategy, 2013). Indeed, people with sight loss have reported that they want someone to talk to (UK Vision Strategy, 2011).

iii. What do we mean by emotional support?

The Royal National Institute for Blind people (RNIB) defined this as a three-tier stepped support system (See Figure 7, p 39). Skilled listeners or peer supporters would provide Tier One support. Counsellors, psychotherapists and psychologists would provide Tier Two support, and Tier Three support would be provided in acute mental health services.

iv. Why do we need different tiers of support?

I proposed a five-stage transition model of acquired sight loss (Thurston, 2010). It described different stages of the process of acquiring sight loss (See Figure 6, p 41). Different types of support may be needed at different stages of this process. For example, at diagnosis, Tier One support at an eye clinic may help someone with the shock of diagnosis. During the Point of Impact, Tier Two counselling might help someone with feelings of loss. During rehabilitation, Tier One peer support might provide positive role models for living with blindness or Tier Two Counselling might help someone explore their changing identity. Tier Three might be helpful following an attempted suicide or for someone with sight loss who has a long-term mental health condition.

v. What is unknown within the sector?

a. What sort of emotional support really helps?

In response to this question I carried out systematic case study research (papers 3 and 4), in which the process and outcomes of therapy with blind and partially sighted clients were analysed. This identified effective factors in therapy for blind and partially sighted clients. It resulted in the development of Therapeutic Tasks for Sight Loss. These tasks were groundbreaking in that they represented an attempt to design a therapeutic intervention based on the voice of the blind person. These tasks will form the basis of a future training manual for practitioners working within the sight loss sector.

b. *Who delivers emotional support, where is it being delivered, who is paying for it and what do clients want to talk about?*

In response to these questions, I co-designed a scoping survey to determine the nature of emotional support and counselling service provision for blind and partially sighted adults in the United Kingdom (paper 10). Analysis of the results revealed that emotional support and counselling services were being delivered within a range of settings (charities, NHS, social care and private providers) and that staff with varying degrees of relevant training delivered these services. Some counselling and emotional support service provision was being delivered by unqualified staff. Results also showed that, as well as sight loss, clients wanted to talk about a range of problems, such as sexual problems, domestic abuse, self-harm, alcohol, drugs, relationships, trauma, anger, identity, loss, bereavement, self-esteem, depression and anxiety. Services offering **only** emotional support (not trained counsellors) reported seeing clients with depression, anxiety and self-harm. Staff working outside their area of competence constitutes a quality standard issue. My thesis asserts that people providing emotional support or counselling to blind and partially sighted people should be appropriately qualified and receive specialist training in sight loss issues.

vi. What should the future priorities for the sight loss sector be?

Through my research, I identified the need for quality standards and training for services delivering emotional support and counselling for sight loss to blind and partially sighted people in the UK. I also identified the need to develop Tier 1 and Tier 2 services throughout the UK, along with appropriate referral pathways. In addition, I identified the need for understanding where services are delivered and from whom they are receiving funding. Allocating responsibility for funding is a vital part of future service development within the UK.

As chair of the VISION2020UK Counselling and Emotional Support Services group, I am working in collaboration with the CEO of

VISION2020UK to begin the process of National Institute for Health and Care Excellence (NICE) accreditation for Counselling for Sight Loss in order to provide a blueprint for quality service development and training. This needs funding before it can be progressed. I have been approached by RNIB Emotional Support Services London about collaborating in the development of a training package for counsellors working with clients with sight loss. In a report commissioned by the R S MacDonald Charitable Trust, I was asked to identify charitable funding priorities for Visual Impairment in Scotland. My transition model was cited to provide a theoretical context for the emotional impact of sight loss and the need for specialist counselling services for visually impaired people throughout Scotland was identified (Boswell & Kail, 2016). At a round table meeting with the director of the trust and the authors of the report, I highlighted the importance of research in order to provide an empirical basis for emotional support service development and training.

The diagram below (Figure 1) shows the inter-relationship and development of my papers.

Three key research questions form the basis of the thesis:
- (i) What is the emotional impact of sight loss? (Papers 1 and 2)
- (ii) How do blind and partially sighted people experience inclusion? (Papers 5, 8 and 9)
- (iii) What do blind and partially sighted people find helpful in therapy? (Papers 3 and 4)

Papers 6 and 7 are supporting papers, which developed from paper 5. They represent an attempt to increase inclusion in healthcare and gaming for blind and partially sighted people through informing nurse education and influencing gaming design.

Paper 10 developed from papers 1, 2, 3 and 4. It scoped existing services to identify the sector needs and to feed forward into my future research agenda (thus the arrows pointing upwards).

Paper 11 (not included in this thesis) developed from papers 1, 2 and 8. It is included in the diagram to show how my work has served as a template for new research involving other long-term health conditions and disabilities. It has also served as a template for the development of Counselling for Diabetes (McLeod, Thurston & Smith, 2015).

Emotional support and inclusion for blind and partially sighted people: The development of Counselling for Sight Loss, a pluralistic practice model

RQ1: What is the emotional impact of sight loss?

RQ 3 What do blind and partially sighted people find helpful in therapy?

RQ2: how do blind and partially sighted people experience inclusion?

Paper 1. Thurston, M. (2010). An enquiry into the emotional impact of sight loss and the counselling experiences and needs of blind and partially sighted adults. *Counselling and Psychotherapy Research, 10 (1),* 3-12

Paper 3. Thurston, M., McLeod J. & Thurston, A. (2013). Counselling for sight loss: Using systematic case study research to build a client informed practice model. *British Journal of Visual Impairment, 31(2),* 102-122.

Paper 5. Thurston, M. & Thurston, A. (2013). Risks to client confidentiality when communicating health information to blind and partially sighted patients. *Disability, CBR &Inclusive Development. 24(1),* 22-39.

Paper 2. Thurston, M., Thurston, A. & McLeod, J. (2010). The socio-emotional effect of the transition from sight to blindness. *The British Journal of Visual Impairment, 28(2),* 90-112.

Paper 4. Thurston, M., McLeod, J., & Thurston A. (2012). Counselling for sight loss. Using Hermeneutic Single Case Efficacy Design methods to explore outcome and common factors. *Counselling Psychology Review 27(4),* 59-70.

Paper 6. Willis, D & Thurston, M. (2014). Working with the disabled patient: Exploring student nurse views for curriculum development using a swot analysis. *Nursing Education Today.*

Paper 7. Scott-Brown, K. C., Harris, J., Simmers, A., Thurston, M., Abbas, M. deMajo, T., Reynolds, I. Robinson, G. Mitchell, I. Gilmour, D. Martinez, S., & Isaacs, J. (2014). Tapology: A game-based platform to facilitate e-health and e-inclusion. In Stephanidis, C. & Antona, M. (Eds) *Lecture Notes in Computer Science: Universal Access in Human-Computer Interaction.* Part III, 8515, pp. 368-377.

RQ4: What is the nature and extent of existing emotional support services available to blind and partially sighted people in UK?

RQ5: How do blind and partially sighted pupils experience inclusion in mainstream education?

RQ6: What is the impact of undiagnosed sight loss in the early years of school?

Paper 10.The nature of emotional support and counselling provision for people with sight loss in the United Kingdom (2016 in press). Pybis, J. Thurston, M., Dennison, C., Broom, M., Miller, A. *British Journal of Visual impairment*

Paper 8. Thurston, M. (2014). 'They think they know what's best for me'. An interpretative phenomenological analysis of the experience of inclusion and support in high school for vision impaired students with albinism. *International Journal of Disability, Development and Education. 61(2)* 108-118.

Paper 9. Thurston, A. & Thurston, M. J. (2013). A literature review of refractive error and its potential effect on reading attainment in the early years of school. *Optometry and Visual Performance. 1(1),* 44-56

Paper 11 (not presented in thesis) Lumsdaine, S. & Thurston, M. (2016 in press) Growing up in a mainstream world: A retrospective enquiry into childhood experiences of mobility disability. *International Journal of Disability, Development and Education*
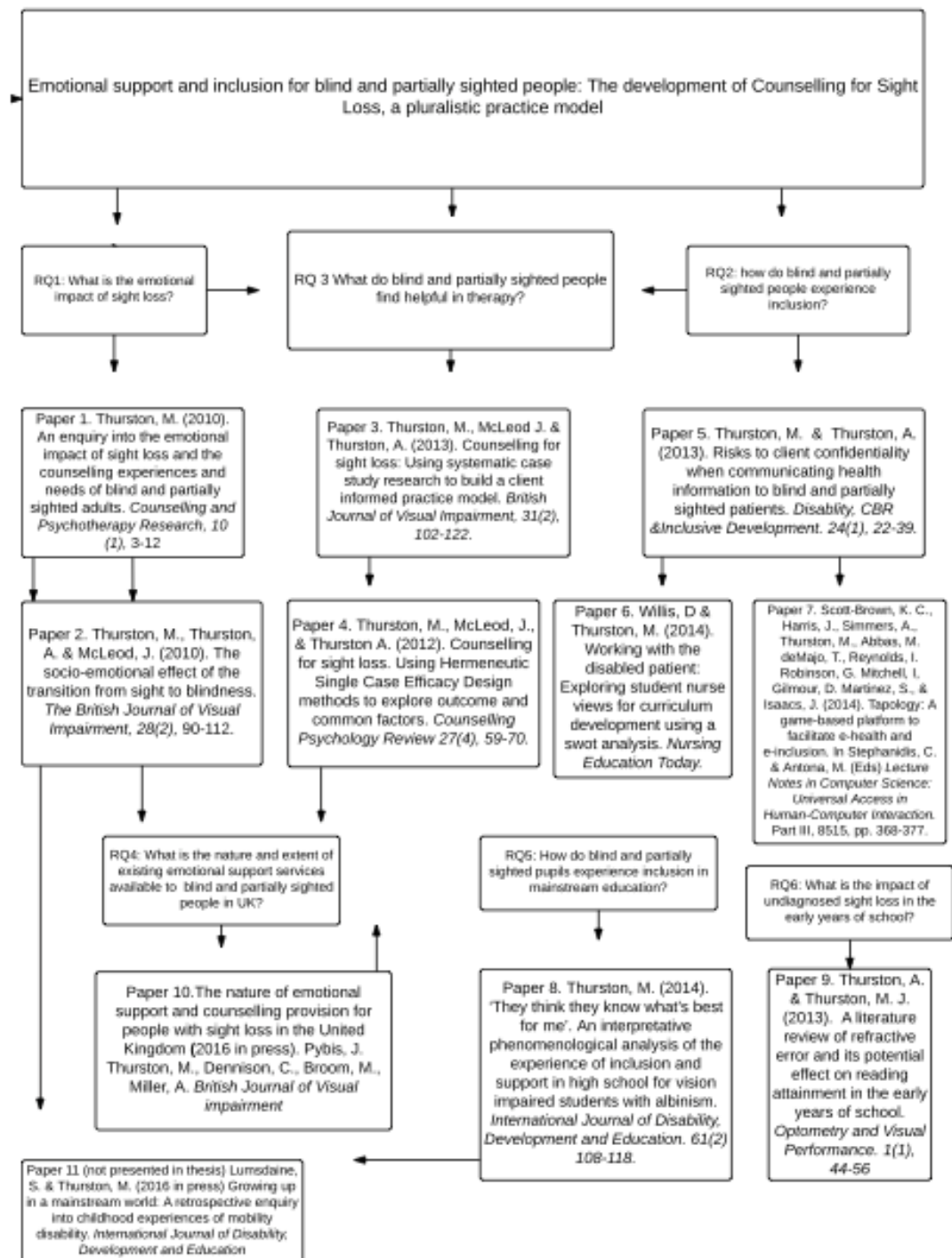
Figure 1 Inter–relationship and development of the papers

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1.2   What is Sight Loss?

There are around two million people in the United Kingdom living with sight loss. With an aging population, this number is predicted to increase to four million by 2050, as sight loss affects around one in five people over the age of seventy-five (Fight for Sight, 2016). Different sight conditions affect the way a person sees. The majority of blind and partially sighted people retain some kind of residual vision, with only a small percentage having no sight at all (NHS Choices, 2016). In fact blindness can be conceptualised as a different way of seeing.

Those who have a visual acuity problem may have little or no ability to read. They may retain shape perception or a light and dark awareness (see Figure 2).

Figure 2 Visual acuity problem (Action for Blind People, 2015)

Those who have a visual field problem (see Figure 3) may retain the ability to read, often with magnification. They may have usable central vision or peripheral vision depending on their sight condition. Usable central vision gives a person the ability to maintain focus on objects, but it may affect mobility, as that person may have trouble locating where they are in relation to other objects.

Figure 3 Visual field problem with residual central vision only. (Action for Blind People, 2015)

Usable peripheral vision on the other hand may result in problematic focus but better mobility (see Figure 4).

Figure 4 Visual field problem with residual peripheral vision only (Action for Blind People, 2015)

Some sight conditions, such as diabetic retinopathy, may result in patchy vision. This may make reading difficult and slow, but might not interfere too much with that person's mobility, as their field of vision may be wide enough to compensate (see Figure 5).

Figure 5 Patchy vision (Action for Blind People, 2015)

There is an interface between different ways of seeing and the required accessible formats for blind and partially sighted people (European Blind Union, 2016). For example, a person with a visual acuity problem may prefer to use braille, a screen reader, an audio CD, telephone or face-to-face conversation. A person with a visual field problem on the other hand, may be able to engage standard print with magnification, but prefer large print, an audio CD, telephone or face-to-face conversation.

In summary, the prevalence of sight loss is increasing. Sight loss is a generic term for a complex number of sight conditions, which affect people in different ways and can vary depending on inter alia lighting conditions, time of day or stage of development. There is a crucial difference between sight conditions that affect acuity, and those that affect field of vision. This can pose a challenge in terms of a cohesive approach to inclusivity, as there is not a "one size fits all" solution.

1.3   UK Policy context

In order to construct a real-world answer to a real-world problem, it is vital to have a real-world understanding of the sector in addition to an academic understanding. This includes an understanding of relevant policies and practices and knowledge of relevant strategic bodies. There are a number of contexts that frame the work which are not fully explored

within the papers presented in this thesis, due to word constraints imposed by journals. The UK Vision Strategy (2013) and the Scottish Vision Strategy (2013) are pan-sector strategies used to define good practice and to inform national and local commissioners of services. They are essentially lobbying documents produced by the sector for the sector. They represent an attempt to unify what was, and is, a complex field encompassing aspects of both health and social care. The VISION2020UK Counselling and Emotional Support Services group is one of the standing committees of the UK Vision Strategy. The Adult UK Sight Loss Pathway (UK Vision Strategy, 2013) is an attempt to articulate the patient's journey from diagnosis, to treatment, to registration, certification and then to social care and rehabilitation.

1.3.1 The UK Vision Strategy

The first UK Vision Strategy (2008) identified three main outcomes, which it aimed to progress over a five-year time period using a pan-sector approach involving all stakeholders in eye health, e.g., clinicians, service users, public health bodies, health and social care providers, commissioners of services, charities, optometrists, rehabilitation workers, health boards in order to:

> 1. *Raise awareness among the public including those most at risk.*
> 2. *Improve coordination and integration of eye health services and support for those with permanent sight loss.*
> 3. *Improve attitudes towards people with sight loss and remove barriers to inclusion* (UK Vision Strategy 2008-2013).

As part of the UK Vision Strategy agenda, RNIB surveyed 1,182 blind and partially sighted people in the UK in order to develop a set of outcome indicators to represent the voice of the service user in the development of service provision. After an analysis of the data, the 'Seeing It My Way' document was produced and 10 outcomes were identified representing the priorities of blind and partially sighted people in the UK:

> 1*: That I understand my eye condition and the registration process.*
> 2*: That I have someone to talk to.*

3: That I can look after myself, my health, my home and my family.

4: That I receive statutory benefits and information and support that I need.

5: That I can make the best use of the sight I have.

6: That I can access information making the most of the advantages that technology brings.

7: That I can get out and about.

8: That I have the tools, skills and confidence to communicate.

9: That I have equal access to education and life long learning.

10: That I can work and volunteer (UK Vision Strategy, 2011).

These outcomes underpin the current UK Vision Strategy outcomes (UK Vision Strategy, 2013) and form the foundation of good practice in service development. For example, developments in emotional support provision cite outcome 2 (That I have someone to talk to) as a rationale for provision need and service expansion.

The refreshed UK Vision Strategy (2013) refined the strategic outcomes:

1.Everyone in the UK looks after their eyes and their sight.

2.Everyone with an eye condition receives timely treatment and, if permanent sight loss occurs, early and appropriate services and support are available and accessible to all.

3.A society in which people with sight loss can fully participate (UK Vision Strategy, 2013-18).

The refreshed strategy additionally takes into account the needs of children and young people. The Royal College of General Practitioners made eye health one of four clinical priorities for 2013-16 (Royal College of General Practitioners, 2013).

1.3.2 The Scottish context

To provide a Scottish context for the UK Vision Strategy, the Scottish Vision Strategy (SVS) (RNIB Scotland, 2008) was conceived with an Advisory Board comprising key stakeholders throughout the country. I am

an SVS advisory board member and a signatory of the current SVS document (RNIB Scotland, 2013). In addition, a Cross-Party Advisory Group for Vision Impairment was set up in Scottish Parliament. Again, this advisory group was formed from key stakeholders throughout the country. With quarterly meetings, the role of the group is to bring sight loss issues into political awareness. These issues can be progressed into questions for wider debate if deemed nationally significant. Issues such as accessible health information, shared spaces in town planning, electronic referrals and certification have all found their way onto the Scottish political agenda. In 2010, I presented evidence about accessible health information to the Health and Sport Committee considering the Patient Rights (Scotland) Act 2011, having first brought the issue to the attention of the Cross Party group. This resulted in accessibility being a requirement of the principles of patient care in Scotland.

1.3.3 VISION202UK Counselling and Emotional Support Services group (CESS)

The Counselling and Emotional Support Services group (of which I am Chair) is a standing committee of VISION 2020 UK. It was formed to raise awareness of the need for emotional support in sight loss. Essentially it was a practice network for those working within the field. The need for emotional support in sight loss was recognised and embedded in the UK Vision Strategy (2013). The remit of CESS was, therefore, no longer to raise awareness of the need for emotional support, but to form a strategic group who could work towards the development and implementation of emotional support services throughout the UK. In light of this, I repopulated the group to include key heads of services and stakeholders from throughout the UK who would be able to progress this agenda. The role of CESS was to:

- *Support the development of collaborative working between counsellors, emotional support service providers and commissioners of services*
- *Provide a forum to share good practice, service developments, evaluation and research outcomes*

- *Influence the development of counselling and emotional support services for adults, children and families affected by sight loss*
- *Support the UK Vision Strategy (2013); strategy outcome 2.4* (Terms of Reference, CESS 2014).

An additional strategic aim for the group was accreditation for Counselling for Sight Loss by the National Institute for Health and Care Excellence (NICE). VISION2020UK is seeking funding to facilitate the development of a NICE Recommendation Development Committee.

1.3.4 Adult UK Sight Loss Pathway

The Adult UK sight loss pathway, Appendix C of the UK Vision Strategy (2013) essentially describes the health and social care process a patient with sight loss should expect to experience. For example, if a person attends a routine eye test at a high street optician and the optician detects an abnormality, they will refer that individual to an ophthalmologist. The ophthalmologist, usually based in a hospital clinic, examines the patient to determine the severity and the cause of any abnormality. In order to receive a diagnosis of a sight condition, the person may have to attend more than one hospital appointment to allow for a variety of tests to be carried out. Once the ophthalmologist has reached a diagnosis, the patient is informed. If the diagnosis indicates a stable, treatable sight condition, the patient will continue to receive treatment and stay within a health pathway. If the diagnosis reveals a degenerative, treatable sight condition, the patient will continue to receive treatment and stay within a health pathway until the sight condition deteriorates to the point that a consultant ophthalmologist determines the patient is eligible for certification (CVI) as 'sight impaired' (partially sighted) or 'severely sight impaired' (blind). The CVI is then sent to local social services where the patient is offered registration as sight impaired. Registration is the gateway to a social care pathway. When a patient is registered as sight impaired, they can access their local social services for support, rehabilitation, low vision aids and access to financial benefits. Some ophthalmology clinics have an Eye Clinic Liaison Officer (ECLO)

attached to them. The ECLO helps the patient understand both the health and social care pathways. They can advise on an eye condition, or signpost to available social services. If a person is registered as severely sight impaired, they will be on a social care pathway. If they are continuing to receive treatment for their eye condition they will also be on a health pathway. At the point where no further treatment is possible, they will be discharged from the health pathway, but remain on the social care pathway.

Thus the adult sight loss pathway may involve both health and social care in varying degrees. This adds complexity in terms of policy-making and funding for support services, e.g., ECLOs may be funded from a healthcare budget or from a social care budget, depending on the local authority. Similarly, low vision clinics and rehabilitation services may have different sources of funding depending on the local authority.

It is an aim of the UK Vision Strategy to ensure that the Adult UK Sight Loss Pathway is as seamless as possible. This is challenging because of complex health and social care variables. One of the priorities I have identified within my programme of research is the need to better understand where emotional support and counselling might be located within the adult sight loss pathway. This is important as, at the moment, it is falling through a gap in funding with neither health nor social care taking full responsibility for its delivery.

1.3.5 Certification/Registration

As part of the Network 1000 project, Douglas, Pavey and Corcoran (2009) interviewed 395 visually impaired people to examine their experience of certification and the year following their registration. The findings showed that the experience was mixed, with participants commonly reporting shock, confusion and a lack of information and support. Nearly half of the participants (45%) received no explanation about the certification and registration process. There is a general downward trend in the rate of UK certification of severe sight impairment,

which does not reflect the increasing prevalence of sight loss. In a review of the literature, Bryce (2012) reported barriers and delays in the certification process, due to inconsistencies of practice. In response to this, the Royal College of Optometrists surveyed its members to gain a clearer picture about clinical experiences of certification (Professional Standards Committee, 2013). The findings highlighted widespread inconsistencies in the certification process. Indeed, the process of certification and registration is currently under review by the Scottish Government, led by Professor Carrie McEwan. I am also a member of the review panel. Throughout the review process I was able to advise on the importance of appropriate emotional support throughout the certification/ registration process. It has been proposed that a supplementary information booklet, which includes information about the emotional impact of sight loss, be adopted by the four UK nations and distributed at the point of certification/registration. This leaflet has been written by blind people, for blind people. I was asked to review it before its adoption in Scotland.

1.3.6 Summary of policy context in relation to the publications presented in this thesis

Sight loss sector policy-making is a complex landscape, which represents an attempt to assimilate contrasting and sometimes contradictory perspectives: clinicians (GPs, optometrists and ophthalmologists), service providers (health boards, local authorities, charities and local societies), service users (elderly, working age, adults, children) and public health. Research plays an important part in policy-making, particularly in its capacity to represent the views of different stakeholders. It is used to influence debates about funding and service priorities. In a political climate where funding is limited, it is important to evidence prevalence and need. Some tensions exist between the need to recognise and prioritise the voice of the service user (UK Vision Strategy, 2011), demonstrating the principles of person centred care within the constraints of funding and limitations of service implementation. For example, within the certification/registration process, there are competing needs: 1.

Ophthalmologists need a workable certification form, which they can complete with the patient within the normal span of an eye clinic appointment. 2. Patients need to have the complex certification process explained to them by the ophthalmologist at a time when they may be dealing with the shock of their diagnosis. This takes time and yet it needs to be fitted into their routine eye hospital appointment. 3. The social care providers want ophthalmologists to supply detailed information about patients (for example, do they live alone, have they had sudden sight loss?) to help them prioritise new referrals to their service for registration. This would mean increasing the complexity of the certification form, so that more nuanced information could be gathered by the clinician. A more nuanced form would take longer to complete within a regular eye hospital appointment slot. Which of these needs is prioritised? Underpinning all these competing priorities is an eye clinic within a hospital system, straining under the volume of patients whilst trying to cut patient waiting lists to meet government targets, and a social care system struggling to maximise limited resources. There is no easy answer to address the tensions that underpin the landscape of policy making.

The papers presented in this thesis regarding the emotional effects of sight loss address UK Vision Strategy Outcome Two targets:

> *To ensure that when permanent sight loss occurs, emotional support, habilitation and/or rehabilitation will be provided in a timely fashion enabling people to retain or regain their independence* (Refreshed UK Vision Strategy 2013-2018).

The papers presented regarding the social effects of sight loss address UK Vision Strategy Outcome Three targets:

> *"To ensure that children and young people with sight impairment can take their place in society" and "to achieve improved compliance with equality legislation"* (UK Vision Strategy 2013-2018).

I am a member of the Scottish Vision Strategy Advisory Group and the Scottish Executive Cross Party Advisory Group on Vision Impairment. I

am Chair of the VISION2020UK Counselling and Emotional Support Services group. I am on the review panel for Certification of Vision Impairment in Scotland and, in addition, I sit on the advisory board of the Early Intervention and Rehabilitation in Eye Care Services Project Board, which is refreshing the Adult UK Sight Loss Pathway. My involvement in the above groups has enabled me to produce research, which is both anchored in sector experience whilst having "real world' relevance.

1.4 Theoretical context

1.4.1 Paradigms of disability

This section presents a brief overview of different paradigms of disability, not previously discussed in detail within the papers, in order to provide a theoretical context for this thesis. It outlines classic disability theory, conceptualising it in terms of external and internal human experiences. The paradigms presented in this section are in some ways representative of underlying tensions within the sight loss sector, which straddles both medical (diagnosis and treatment of impairment) and social dimensions (care packages, rehabilitation and benefits). As part of the first study presented in this thesis, my theoretical model explaining the transition from sight to blindness, which encompassed both the internal and external experiencing of sight loss (see Figure 6, p 41), emerged from data grounded in people's lived experience of sight loss.

1.4.2 Disability as an external experience

The medical model of disability conceptualises disability as a medical matter, a deficiency of some kind requiring medical intervention (Oliver, 1990). The rehabilitation model of disability has emerged as an offshoot of the medical model. Its assumption was that disability was a deficiency, which could be overcome with the help of rehabilitation professionals, practical aids and interventions (Kaplan, 2007). The social model of disability offered a different way of looking at disability. The origins of the social model of disability can be traced to the Union of the Physically Impaired Against Segregation, or UPIAS (1976), who advocated that

although it might be a personal tragedy to have a physical impairment, it was, in fact, society which disabled physically impaired people. Oliver's social model of disability (1990) went further. It viewed disability entirely as a form of oppression of disabled people by the restriction of participation within an able-bodied society and not as a medical matter. It disembodied disability by asserting that it was wholly and exclusively social. One sociological interpretation of illness and disability argues that society casts people into "the Sick Role", which affords them a unique and universally recognisable status, in which full participation in society is not expected (Nettleton, 2006).

1.4.3 Disability as an internal experience

Morris (1991) criticised the social model of disability for denying the bodily experiences of the person with the impairment. Morris highlighted the importance of addressing the bodily experience of disability, advocating anatomy should not define destiny. The loss model of disability suggested that a disabled person needed to come to terms with their impairment, going through a process of mourning akin to that of bereavement before they could become psychologically whole again (Lenny, 1993). Alternatively, French (2004) argued for a positive personal theory of disability. French tried to refute the idea of disability as a personal tragedy, which she felt pervaded all aspects of society, particularly media representations, language and culture. She drew attention to words in common usage, such as *suffering* and *sufferer,* to refer to experiences of disability (p34). French acknowledged that, in some cases, people may indeed have experienced disability as a personal tragedy, such as a sighted person whose identity was founded on being sighted and who had been subjected to a daily diet of the personal tragedy model of visual impairment. However, she asserted that for many, disability was a normal and positive experience. Reeve (2006) also asserted that the internal experience of external oppression had emotional consequences for disabled people. The common theme across these internal models of disability is that they highlight the internal meaning of the disability for the person.

The pluralistic conceptual framework adopted within this thesis acknowledges both the social and physical conceptualisations of disability and both the internal and external experience of it, with respect to blind and partially sighted adults. Such a pluralistic perspective is consistent with my own epistemological experience of both the 'able-bodied' perspective and the 'disabled' perspective. It stems from my belief that knowledge is constructed rather than absolute and that there exist multiple 'truths'. This is indeed the essence of the pluralistic model of counselling (Cooper & McLeod, 2011) that informs Counselling for Sight Loss. Counselling for Sight Loss encompasses a rich mix of theoretical influences ranging from existential questioning (such as 'who am I now that I can't see'?) to behavioural changes (such as 'coming out as a blind person').

1.4.4 Summary of the theoretical context in relation to the papers presented in this thesis

This section has described different paradigms of disability. The work presented in this thesis acknowledges both the internal and external experience of disability. In Paper 1, The Emotional Impact of Sight Loss, participants made meaning of their emotional, social and bodily experiences of acquired sight loss. In the Counselling for Sight Loss study (papers 3 and 4), the therapist took into account the remaining 167 hours within the weekly life of the client and helped the client maximise available resources whilst exploring the physical and emotional impact of living without sight. The Access to Health Information study (paper 5) examined experiences of social oppression arising from barriers to accessing health care. The Inclusion in Mainstream Education study (paper 8) examined the internal processes and external experiences of two visually impaired teenagers within a mainstream school setting.

1.5 Research context

Research can play a vital role in informing service development. Indeed, there is a growing expectation of evidence-based practice within the

health professions (NICE, 2016). Empirical studies test the efficacy of interventions and build an evidence base to inform practice. This section presents a summary of recent empirical evidence in order to provide a research context for my work. In addition, there is a summary of scoping surveys and service evaluations, which seek to build practice-based evidence. Also included in this section is a summary of a secondary analysis of National Census Data, which presents evidence about the current social and emotional effects of sight loss in comparison to the sighted population of the UK.

1.5.1 Empirical evidence

Nyman, Dibb, Victor and Gosney (2012) conducted a meta-synthesis of qualitative studies looking at emotional well-being and adjustment to sight loss in people over 60. Seventeen papers were reviewed and the results were thematically analysed (Paper 1. *The socio-emotional effects of the transition from sight to blindness* was included in the papers reviewed). Key themes across the papers included the negative experiences of diagnosis of a sight condition, problems in daily living and the lack of social and psychological well-being due to acquired sight loss. The majority of the studies came from the USA (n=7). In addition there were 4 studies each from Australia and the UK and one study each from Sweden and the Netherlands. Within the Western societies represented in these studies there are common threads of the lived experience of acquired sight loss. It would be interesting to duplicate the study using papers from Eastern cultures and to compare and contrast the findings. Good social support was found to be a contributory factor towards positive psychological well-being, but perhaps lack of effective social support is uniquely problematic within individualistic western culture. Further research might enhance our understanding of the implications of different cultural contexts for acquired sight loss.

Senra, Barbosa, Ferreira, Viera, Perrin, Rogers, Rivera and Leal (2015), conducted a systematic review of the literature regarding psychological adjustment to irreversible vision loss in adults. 52 eligible studies,

published between 1946 and 2014 were identified. Papers 1 and 2 were included in this review. A thematic analysis of findings suggested that sight loss had negative effects on a person's quality of life and mental health and, crucially, that these effects were enduring. The authors asserted that more longitudinal research was needed to track the short term and long term effectiveness of psychological interventions for people experiencing sight loss.

There have been several studies of relevance in this area. Horowitz, Reinhardt and Boerner (2005) found that there was a decline in depressive symptoms after 2 years following an intervention that combined counselling and low vision aids. Brody, Roch-Levecq, Kaplan, Moutier and Brown (2006) found that a self-management programme, designed to enhance problem-solving skill, resulted in a reduction in depressive symptoms after 6 months. These findings were supported by Rees, Saw, Lamoueux and Keeffe, (2007). In addition, Girdler, Boldy, Dhaliwal, Crowley and Packer (2010) reported improvement in depressive symptoms after 12 weeks of participation in a self-management programme. Rovner and Casten (2008) reported improvement in depressive symptoms after two months of a problem-solving intervention. However, these gains were not sustained after 6 months, when there appeared to be no significant difference in the depressive symptoms reported by the trial group and the control group. Rovner, Casten, Hegel, Massof, Leiby, Ho and Tasman (2014) compared the effects of a behaviour therapy intervention and a non-directive supportive therapy intervention on the functioning capacity of people with macular degeneration, with the assumption being that a reduction in depressive symptoms leads to an improvement in function. They reported that, although there appeared to be no difference in quality of life, the behaviour therapy accompanying low vision rehabilitation was more effective in improving visual functioning and thus social engagement.

Margraine, Nollett, Shearn, Stanfors, Edwards, Ryan, Bunce, Casten, Hegel and Smith (2012) trialled a Problem Solving Therapy intervention

(Rovner et al., 2007) using a Randomised Control Trial design and protocol (DEPVIT). The Problem Solving Therapy intervention was delivered in the participant's home or at the research clinic by a psychologist trained specifically in the method. The method itself was an individualised therapy programme delivered over six to eight weeks, focussing on identifying the participant's specific problems, identifying an achievable goal and then a workable solution of their choice. In addition participants were given self-help material explaining depression and outlining various treatment options. A similar Problem Solving Therapy intervention was trialled previously (Rovner et al., 2007) and whilst it had shown some effectiveness in the short term, there were no long term gains reported in the treatment of the participant's depressive symptoms. Perhaps the most striking finding of the DEPVIT trial (n=1008) (Nollett, Bray, Bunce, et al., 2016) was that 43% of the participants with sight loss displayed clinically significant depressive symptoms. Within the trial sample, three quarters of participants who scored highly in the screening tool used to indicate the presence of depression were not receiving any type of treatment. The authors concluded that people with sight loss in Britain appear not to be getting the help they need.

These empirical studies attempt to ascertain the efficacy of treatment using existing psychological interventions for blind and partially sighted people based, in the majority, around Problem Solving Therapy (PST). PST was developed in the 1970s as a version of CBT (Mynor-Wallis, 2001). The distinctive features of PST were that it was based in a model of stress, and that clients were invited to engage in an active process of brainstorming about potential solutions of everyday problems associated with their difficulties in coping with stressful situations. Versions of PST have been developed in relation to a range of disorders, such as depression, and for use by nurses and physicians in primary care settings. More recently, Contemporary Problem Solving Therapy (CPST) (Nezu, Nezu & D'Zurilla, 2013; Nezu, Nezu, & Colosimo, 2015) has emerged. CPST involves more attention to the quality of the therapeutic alliance, and makes use of a process of collaborative case formulation,

while maintaining a conceptual framework based in CBT and stress theory.

There are important similarities between Contemporary Problem Solving Therapy (CPST) and Pluralistic Counselling for Sight Loss. Both approaches favour active collaboration between therapist and client, recognise and use client strengths, recognise and use cultural resources, prioritise goal setting, implement breaking down goals into smaller parts and evaluating them, and make use of collaborative case formulation that incorporates visual mapping. However, there are crucial differences between counselling for sight loss model and PST. Essentially, in stages 4,5 and 6, PST becomes a one size fits all behavioural treatment based on solving problems by finding practical solutions. For example, if a visually impaired person is feeling stressed at work, they can decide to take sick leave. By contrast, a pluralistic approach allows for a wider perspective on such a problem, for example through a collaborative focus on meaning-making.

Counselling for sight loss attempts to understand the scope and nature of both practical and psychological problems encountered by clients with sight loss. As such, it is a more flexible approach and potentially more comprehensive than either PST or CPST. It originates from systematic case study research data, specifically analysis of blind and partially sighted people's reports of helpful aspects of therapy. It offers clients a therapeutic task menu, which can be approached by therapists and clients collaboratively using an wide variety of methods, informed by the client's preferences, the therapist's skills and knowledge, and available cultural resources.

For example, coping with the experience of gradually deteriorating sight can be problematic for people with sight loss. Whereas the behavioural orientation of CPST/PST would limit the therapeutic options that might be applied in relation to such an issue, pluralistic counselling is in principle to

a broad range of potentially therapeutic methods that could be helpful in dealing with this:

- Some people may find mindfulness techniques useful in helping them remain grounded in the present moment as fear of the future can feel overwhelming and can rob the person of an appreciation of the present and things they still enjoy doing.
- Some people may find it helpful to explore and express the difficult emotions associated with fear of the future without sight, such as panic, despair, hopelessness or anger.
- Some people may want to express suicidal intentions.
- Some people may want to learn practical coping strategies, such as learning how to use assistive technology in order to feel more prepared.
- Some people may want to reflect on their ability to cope with change in order to increase their feeling of empowerment.
- Some clients may find that fears associated with sight loss may re-evoked memories of traumatic experiences or deprivation in early childhood, and may choose to spend time exploring and resolving such issues.
- Some people may express difficult emotions arising from their loss, within the relationship with their therapist, and may be invited to reflect on the learning that could arise from attention to such processes.

The Pluralistic Counselling for Sight Loss approach does not privilege practical, behavioural solutions to problems as in PST. Indeed, all different types of therapy are valued and seen as helpful for different clients. The therapist collaborates with the client to find out what their problem is and how they would like to approach it. The therapeutic task menu for sight loss serves to tailor the therapy provided to the learning style of life experience of the client. A crucial aspect of this process lies in the wish of many clients to understand and make sense of the issues with which they are faced. In PST/CPST, clients are offered a stress

perspective through which problems can be understood. By contrast, in Pluralistic Counselling for Sight Loss, clients are encouraged to find meaning in any source of ideas that seems useful to them.

It would be valuable to carry out further research into the similarities and differences between PST/CPST and pluralistic counselling, and to explore potential areas of mutual learning and collaboration across these two models. In terms of application in UK contexts, it is likely that pluralistic counselling may fit more readily with existing skills and practices of psychodynamic and humanistic counsellors, whereas PST/CPST will be more accessible for clinicians with initial training in CBT

In this thesis, I propose Counselling for Sight Loss is a unique psychological intervention, informed *by* blind and partially sighted people *for* blind and partially sighted people, which provides a more nuanced understanding of their needs. Follow up studies will be needed to establish efficacy of this approach.

1.5.2 Scoping survey

Nyman, Gosney and Victor (2010) identified the need for statutory face-to-face counselling services for people with sight loss in the UK. In addition, they called upon existing service providers of emotional support for sight loss to gather evidence that might demonstrate the effectiveness of their services. They observed that the majority of services had not been systematic in gathering outcome evaluation data, making it difficult to prove the effectiveness of psychological interventions on the emotional well being of people with sight loss. Their study was limited to 28 agencies. I was involved in designing a scoping survey about the provision and nature of emotional support and counselling service provision in the UK, which received 182 responses (Pybis, Thurston, Dennison, Broom & Miller, 2016). It is unclear whether there are simply more services in existence than at the time of the Nyman et al. study, or

whether our study had more effective network links to agencies providing emotional support to blind and partially sighted people.

1.5.3 Service evaluations

RNIB commissioned an evaluation of the Finding Your Feet Programme, which was a series of peer support workshops designed to help people cope with the social and emotional effects of sight loss (Kirkaldy & Barr, 2011). This intervention shared some similarities with the Rovner (2007) intervention cited above, in that it attempted to combine practical support with emotional support, encouraging participants to develop a plan of action to access the support they needed. Whilst participants reported the benefits of a peer group form of support, the report was inconclusive about the psychological benefits of this, being more anecdotal than clinically robust. The Finding Your Feet Programme to date has not been progressed by RNIB.

Barr, Hodge, Leeven, Bowen and Knox (2012) and Hodge, Barr, Leeven, Bowen and Knox (2013) evaluated a three-year pilot project for RNIB in which emotional support and counselling (ES and C) was delivered as part of an integrated low vision service in Gateshead and London. At assessment, clients were offered up to 12 sessions of humanistic counselling or emotional support from a trained counsellor or counselling psychologist. Although the findings suggest that there were some improvements in participants' mental wellbeing through improvement in their CORE scores, the main weakness of this study comes from the high attrition rate (only 35 participants out of an initial 190 completed the study). In addition, there is a lack of clarity regarding definitions of counselling and emotional support. The authors concluded that the counsellors used a pluralistic approach (Cooper & McLeod, 2011) in responding to client needs, suggesting that some clients simply wanted empathic listening and normalising while other clients wanted a more structured counselling approach. In reality, this paper highlights a challenge for the sight loss sector - the operationalization of the terms counselling and emotional support. This is discussed in some detail later

in the thesis. The main significance of this study is that it advocates that a humanistic approach to counselling is well suited to the needs of a visually impaired client group. This would appear to challenge (or perhaps compliment) the behaviour therapy interventions used in the RCTs.

1.5.4 National Census - Social Research

One of the most compelling pieces of evidence about the experience of living with sight loss in the United Kingdom comes from a secondary analysis of the national census survey data, commissioned by RNIB (McManus & Lord, 2012). The analysis compares and contrasts the reported experiences of adults without sight loss to those with sight loss. The results showed inequalities in experiences of wellbeing, health, learning, work, leisure and culture, finances and relationships. Nearly half of the participants (44%) reported experiencing some kind of discrimination by the general public, whilst 33% reported discrimination from employers, healthcare workers and even friends and neighbours. In addition, 38% of participants reported feeling depressed. The analysis has recently been updated (Flynn & Lord, 2015) and the findings show that the number of people reporting depressive feelings has risen to 44%. There have been no improvements in the other findings, which have remained largely stable, indicating continuing inequality in employment participation and in experiences of discrimination. These reports highlight both the social and emotional effects of sight loss and provide the social context for the findings of the papers presented in this thesis, particularly regarding the emotional impact of sight loss and the inaccessibility of health information for blind and partially sighted people.

1.5.5 Summary of research context

Recent literature continues to build a compelling picture about the negative emotional and social effects of sight loss. The quest to identify an effective psychological intervention for the emotional effects of sight loss continues, as there is inconclusive evidence about the effectiveness of existing psychological interventions. Papers presented in this thesis Paper 1 - Thurston (2010); Paper 2-Thurston, Thurston, & McLeod

(2010); Paper 3 - Thurston, McLeod & Thurston (2013) and Paper 4 - Thurston, McLeod & Thurston (2012) - represent an attempt to understand the emotional impact of sight loss and to design an effective psychological intervention using a systematic case study methodology to identify client-defined helpful aspects of therapy. This psychological intervention positions the voice of the blind and partially sighted person at its heart. The aim is to identify specific therapeutic tasks, which can be used as a 'counselling menu' (McLeod & McLeod, 2011) for blind and partially sighted people.

Regarding the social effects of sight loss, the papers – Paper 5 - Thurston and Thurston, (2013 a); Paper 9 - Thurston and Thurston, (2013 b); Paper 8 -Thurston (2014); Paper 7 - Scott-Brown, Harris, Simmers, Thurston, Abbas, deMajo, Reynolds, Robinson, Mitchell, Gilmour, Martinez, and Isaacs, (2014) and Paper 6 - Willis and Thurston (2015), support the National Census (2015) findings by highlighting inequalities in health and education participation for blind and partially sighted people.

1.6   The methodological context

This section provides an outline of the range of methods used in the thesis. I adopted a pluralistic methodological stance, which acknowledges that different methods are suited to answering different types of research questions. Methodological pluralism rejects the notion that one type of research method is inherently better than another. Philosophically it is aligned with a postmodern and poststructuralist way of thinking, that there is no single definitive truth (Cooper & McLeod, 2011). This concept has been used previously in sociological research. Bell and Newby (1977) promoted the merits of tailoring research method to research question. Subsequently, Bell and Roberts (1984) advocated that individual researchers within the discipline of sociology were not expected to be proficient in executing an entire range of research methods, but that the range of their individual contributions might enable the achievement of research plurality across the entirety of the discipline. The concept of pluralist methodology can be found in Information Systems research

(Mingers, 2001). The Information Systems (IS) discipline integrates a wide range of disciplines including technology, mathematics, sociology, psychology and linguistics. Mingers (2001) argued for the construction of a pluralist research framework to address the issue of diversity of disciplines and diversity of appropriate research methods within IS research. However, there are underlying philosophical tensions existing in a pluralistic methodological stance, which require the researcher to embrace both positivist and interpretative epistemological and ontological positions. In this section I hope to show that I adopted a pluralistic approach to research methods, which afforded me the opportunity to explore a range of research questions by tailoring the method specifically to fit the question rather than aligning my self to one particular research paradigm.

1.6.1 A pluralistic approach to research methods

In papers one and two, I chose a grounded theory method (Strauss & Corbin, 1990) to explore how sight loss impacted emotionally on people. This method is particularly suited to the exploration of lived experience. It is free from preconceptions and facilitates the emergence of models or theories entirely grounded in the data. My model describing the transition from sight to blindness (Figure 6) emerged from the data as a result of this method.

In paper eight, I chose Interpretative Phenomenological Analysis (IPA)(Smith, Flowers & Larkin, 2010) to explore the lived experience of two, mainstream, high school children with albinism and impaired vision. This was a more appropriate choice for exploring their lived experience than grounded theory, as it is particularly suited to small sample sizes.

In papers three and four, I chose Quasi Judicial Hermeneutic Single Case Efficacy Design to drill down into the process and outcomes of counselling for sight loss. This methodology is especially useful for understanding exactly how counselling sessions contribute to therapeutic

change in clients. Historically single case studies have been easy to dismiss methodologically, as they relied on one interpretation of one source of data and lacked external scrutiny (McLeod & Elliott, 2011). The systematic case study research method I chose addressed this weakness by gathering multiple sources of client data and using multiple researchers to analyse it. The data sources in this particular case included a variety of out come measures, process measures, client transcripts, therapist reflections and change interviews. These were compiled into a rich case record. In order to mitigate for researcher bias, the rich case record was analysed by multiple student researchers. A group of approximately twelve student researchers analysed the data from an affirmative stance. They gathered evidence that this was a positive outcome case, in which the success was entirely attributable to the counselling. In contrast, another group of approximately twelve student researchers analysed the data from a sceptic stance, gathering evidence that this was not a positive outcome case or that gains made were not due to counselling. The sceptic and affirmative evidence was then presented to a group of four impartial judges who passed a verdict. This quasi- judicial method is an innovative approach to systematic case study research (Elliott, 2002). In an unpublished study, I re-analysed the same data using the Ward method of creative consensus (Schielke, Fishman, Osatuke & Stiles, 2009). The findings were broadly similar, indicating that this would make an interesting comparative paper in due course.

In contrast with these qualitative methods, I chose a quantitative method, (survey) to answer the research questions proposed in papers five and ten, as both projects involved larger samples (n=228 and n= 182). I chose a range of methods to answer research questions in the remaining papers. A SWOT analysis was useful in understanding how student nurses evaluated the strengths, weaknesses, opportunities and threats associated with caring for patients with disabilities in paper six. In paper nine, a literature review was chosen as a precursor to a future research project. In paper seven, a user trial gathered data from visually impaired

participants about the game design, which influenced further design developments.

1.6.2 Critical overview of methodology

Although each method was specifically matched to each research question, there were limitations throughout. In papers one and two, all the participants were adults who had experienced full sight at some point in their life. Therefore we cannot assume the findings of the study would be applicable to people blind from birth or whose age lay outside the sample age range of between forty-five and seventy-four years old. In papers three and four the main limitation was that it represented one therapist's work with one client. More evidence needs to be gathered in order to carry out cross case comparisons or a further quantitative enquiry verifying the therapeutic task list. The main limitation in paper five lay in the sample size (n=228), which was too small to represent the blind and partially sighted population of Scotland (n=37,000). Similarly, in paper ten, it was unclear if the sample size (n=182) was representative of all the service providers of emotional support and counselling in the United Kingdom, despite exceeding the number of services registered on the RNIB Sightline Directory. The sample composition in paper six was also problematic. It was unclear how many students from the class of twenty-five had participated by posting comments, so it is unclear whether the comments represented the whole group. In addition, the small sample size represented a snapshot of one class in one university in one country and as such, the findings need to be treated with caution.

1.6.3 Summary of methodological context

Different methods were specifically chosen to find answers to different research questions. There was not a one size fits all solution. This is a pluralistic approach to research methods, where no one method is privileged above another. Methodological limitations were identified across the papers.

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1.7 Chapter summary

This chapter provided a brief outline of my thesis. This was presented along with explanatory information about sight loss and the implications of this for preferred formats of information. The chapter described the context of policy, theory, research and methodology for the body of work presented in this thesis. The chapter highlighted the complexity of the sight loss sector in terms of the nature of sight loss, organisation, co-ordination, interaction and funding of social and healthcare pathways and voluntary bodies. In addition, it highlighted the complexity of the adult sight loss pathway through the health and social care system. Theoretical complexity also existed in the contrasting and opposing paradigms of disability, which the author attempted to address through the conceptualisation of disability as both an internal and external experience. Methodological complexity was exhibited in the range of research methods chosen to address the research questions underpinning my thesis. Existing research evidence demonstrated the negative effects of sight loss both socially and emotionally, highlighting the need for an effective psychological intervention to help people cope with the realities of acquired sight loss. I have attempted to design an effective psychological intervention to address this and have highlighted the need for emotional support to be embedded within the UK adult sight loss pathway with the development of clear funding avenues and quality standards.

Chapter 2. Review of publications

2.1 Introduction

This chapter provides a summary of each paper. It identifies the author's contribution to each study. It provides a narrative account of the development, dissemination and impacts of the projects relating to the emotional and social effects of sight loss, along with the proposed future development of the project.

2.2 Summary of publications

Paper 1. Thurston, M. (2010). An enquiry into the emotional impact of sight loss and the counselling experiences and needs of blind and partially sighted adults. *Counselling and Psychotherapy Research, 10*(1) 3-12.

Summary

This study aimed to explore the emotional impact of sight loss at a time when there was very little qualitative literature about this subject. It focussed particularly on self-concept, social connectedness, mood and loss. In addition it aimed to explore the counselling experiences and needs of blind and partially sighted people. I conducted semi-structured interviews with 18 blind and partially sighted participants from Scotland. These were analysed using a grounded theory technique. Items from the mental health and social functioning sub-scales of the National Eye Institute Visual Functioning Questionnaire-25 were used to define the sample. Results showed that participants experienced commonalities in their transition form sight to blindness. I proposed a five–stage theoretical model to describe the process. In addition I identified that participants had negative expectations of counselling and a lack of opportunity to receive counselling when needed, particularly after diagnosis. I also highlighted specific challenges associated with providing counselling for blind and partially sighted clients.

This study won the British Association for Counselling and Psychotherapy New Researcher prize 2009.

Paper 2. Thurston, M., Thurston, A. & McLeod, J. (2010). The socio-emotional effect of the transition from sight to blindness. *The British Journal of Visual Impairment, 28*(2) 90-112.

No 3 most cited paper (28 citations) British Journal of Visual Impairment, March 2016). In an independent Abertay pre-Research Excellence Framework review, this paper was rated as a 3* submission.

Summary

This paper was based on the same data analysis as Paper 1. I conducted semi-structured interviews with 18 blind and partially sighted participants from Scotland. These were analysed using a grounded theory technique. Items from the mental health and social functioning sub-scales of the National Eye Institute Visual Functioning Questionnaire-25 were used to define the sample. Results showed that participants experienced commonalities in their transition from sight to blindness. I proposed a five–stage theoretical model to describe the process. The paper was presented specifically for the sight loss sector rather than for counsellors. To this end, the counselling content was extracted.

Paper 3. Thurston, M., McLeod J. & Thurston, A. (2013). Counselling for sight loss: Using systematic case study research to build a client informed practice model. *British Journal of Visual Impairment, 31*(2) 102-122.

Summary

The aim of this study was to examine the process and outcome of counselling for a 70-year-old client who had experienced complete, irreversible, post-operative sight loss. The client received six sessions of counselling from a vision-impaired counsellor working within a pluralistic framework. The client completed outcome and process measures at every session, as well as at pre- and post-counselling. All sessions were

recorded and transcribed. The client also participated in pre- and post-counselling interviews. The data formed a rich case record that was analysed by a quasi-judicial enquiry team. The results suggested that this was a successful outcome case. The client-defined helpful aspects of therapy were (1) feeling understood; (2) being able to express emotions around the loss of sight; (3) finding a new identity; (4) finding ways to cope with fear, loss, dependency and other people's perceptions; (5) exploring the possibility of a positive future without sight; (6) making sense of things; and (7) finding ways to become more socially connected. These formed the basis of a therapeutic task list. Four key aspects of therapy were identified, which have implications for the development of a practice model.

Paper 4. Thurston, M., McLeod, J., & Thurston A. (2012). Counselling for sight loss. Using Hermeneutic Single Case Efficacy Design methods to explore outcome and common factors. *Counselling Psychology Review, 27*(4) *59-70.*

Summary

This paper was based on the same data analysis as paper 3. This paper viewed the model of counselling for sight loss from a common factors perspective and highlighted that a common factors perspective had the potential to deepen understanding of specific client groups.

Paper 5. Thurston, M. & Thurston, A. (2013). Risks to client confidentiality when communicating health information to blind and partially sighted patients. *Disability, CBR &Inclusive Development, 24*(1) *22-39.*

Summary

This paper developed out of research carried out by RNIB Scotland, which I was asked to analyse and write up as a report for the

organisation. The original research explored the accessibility of health information for blind and partially sighted people living in Scotland. Data was gathered from a survey of 228 blind and partially sighted persons in 15 health authorities across Scotland. The data indicated that about 90% of participants did not receive communications from various NHS health departments in a format that they could read by themselves. This had implications for client privacy, confidentiality and the wider impact on life and healthcare. The implications for professional ethical medical practice and for public policy were highlighted in this paper, and recommendations for improved practice were made.

Paper 6. Willis, D. & Thurston, M. (2014). Working with the disabled patient: Exploring student nurse views for curriculum development using a swot analysis. *Nursing Education Today, 35*(2) 383-387.

Summary

This study looked at how the Patient Rights (Scotland) Act 2011, which requires health care to be accessible to all people and to take into account individual patient needs (See paper 5 for my contribution to this Act), has particular implications for the nursing care of disabled patients. This, in turn, necessitates nursing curricula that reflects the needs of people who have disabilities to equip the future workforce with knowledge and skills to provide appropriate care. The aim of this study was to explore student nurses' strengths and weaknesses in this area and to identify opportunities and threats to their knowledge and skills development.

As part of a study day about disability (particularly sight loss and learning disability), first year nursing students were asked to take part in a SWOT analysis and to post comments under the categories: strengths, weakness, opportunity and threats on a central wall about working with people with disabilities.

Students appeared to be aware of the challenges faced by disabled people, especially in a hospital setting. However, they believed they were developing skills that would enable them to provide holistic care, which would promote autonomy. Communication was viewed as both a strength and weakness and was identified as an essential skill to working effectively with people who had a disability. Students welcomed the opportunity to work with experts and clients as well as being directed to resources to increase their knowledge. The study concluded that the integration of disability into the nursing curriculum is needed to ensure students have awareness and confidence to work effectively with people who have a range of cognitive and physical disabilities alongside other medical problems.

Paper 7. Scott-Brown, K. C., Harris, J., Simmers, A., Thurston, M., Abbas, M. deMajo, T., Reynolds, I. Robinson, G. Mitchell, I, Gilmour, D. Martinez, S., & Isaacs, J. (2014). Tapology: A game-based platform to facilitate e-health and e-inclusion. In Stephanidis, C. & Antona, M. (Eds) *Lecture Notes in Computer Science: Universal Access in Human-Computer Interaction.* **Part III, 8515, pp. 368-377.**

Summary
This paper described the development of a tablet computer game app developed specifically for people with age related macular degeneration. The primary goal of the app was to present an amusing and engaging means for elderly participants to engage with Information Communication Technology (ICT) whilst also engaging in visual rehabilitation. A long-term goal of the project was the construction of a platform, which could gather data on visual function by creating a suite of games that could generate sufficient regular visual engagement to enable users to learn how to maximise any residual vision they might have. The inclusive design process took into consideration the perceptual and cognitive constraints of the visually impaired user group. The 'Tapology©' app was formally launched at a large computer games festival where data was gathered from a range of users to inform the development of the

gameplay. The initial results and feedback informed the ultimate goal of creating a suite of applications that have a wide social and geographic reach to promote and inform e-inclusion and e-health. This has particular significance for the e-inclusion of blind and partially sighted people.

Paper 8. Thurston, M. (2014). 'They think they know what's best for me'. An interpretative phenomenological analysis of the experience of inclusion and support in high school for vision impaired students with albinism. *International Journal of Disability, Development and Education, 61*(2) 108-118.

Summary

This study tried to understand the experience of being a visually impaired pupil with albinism in a mainstream high school. The participants, aged 16 and 15, had approximately 10% functional vision, stable from birth and had a record of additional support needs at their respective schools. Both had albinism. They were interviewed using a schedule of open questions to explore their perceptions of inclusion and of using low-vision aids in school. This data was recorded, transcribed and analysed using Interpretative Phenomenological Analysis. From the analysis, I identified a negative cycle of inclusion, based on the students' internalised feelings of difference. I also identified discrepancy between the low-vision aid priorities identified by experts and those identified by students. I suggested that staff could have improved the participants' feelings of inclusion by listening to their views and by being more responsive to their particular needs.

Paper 9. Thurston, A. & Thurston, M. J. (2013). A literature review of refractive error and its potential effect on reading attainment in the early years of school. *Optometry and Visual Performance, 1*(1) 44-56.

Summary

This paper presented a critical review of the literature about the potential impact of undiagnosed and untreated refractive vision problems on

reading development in the early years of primary school. The literature suggested correlations between uncorrected refractive vision problems and poor reading development. However, the relationships reported were complex, with myopia being reported to correlate with high reading ability in some studies. In addition it was emphasised that correlation did not necessarily imply causation. This study recommended future research to explore whether refractive error causes poor reading development for some children in school.

Paper 10. Pybis, J., Thurston, M., Dennison, C., Broom, M. & Miller, A. (2016). The nature of emotional support and counselling provision for people with sight loss in the United Kingdom. *British Journal of Visual Impairment, 34(2*) 169-178.

Summary

This study developed and distributed an on-line survey about the provision of emotional support and counselling for blind and partially sighted people in the UK. The survey received 182 responses from across the UK. There were more services offering 'emotional support', in the form of listening and information and advice giving, than offered 'counselling'. Providers with differing qualifications delivered services in a variety of formats. Waiting times were fairly short and clients presented a wide range of issues including depression and anxiety. Funding came from a range of sources, but many felt that their funding was vulnerable. We identified a quality standards issue and suggested the need for a national standardised framework for the provision of emotional support and counselling services for blind and partially sighted people in the UK.

2.3 The author's contribution to each publication

The International Committee of Medical Journal Editors (ICMJE) suggest four criteria upon which to base authorship of publications:

- *Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND*

- *Drafting the work or revising it critically for important intellectual content; AND*
- *Final approval of the version to be published; AND*
- *Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.*
(ICMJE, 2009)

I asked my co-authors to advise what percentage of the relevant paper(s) they thought attributable to me (Papers 1 and 8 are not included as they were sole author papers).

Paper 2. Thurston, M., Thurston, A. & McLeod, J. (2010). The socio-emotional effect of the transition from sight to blindness. *The British Journal of Visual Impairment, 28*(2) 90-112.
Co-authors AT and JMcL both estimated my contribution was 90%

Paper 3. Thurston, M., McLeod J. & Thurston, A. (2013). Counselling for sight loss: Using systematic case study research to build a client informed practice model. *British Journal of Visual Impairment, 31*(2) 102-122.
Co-authors AT and JMcL both estimated my contribution was 90%

Paper 4. Thurston, M., McLeod, J., & Thurston A. (2012). Counselling for sight loss. Using Hermeneutic Single Case Efficacy Design methods to explore outcome and common factors. *Counselling Psychology Review, 27*(4) 59-70.
Co-authors AT and JMcL estimated my contribution was 90%

Paper 5. Thurston, M. & Thurston, A. (2013). Risks to client confidentiality when communicating health information to blind and partially sighted patients. *Disability, CBR & Inclusive Development, 24*(1) 22-39.
Co-author AT estimated my contribution was 70%

Paper 6. Willis, D & Thurston, M. (2014). Working with the disabled

patient: Exploring student nurse views for curriculum development using a swot analysis. *Nursing Education Today, 35*(2) 383-387.
Co-author DW could not be contacted. I estimate my contribution was 10%

Paper 7. Scott-Brown, K. C., Harris, J., Simmers, A., Thurston, M., Abbas, M. deMajo, T., Reynolds, I. Robinson, G. Mitchell, I, Gilmour, D. Martinez, S., & Isaacs, J. (2014). Tapology: A game-based platform to facilitate e-health and e-inclusion. In Stephanidis, C. & Antona, M. (Eds) *Lecture Notes in Computer Science: Universal Access in Human-Computer Interaction.* Part III, 8515, pp. 368-377.
Co-author KSB estimated my contribution was 10%

Paper 9. Thurston, A. & Thurston, M. J. (2013). A literature review of refractive error and its potential effect on reading attainment in the early years of school. *Optometry and Visual Performance, 1*(1) 44-56.
Co-author AT estimated my contribution was 20%

Paper 10. Pybis, J., Thurston, M., Dennison, C., Broom, M. & Miller, A. (2016) The nature of emotional support and counselling provision for people with sight loss in the United Kingdom. *British Journal of Visual Impairment, 34*(2) 169-178.
Co-author JP estimated my contribution to be 50%

2.4   The development of Counselling for Sight Loss

In this section I will give an account of the development of Counselling for Sight Loss, starting with an explanation of its theoretical underpinning. I hope this account can be used as a blueprint for the development of counselling for other long-term health conditions, such as Diabetes or Multiple Sclerosis (McLeod, Thurston & Smith, 2015).

2.4.1   The Transition from Sight to Blindness

The most prevalent attempt to conceptualise adaptation to acquired sight loss using existing theoretical models (Bergeron, and Wanet-Defalque,

2012) is the grief model (Kubler-Ross, 1970), a five-stage model describing a grieving process of adaptation to loss. Stage one of the process is characterised by denial, where the person may not acknowledge the reality of the loss. This may be followed by anger at stage two, where the person feels the emotion of the loss and may express this as anger towards themself or others. Stage three may involve bargaining, where the person may give anything to avoid the pain of the loss. This may be followed by depression at stage four with a shift to acceptance at stage five. The rationale behind its application to the experience of acquired vision impairment is that vision impairment can be viewed as a loss, much like any other loss. Although this is true to a certain extent, it does not recognise the holistic complexities of transitioning from being able-bodied to becoming disabled. In some ways it is a two-dimensional conceptualisation of loss, which is situated within a medical model rather than a social model of disability.

The Transition from Sight to Blindness model (Figure 6, p41) which attempts to conceptualise both the internal and external experiencing of a person's acquired sight loss, emerged organically from data collected about the lived experiences of people who had acquired sight loss in my initial grounded theory study (Thurston, 2010; Thurston, McLeod & Thurston 2010). Positionally, this is different from applying an existing theoretical framework to make sense of the experiences. As such, it presents a more accurate and nuanced theoretical representation of the process of acquired sight loss. It forms the theoretical basis for the subsequent studies presented in this thesis.
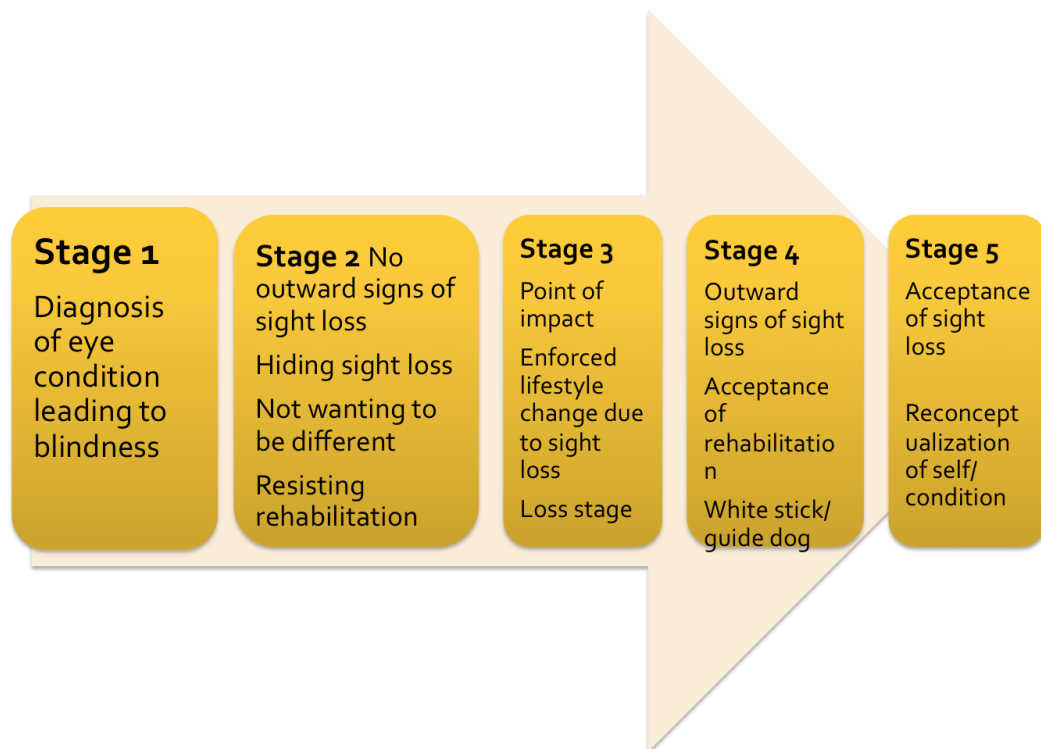
Stage 1	Stage 2 No outward signs of sight loss	Stage 3	Stage 4	Stage 5
Diagnosis of eye condition leading to blindness	Hiding sight loss Not wanting to be different Resisting rehabilitation	Point of impact Enforced lifestyle change due to sight loss Loss stage	Outward signs of sight loss Acceptance of rehabilitation White stick/ guide dog	Acceptance of sight loss Reconceptualization of self/ condition

Figure 6. The transition from sight to blindness model (Thurston, 2010).

Stage one of the 'Transition from Sight to Blindness model' occurs around the diagnosis of an eye condition leading to severe sight impairment. This stage encompasses medical reality. During this stage, shock, panic and fear may be typical responses.

During stage two, there may be no outward indications of the person's sight loss. Strategies to hide their sight loss may be employed. For example, a person may be reluctant to use low vision aids in public, such as a white cane or a liquid level indicator. It appears important, at this stage, for life to carry on as if unaffected by sight loss. Engagement with the rehabilitation is unlikely to be successful in this stage because of resistance to change in identity and in public persona. Stage three represents a point where the loss of sight begins to impact on the person's life, so that there are enforced lifestyle changes, for example, the loss of a driving licence or the inability to get out and about unaided. It is at this point that the person experiencing sight loss may be particularly aware of a multitude of losses, practical, emotional and

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aspirational. This may lead to the very challenging realisation that life can no longer be lived as it previously was before sight loss. Engagement with rehabilitation at this point may be more successful. It does not make engagement with rehabilitation any easier, as it is likely to lead to external signs of sight loss, which, in turn, elicit a public response to blindness. This is an immensely difficult stage, in which the person may struggle to come to terms with a public identity as a blind person and experience first hand discrimination and social oppression. The final stage in this theoretical model is a stage where the person begins to accept their sight loss, perhaps through re-conceptualisation of self or their sight condition. A variety of strategies such as scaling the eye condition against a life-threatening condition, looking on the bright side of life, or appreciating how sight loss may have brought unexpected, positive life changes may be employed during this stage.

This model is not intended to be prescriptive. It is a flexible conception of a process, not a strictly linear progression. For example, one participant from the first study recounted his experience of attending an eye appointment at the hospital clinic. During the appointment, he was advised not to drive again as his sight had significantly deteriorated. As driving was a significant aspect of his employment, he immediately phoned his employer to share this important information. The employer identified a solution involving registering him as disabled at work. So for this person, the point of impact came almost simultaneously at the time of his diagnosis. In contrast, another participant described losing her sight over many years. She reported it was not until her partner died in later years that her sight loss really impacted on her. In this case, the point of impact came many years after diagnosis. These examples show that model attempts to capture *a process* of acquiring sight loss. Understanding this process will better inform those who seek to meet the social and emotional needs of blind and partially sighted people.

The model highlighted that different types of emotional support might be needed at different times in the process of losing sight. For example, in

stage one (diagnosis of a serious eye condition), frontline support might help a person cope with the shock of the diagnosis. In stage three (point of impact), counselling might help a person identify and cope with multiple losses. In stage four (outward signs of sight loss) counselling might help a person explore how they feel about change of identity, whilst peer support might help model practical ways of coping. People who are unable to move on beyond the point of impact (stage three), may be most at risk.

2.4.2 Sector issues

One of the key issues for the sight loss sector was defining the term emotional support. It was widely referred to in a range of documents, yet the definition was vague. What constituted emotional support? Was it tea and sympathy from a volunteer, a meeting with the social worker, a peer support group or professional counselling? In response to this RNIB UK drafted a framework for emotional support, which defined it as a three-tier system (See Figure 7).

RNIB Group Framework for Emotional Support

Tier 3	**Service/Interventions** •Mental health professionals i.e. •Psychiatrist/Mental Health Services •GP	**Functions** •Statutory Health Support	
Tier 2	**Services/Interventions** •RNIB Emotional Support Service •Action Counselling Services (e.g. Bristol, Merseyside) •Some local societies counselling provision •Genetic counselling (CCYP) •Specialist support (e.g. Macular Disease Society) •GP and IAPT (Improving Access to Psychological Therapies - NHS programme) •Middle Step Programme (spans Tiers 1 & 2 - To be agreed)	**Functions** •Structured counselling support delivered by a qualified professional, supported by an ethical framework •Allows for - regression, acceptance, beginning and end and relief in between	**Triggers into Tier 3** •Continued threat of suicide •Other diagnosable mental health disorders * Tier 2 services might work in partnership with a Tier 3 Services if it is in the best interest of the client
Tier 1	**Services/Interventions** •ECLOs •Helpline •Advice Team •Local info & advice services •Rehabilitation officers/ILCOs •"Finding Your Feet" programme •Local societies •"Middle Step" Programme (spans tiers 1 & 2 - To be agreed)	**Functions** •Initial hearing and identification of distress •Listening Ear •Next step-signposting •Checking understanding of information •Normalisation (acknowledging where thoughts and feelings are a normal reaction for the context)	**Triggers into Tier 2** •Suicide ideation •Repeat story telling •Not taking up practical support •Not moving on •Denial •Depression •Anxiety •A client requesting support

Figure 7. RNIB group framework for emotional Support

Tier One services referred to front-line support services or interventions, for example Eye Clinic Liaison Officers (ECLO), peer support groups,

embedded counselling etc. The function of Tier One services was essentially to provide a listening ear, practical advice, normalisation and identification of distress. Recognised triggers into Tier Two services included depression, anxiety and symptoms of distress, such as suicidal thoughts. There was a recognised pathway into Tier Two services. Tier Two services referred to specialist counselling services such as RNIB emotional support services and other face-to-face or telephone counselling services. The function of Tier Two services was to provide more structured psychological support. Triggers into Tier Three services included a continued threat of suicide or evidence of a more complex mental health issue. There was a recognised pathway into Tier Three services, although Tier Two and Tier Three services might work in partnership for the benefit of the client.

I used the RNIB Group Framework for Emotional Support to describe different types of emotional support within the sight loss sector in the dissemination of my research. Having a shared language with which to refer to different types of services has been pivotal in allowing the sector to communicate effectively around a shared understanding.

2.4.3 Sector unknowns (Paper 10)

 I identified four key sector unknowns:
1. Who would deliver emotional support?
2. Where would it be delivered?
3. Who would pay for it?
4. What type of emotional support would be most effective?

In order to address the first three unknowns, in 2012, I regrouped the VISION2020 UK Counselling and Emotional Support Services group to include key figures within the major sight loss charities along with representatives from the British Association for Counselling and Psychotherapy and low vision services. I suggested that the group design and execute a scoping survey to map the nature and provision of emotional support services in the UK for blind and partially sighted people (Paper 10

- Pybis, Thurston, Dennison, Broom & Miller, 2016). This would provide an opportunity to empirically examine the extent to which actual practice mapped onto the framework.

The survey asked questions about the nature of emotional support/counselling being offered, including funding streams, service usage and type of interventions. The results found that there was some Tier One provision, but much less Tier Two provision. These survey findings provided important information about service provision in the UK and, in addition, provide an evidence base for future funding requests and the development of Tier One and Tier Two services. One of the key findings of the study was the need for quality standards benchmarking in the delivery of services. A small proportion of emotional support and counselling services for blind and partially sighted people in the UK is currently being delivered by unqualified staff.

2.4.4 Addressing the fourth unknown (Papers 3 and 4)

The fourth unknown needed to be addressed - what type of emotional support is most effective for blind and partially sighted people? In other words, what do people with sight loss really want to talk about, what type of talk helps and why? These questions formed the rationale for papers 3 and 4.

2.4.5 Systematic case study research – the development of therapeutic tasks

I chose systematic case study research in an attempt to answer the fourth unknown. Systematic case study methodology is not anecdotal. Multiple sources of data are collected and analysed by a team of researchers. It drills down into the processes and outcomes of counselling for sight loss and gathers data about what blind and partially sighted people find helpful in therapy (Thurston, McLeod & McLeod, 2014). Two systematic case studies were carried out, although only one of them was written up for publication and is presented for consideration in this thesis (Papers 3 and 4 - Thurston, McLeod & Thurston 2012, 2013). Both cases involved a

client with sight loss, who attended the Abertay University Counselling Research Clinic (TCC) for six sessions of pluralistic counselling. A different method of analysis was used on each case. In the first case a quasi-judicial hermeneutic single case efficacy design was used. In the second case a creative consensus (Ward) methodology was used. Both were successful outcome cases. The case of Sylvia, presented for consideration, involved a 70-year-old woman who lived alone in a rural location. She had sudden and complete sight loss after a routine operation. Sylvia summed up her situation by saying

"I feel that my life, quite honestly, has been taken away from me. I'm in the world but I'm not really here. There doesn't seem to be a future for me really. No purpose. I do quite wish I were dead. I mean, I don't have plans to end my life, but that is my weekly wish" (Thurston, McLeod & Thurston, 2013).

In addition to an initial assessment, Sylvia completed process and outcome measures each week. This presented some challenges, in that Sylvia couldn't engage with any written material due to her lack of sight. A research assistant administered and gathered all data orally. The process data (Helpful Aspects of Therapy) identified what Sylvia found helpful about her counselling. Analysis of this data led to a therapeutic task menu and from the Sylvia case, seven therapeutic tasks for sight loss were identified:

1. Clarifying thoughts (about what has happened and what is happening)
2. Feeling heard and understood (by someone with specialist insight into sight loss)
3. Expressing difficult emotions (fear, anxiety, low mood)
4. Exploring identity (integrating sight loss with sense of self as a whole)
5. Examining and challenging negative self concepts (fostering self care and compassion)
6. Exploring a future without sight (planning for future strategies, living in the present)

7. Making the most of support and cultural resources (groups, relationships and activities).

Analysis of data from the second case, in which the client had degenerative sight, identified seven identical and three additional therapeutic tasks related to degenerating sight:

1. Recognising the development of skills and coping strategies (collecting positive evidence)
2. Coming out as a blind person (letting people see me as a blind person and developing societal interactions)
3. Nurturing empowerment (combating vulnerability).

Further cross-case analyses would test the generalizability of this therapeutic task list. In order to do this, more data would need to be collected from more cases.

Development and strategic partnerships

The next steps in the development of Counselling for Sight Loss involved scaling up the project and forging and maintaining partnerships within the sector. An effective way of doing this was to attempt to embed systematic case study research within an existing counselling setting, so that data could be gathered on multiple clients.

In July 2014, I delivered staff training in case study research methods for RNIB Emotional Support Services counsellors in London. This took place on two separate dates, to ensure that the counsellors were fully briefed about case study research methods. The counselling team were then invited to participate in case study research by allowing their counselling sessions to be recorded, and by incorporating process measures into their daily client sessions. Three of the team of six counsellors volunteered to do this. Abertay University School of Social and Health Sciences Research Ethics Committee gave approval for the pilot study. On initial assessment, new clients to the service were given the option of

finding out more about the research project. If they wished to participate, they were contacted and sent the participant information sheet, which could be read to them if they had no sight. Dedicated telephone lines were allocated to the counsellors participating in the research. These telephone lines were numbered and recorded. Clients who had given consent to be part of the study were transferred to the dedicated telephone lines and were contacted by telephone both before and after each session so that data collection could be administered orally. They were also contacted by telephone after the completion of their counselling to take part in a Change Interview, which the author conducted as she was external to RNIB.

RNIB subsequently explored ways of continuing to expand case study research within their telephone counselling service.

The development of the accessibility/inclusion studies (Papers 5, 6 & 7)

This section charts the development of the social inclusion studies. The aim of the first social inclusion study was to examine the experiences of blind and partially sighted people accessing health information from various NHS health services in Scotland, including GP practices, practice nurses, hospitals, accident and emergency rooms and NHS dentists, and to make recommendations for policy and practice based on their findings. Health information was defined as any information relating to a person's health, such as prescriptions, test results, medical instructions, appointment notifications, in-patient information, out-patient information and self-help leaflets. A survey was designed and disseminated to 400 RNIB Scotland members by post and by email. The survey asked questions in seven categories - about you, about your sight, access to healthcare services, communications support, communicating with staff, understanding your condition/treatment and making a complaint. Qualitative and quantitative data was generated. The findings showed that almost all the respondents (96%) had a preferred reading format. 9/10 respondents received information in an inaccessible format and the

majority of respondents did not complain. From these findings, recommendations were made about education and training for health care professionals. These included continuing professional development and enhanced awareness for healthcare professionals on how best to support blind and partially sighted people physically and emotionally in healthcare settings. In addition, education about different types of blindness and the impact of this on communications and support was suggested, in addition to an awareness of stealth breaches of confidentiality that were taking place due to the lack of accessible health information.

2.4.6 Dissemination and development

The findings in the above study (Paper 5 - Thurston &Thurston, 2013) were first published as a campaign document (RNIB Scotland, 2010). The recommendations we made in this document formed the basis of the student teaching input given in the supporting paper presented in this thesis (Paper 6 - Willis & Thurston, 2015). In addition, inclusive health for those with sight loss became the subject of a 'Games for Good' project, led by Abertay colleague, Ken Scott Brown. This gave rise to the game 'Tapology', which is presented as a supporting paper (Paper 7 - Scott-Brown, K. C., Harris, J., Simmers, A., Thurston, M., Abbas, M. deMajo, T., Reynolds, I. Robinson, G. Mitchell, I, Gilmour, D. Martinez, S., & Isaacs, J., 2014).

2.4.7 The second inclusion study (Papers 8 & 9)

The main focus of all the research studies preceding this one had been adult experiences of acquired sight loss. I had 20 years prior experience as a schoolteacher and was curious about the impact of sight loss on school pupils. The main assumption that underpinned paper 8 (from policy documentation and previous research) was that many mainstream schools adopted a model of inclusion for vision-impaired pupils, which focused on the physical needs of the pupil to the deficit of their socio-emotional development. It proved difficult to recruit participants to this study despite exhausting all avenues – youth forums, schools, teachers,

radio broadcasts and national conferences for vision impaired young people. Only two participants were recruited, both of whom had sight loss due to albinism. IPA (a qualitative methodology that is appropriate for the analysis of small numbers of cases) was used to investigate their lived experience. Two main themes emerged – *experiencing low vision in schools*, and *experiencing additional support in schools*. It appeared that these vision impaired pupils valued 'blending in' whilst the teachers valued improvement in function. This led to a tension between what pupils prioritised in terms of their support needs and what teachers prioritised. The findings of this study were presented to the Scottish Teachers of Vision Impaired Pupils as part of their Continuing Professional Development Programme. The teachers reported recognising this tension within their own school settings.

This paper was the starting point for the literature review on undiagnosed sight loss and its effect on reading attainment in primary school children (Paper 9 - Thurston & Thurston, 2013a).

2.5 Chapter summary

This chapter summarised and identified my contribution to each paper. In addition it charted the development of two strands of research – one strand investigating the emotional effects of sight loss and the other investigating the social effects of sight loss. Both strands were needed to understand the full impact of sight loss. I then gave an account of how strategic dissemination and partnerships helped maximise research impact in both cases. I wanted to provide a blueprint for how this research was developed so that it might be replicated for other long-term health conditions. This chapter has therefore charted the development of a cohesive programme of research, which has responded to sector needs and in which the projects encompass a holistic understanding of the effects of sight loss. The real-world application of research findings has been a crucial aspect of this body of work (for example, giving evidence to Scottish Parliament and influencing the wording of the Patient Right (Scotland) Act, 2011 and teaching RNIB staff how to gather case study

data within their counselling service). It has been important to have a practical understanding of the needs of the sight loss sector.

Chapter 3. Contributions and reflections

3.1 Introduction

This chapter identifies the contribution of the body of research to theory, practice and policy. In addition, a critical reflection on the body of work and its limitations is presented.

3.2 The contribution of the research to knowledge

The work presented in this thesis has made a significant contribution to existing knowledge in the following ways:

1. The transition model from sight to blindness offers a more comprehensive and nuanced account of the socio-emotional process involved in acquiring sight loss. Other attempts have been made to use existing theories to explain the process of sight loss (Bergeron & Wanet-Defalque, 2012), but the transition model was created from the lived experience of people with acquired sight loss. This model provides an empirically-grounded understanding of the ways in which different types of people require different types of emotional support and counselling at different times.

2. The paper describing the model (Paper 2-Thurston, Thurston & McLeod, 2010) has informed the sight loss sector and is now the third most cited paper in the British Journal of Visual Impairment (28 citations) (http://jvi.sagepub.com/reports/most-cited accessed 7th Feb 2016).

3. The systematic case study research presented for consideration in this thesis has identified therapeutic tasks specific to sight loss. This is a development of McLeod and McLeod (2011) therapeutic task list and provides a client-specific context to enable those working with people with sight loss an opportunity to open up therapeutic conversations about specific aspects of sight loss. The task list is being piloted with blind clients in the Abertay Counselling Research Clinic (TCC). These findings have not yet been written up for publication. The therapeutic tasks will inform the design and development of specialised training packages for

those delivering emotional support and counselling to blind and partially sighted adults in the UK.

3.3 The contribution of the research to practice

The work presented in this thesis has made a contribution to existing practice in the following ways:

1. The transition from sight to blindness model provides a basis for understanding that different people may need different types of emotional support at different points in the process. This has shaped thinking in the reconsideration of the Early Intervention and Rehabilitation Project, of which the author is a project board member. It is now recognised that emotional support at the time of rehabilitation might prove helpful. The model was referenced in a recent guide for charity funders of visual impairment in Scotland (Boswell & Kail, 2016).

2. The scoping survey has enabled the sector to better understand existing provision of emotional support and counselling in the UK. It has given a reference point for talking about UK provision in terms of tiers of service and has highlighted where there are gaps in provision, particularly at Tier 2 level. It has highlighted the need for the development of quality standards and specialist training packages for those working with blind clients.

3. Counsellors at RNIB Emotional Support Services London have learned how to gather systematic case study data within their service as a result of knowledge exchange training based on my systematic case study research.

4. The Counselling Research Centre at Abertay University (Tayside Centre for Counselling, School of Social and Health Sciences) takes referrals from local societies and provides a specialist counselling service for people with sight loss in Tayside.

3.4 The contribution of the research to policy

The work presented in this thesis has made a significant contribution to existing policy in the following ways:

1.The research carried out for RNIB Scotland regarding Access to Health Information has contributed directly to the wording of The Patient Rights Act (Scotland) 2011. It has made explicit the expectation that health care should be accessible to all.

2.Following on from the Patient Rights Scotland Act 2011, the author has advised RNIB Scotland in their consultation to Greater Glasgow Health Board regarding their accessible health policy.

3.5 Critical reflection

The specific limitations of each study are identified and discussed within the publications presented for consideration. This section aims to provide critical reflection on the body of work as a whole.

In the research presented, I am aware I made meaning of the data through my own lived experience, as well as through prescribed forms of data analysis appropriate to different sources of information. The personal dimension of meaning-making within these studies has been both a strength and a weakness of the research papers. In some ways, my experience of blindness has enabled me to ask relevant questions. It has allowed me to research 'from the inside' (Rooney, 2005). Talking to a blind researcher enabled some participants to talk about issues they believed sighted people might not understand. Indeed, in some cases (Thurston, 2010) it revealed a hidden distrust of a sighted person's ability to understand a blind person, alongside a degree of guardedness around the co-existence of the world of blindness and the world of sight. Within the sight loss sector it is rare for a research leader to hold an 'insider' perspective. Indeed, although there is a growing trend for insiders to be represented within sight loss charities, traditionally they are dominated by those with 'outsider' perspectives.

In contrast, my experience of blindness has also represented a potential limitation of the research, in terms of interfering with my ability to be truly objective. Someone else gathering the same data may have arrived at alternative findings, particularly as qualitative analysis can be subject to researcher bias. In addition, it has been hard to resist adopting a campaigning stance, particularly around some of the issues of inclusion and quality standards in service delivery. In respect of possible bias, it has been essential to engage in collaborative research, involving colleagues who could offer alternative interpretations of data, and to submit my work to journals that provided rigorous and critical peer reviewing.

Important lessons have been learned from the programme of research carried out to date. For example, in relation to the counselling case-study strand of the programme, it has proven difficult to recruit clients within the Abertay Counselling Research Centre. Perhaps this is because counselling has not yet managed to shake off its stigma, particularly for the older generation who are more likely to present with sight loss issues. Partnership with larger sight loss charities, such as RNIB, is crucial for the development of the case study research programme. People tend to trust a sight loss brand such as RNIB and are more likely to use this for support rather than generic counselling. This may reflect their distrust of the sighted world to understand the problems of the blind world. This is a problem that may need to be addressed specifically in future service development.

The majority of the studies represent an East of Scotland monoculture, which has hindered the development of a cross-cultural perspective. This is a fundamental weakness in the body of work and more work needs to be done to assess the culturally specific emotional support needs of other ethnic groups within the UK.

3.6 Practical issues

Carrying out this body of research identified unique difficulties of researching within the blind and partially sighted community. Traditional sample recruitment methods such as posters and leaflets were not effective, as visual material cannot engage this client group. In addition, traditional research outcome measures were not useable. Clients who cannot read the measures rely on others to administer them. This arguably affects the validity of the measures in that the participant essentially co-constructs their answers with the person reading them (the tone of a question read aloud to a participant can affect the response they give). So even in research, this body of people risk being marginalised, misrepresented and excluded.

3.7 Directions for future research

The therapeutic task list for blind and partially sighted people needs to be validated and tested for generalizability. This could be achieved by scaling up the project by gathering multiple case study data. When this is done, large scale cross case comparisons could take place. The next step would be to trial the task list within organisations delivering counselling to blind and partially sighted people. In addition, standards for training for counsellors working with sight loss could be developed and accredited. Likewise, the transition model could be reviewed and tested for generalizability.

More longitudinal research is needed to show the long-term effectiveness of Counselling for Sight Loss on improving mood and wellbeing.

I see the key future development of my research in using the therapeutic task list to design a training package for those delivering emotional support and counselling services to blind and partially sighted people within the UK. Principles of good practice also need to be established and adopted nationally.

3.8 Chapter summary

This chapter has explored the contribution of the research to theory, practice and policy and it has identified issues concerning conducting research within the blind and partially sighted community.

Of particular significance to theory is the Transition model from Sight to Blindness and the Therapeutic Tasks for sight loss. Of particular significance to practice is the scoping survey, which examines current provision of emotional support in sight loss within the UK, and the assertion that different types of support are needed at different points of the Adult UK Sight Loss Pathway. Knowledge exchange about case study data gathering techniques has also played a part in influencing practice at RNIB Emotional Support Services, London. In addition, the provision of a specialist counselling service for people with sight loss in Tayside has given local societies a place to refer clients struggling with the emotional effects of sight loss. Of particular significance to policy is the reference to accessibility with the Patient Rights (Scotland) Act 2011 and the subsequent accessible health policy implemented by Greater Glasgow Health Board. Critical reflection on the body of work highlighted the strengths and weaknesses of the researcher's 'insider' perspective, along with reflection on the co-existence of the world of sight and the world of blindness. It considered the problem of the stigma associated with counselling and how significant it is for clients to trust the sight loss 'brand.' Finally, the lack of multi-cultural perspectives was considered as a direction for future research.

3.9 Conclusion

This research has supported previous findings that sight loss has a negative emotional impact on people. Each stage of the process of acquiring sight loss presents a different emotional challenge, from fear and panic at diagnosis, to feelings of loss at the point of impact, to reassessing identity and engaging with public perceptions during rehabilitation. In addition, this research has highlighted that, across the lifespan, from early years, through school years to adult life to old age, those who live with sight loss may be disadvantaged in their ability to be

fully participative in society. The studies presented for consideration found failings in both education and in healthcare that need to be addressed. Even in leisure activities there were shortfalls in accessibility for blind and partially sighted people (Scott-Brown et al., 2014).

 I have presented a narrative account of the development of a cohesive body of empirical research about the social and emotional effects of acquired sight loss. In response to this, my thesis centres on the development of a Pluralistic Model of Counselling for Sight Loss, based on a set of therapeutic tasks, identified from systematic case study research. It is my intention that these tasks inform future training packages for people delivering emotional support and counselling to blind and partially sighted people. I have scoped existing counselling and emotional support service provision for blind and partially sighted adults within the UK and have identified a quality standards issue. My future research will seek to address this through the establishment of a set of principles of good practice and training materials for the sector, eventually leading to NICE accreditation. I have shown my thesis has implications for knowledge, practice, policy and future research. The opening chapter provided an overview of the context in which the research took place. The second chapter outlined the development of the key projects. The third chapter outlined the contributions of the research and offered critical reflections on arising issues.

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Appendices

Peer - reviewed publications

The content of the Appendices from pages 72-212 have been removed for copyright reasons. The content included 10 peer reviewed journals. The citations to the peer reviewed journals are listed below.

Thurston, M. (2010). An enquiry into the emotional impact of sight loss and the counselling experiences and needs of blind and partially sighted adults. *Counselling and Psychotherapy Research, 10*(1) 3-12. doi**:**10.1177/0264619609359304

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Other publications not included for consideration within this thesis

Armstrong, J., Hawkins, A. & Thurston, M. (2013). Practice Research Networks: Promises, Pitfalls and Potential. *Therapy Today,* (May) 35-37.

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Book Chapters

McLeod, J., Thurston, M. & McLeod, J. (2014). Case study methodologies. In Vossler, A. & Moller, N. (Eds.) *The counselling and psychotherapy research handbook.* (pp198 - 211). London: Sage.

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Awards:

British Association of Counselling and Psychotherapy*: Counselling and Psychotherapy Research. New Researcher Prize 2009.*

Impact of the research to date

The development of NICE Guidelines for Counselling for Sight Loss

VISION2020UK are currently developing a Process Manual as a basis for becoming an accrediting body for National Institute for Health and Care Excellence (NICE). This would allow them to make evidence based recommendations for professionals in the sight loss sector about a range of health and social care topics. As part of the process of becoming an accrediting body, VISION202UK need to demonstrate application of the process using two case studies. One of the case studies will be Counselling for Sight Loss and will involve the Counselling and Emotional Support Services group which the author chairs. A meeting with NICE revealed a shift towards the acceptance of a plurality of evidence types rather than simply RCT evidence. Systematic case study evidence would be considered as a credible source of evidence that represented the voice of the service user, which NICE were keen to locate at the heart of service development. The first part of the process involves the formation of a topic specific Recommendation Development Committee. Funding is being sought to progress this. If successful, the Recommendation Development Committee will consider the scope of the counselling for sight loss area for which recommendations will be made. Funding is needed to progress this.

Accessible Health care

The first inclusion project (Thurston & Thurston, 2013) was initially published as an RNIB Scotland document. We presented the findings at the Cross-party Advisory Group for Vision Impairment at Scottish Parliament. Following on from that, we were invited to submit the findings as evidence to the Health and Sport Committee considering the Patient Rights Bill Scotland 2011. The evidence was accepted and we presented this to the Health and Sport Committee at Scottish Parliament. RNIB

Scotland gave a press release to coincide with the presentation of the evidence, which was reported in most Scottish newspapers and online:

***Demand for better health communication for blind**
Published on Wednesday 29 September 2010 12:07
COMMUNICATION between blind people and health services has to improve following the release of a damning survey, a city charity has said.
The Scottish study found that only one in ten blind or partially sighted people receive crucial information in a format they can understand.
The Royal National Institute of Blind People in Scotland said this put patients' health at risk, and meant mistakes could be made with medical advice, test results and diagnosis.
The charity said the NHS had to do more to consider how blind patients would like to be communicated with, and cited GPs as the most likely so seek a person's preference.
Mhairi Thurston, the academic who conducted the research, said: "Being able to access healthcare information independently is vital to people who are blind or partially sighted. It is also a right.
"Too often people receive information in formats they can't understand, even when healthcare providers know they have a sight loss condition." (News.Scotsman.com. 2010).

I was subsequently interviewed by BBC Scotland and the interview was aired on the national news.

***Blind people struggling with NHS**
By Eleanor Bradford BBC Scotland Health Correspondent

Blind and partially-sighted people are not getting information from the NHS in braille or other formats they can understand, according to research.

A survey found nine out of 10 people with serious sight problems had difficulty reading prescriptions, test results and other correspondence.

The study was commissioned by the Royal National Institute for the Blind.

It said some with sight loss asked other people to read letters containing confidential health information.

One of the researchers, Mhairi Thurston from Abertay University, said the health service was breaching people's confidentiality.

She said: "I think there are some direct breaches of confidentiality but it's also in the form of a stealth breach.

"The implications of having to rely on others hasn't really been thought about." (BBC news, 2010)

The Patient Rights (Scotland) Act 2011

The Patient Rights (Scotland) Act 2011 was passed by Parliament on 24 February 2011, and gained Royal Assent on 31 March 2011. As a direct result of the evidence we presented, specific mention has been made to the accessibility of communication within the health care principles to be upheld by NHS bodies and relevant service providers

HEALTH CARE PRINCIPLES TO BE UPHELD BY RELEVANT NHS BODIES AND RELEVANT SERVICE PROVIDERS
Communication
Communication about a patient's health and wellbeing is clear, accessible and understood.
Communication about general services and processes and decisions is clear, accessible and understood.
(The Patient Rights (Scotland) Act 2011)

Following on from this, I acted as a consultant for RNIB Scotland as they advised Greater Glasgow Health Board on a draft policy about accessible healthcare for blind and partially sighted people.

As a result of my collaboration with Scott Brown (2014), I was invited to meet with the editor and development officer of the Sunday Times Online, at Abertay University, to summarise the accessible healthcare project findings and to raise the profile of online accessibility needs of blind and partially sighted people.

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