Deaf with Dementia: A Narrative

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**Abbreviations and Glossary**

AOHL: Action on Hearing Loss

BDA: British Deaf Association

BSL: British Sign Language

RAD: Royal Association for Deaf People

RNID: Royal National Institute for Deaf People (now known as AOHL)

TextDirect: A relay service that supports communication between Deaf people and hearing people via the use of specific technology called a textphone and the spoken word.

Textphone: a device that allows Deaf people to type to one another using sound emissions across the telephone or to use TextDirect with hearing people who do not have a textphone.

**Author Notes:**

The use of the capital D when typing the word deaf signifies a cultural, linguistic minority community called the Deaf community. Our first language is British Sign Language (BSL). The use of the big D defines us as a separate group of people to those who do not use sign language.

The use of capitals will appear in this thesis when the direct translation of BSL to English is being used. The word order will follow the grammar of BSL, not English.

The use of italics in this thesis is to emphasise the point being made by either myself or by the research participant.

Participants’ quotes are in singular quotation marks. When there are double quotation marks within these quotes, these signify when they are quoting someone else.

The referencing style for this thesis is Harvard (Manchester). All references are in chronological order, oldest first. If the same author has been cited twice, then the years are in chronological order next to their name.
There are two images in Chapter 1 that have been purchased from istock\(^1\) and Alamy\(^2\). These have been reproduced with permission.

There are two sets of Appendices.

The first appendix list, Appendices (i), is all associated Word documents with this research study. These are all lettered in capital letters (i.e. A, B, and so on).

The second appendix list, Appendices (ii), is a list of video clips filmed by the author to represent the signs used in the Deaf community and also by the research participants. Each video is numbered in the corresponding text as V1, V2 and so on. Each video has its own URL which is in Appendices (ii). Please enter each URL into the address bar separately and press Enter. You will then be prompted for the password which is dwd2016. Each video is intended to coincide with the corresponding text in the thesis. A written explanation of each video clip is fully described as it is presented.

\(^1\) istock [http://www.istockphoto.com/](http://www.istockphoto.com/)

\(^2\) alamy [http://www.alamy.com/](http://www.alamy.com/)
Learn from yesterday, live for today, hope for tomorrow. The important thing is not to stop questioning.

Albert Einstein

We may run, walk, stumble, drive, or fly, but let us never lose sight of the reason for the journey, or miss a chance to see a rainbow on the way.

Gloria Gaither
Abstract

A thesis submitted by Emma L. Ferguson-Coleman to the University of Manchester for the Degree of Doctor of Philosophy in the Faculty of Biology, Medicine and Health 2016.

Deaf with Dementia: A Narrative

Background
There are 850,000 people living with dementia in the UK; this number includes Deaf people who use British Sign Language, but little is known of their experience or how services might be improved to support them and their carers, who are often also Deaf. Deaf people are routinely excluded from reports on linguistic/cultural minorities and dementia because their status, as such, is not recognised. They are very different from the much larger population of older people who lose their hearing and may also have dementia.

Aims and Objectives
i) To explore the everyday experiences of living with dementia from the perspectives of Deaf BSL users with dementia and their care partners; ii) To explore the general Deaf community’s knowledge and understanding of dementia, its symptoms and impact on everyday life.

Method
Three focus groups were held with a total of 26 Deaf BSL users, who did not have dementia, to gauge their knowledge about dementia and where they might go for support. Four Deaf BSL users living with dementia with five care partners took part in two semi-structured interviews 6-8 weeks apart. Data were analysed using thematic analysis, storied stories and narrative analysis. All data were collected in BSL by a Deaf researcher.

Results
Lack of access to information and support in BSL impeded early recognition of symptoms, access to diagnosis, and support within the Deaf community. Personal narratives revealed Deaf people’s resilience while living with dementia. Narratives challenged key concerns of personhood, citizenship and embodiment from a different perspective because Deaf people are not usually regarded as full citizens and their capacity is routinely challenged regardless of dementia. Furthermore, embodiment of communication and language is a life-long experience, not residual adaptation. Visual strategies to support agency were also documented.

Conclusions
The Deaf community needs provision of accessible and understandable information about dementia in BSL. Mainstream dementia support services should review their accessibility of effective support for Deaf BSL users who have been diagnosed with dementia and their families. However, Deaf people with dementia remain resilient and positive about their everyday lives with the support of their familial relationships.
DECLARATION:

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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1. Introduction

Please take some time to reflect upon the following scenario:

There is an older woman, Violet, sitting in her armchair. Violet is hard of hearing and she wears two hearing aids. Violet is living with dementia and has carers visiting her at home each day. She is gazing into the distance with a small smile forming on her lips and her hands are in her lap. Out of the corner of her eye, she sees her carer, Mary, coming into her living room with a cup of tea and a biscuit. She turns her head and hears Mary saying to her, “Violet, here’s your tea and the post has just arrived”. Violet begins to smile widely and watches Mary pour the tea. Violet asks Mary to help her open the post after they finish their tea.

It is imagined that Violet is content within her situation. Violet is aware she has a carer called Mary; she enjoys Mary’s regular visits and communicating clearly with her. Violet might have some difficulties in understanding her letters, but she knows Mary will sit with her and discuss them with her.

Now please consider the following scenario:

Next door, an older man, Laurie, sits in his living room. Laurie is Deaf and does not wear hearing aids. He is deep in thought as he is sure that today is an important day for some reason but does not hear his carer, Penny, come into his living room. He jumps slightly when he notices her enter into his line of vision and frowns when her lips start moving in silence. Penny is asking Laurie if he would like a cup of coffee and becomes exasperated when he does not understand her. She gesticulates, ‘CUP’ towards her face and Laurie nods uncertainly, not knowing what drink he is going to receive. Laurie then realises that today is Deaf club day and a small smile lights up his face.
Laurie is a Deaf\(^3\) man who uses British Sign Language (BSL) and he is living with dementia but he does not realise this. He has been Deaf since birth and has grown up in a world where the majority of people around him are hearing and do not use BSL on a daily basis. He does not wear hearing aids as they are of little use to him. Laurie is a happy person with an active social life and he enjoys visiting his local Deaf club where he meets his Deaf friends. He currently has hearing carers from the local authority visiting him twice a day in his home and they do not use BSL. Laurie does not look forward to their visits, as he cannot understand what they are saying.

These two scenarios describe two very different environments in which an older person living with dementia may find himself or herself today. Yet both are ‘deaf’ – they are just not deaf in the same way.

Violet’s story in the first scenario is not of any less significance than Laurie’s. It is important to value Violet’s experience as a predominantly hearing person who has lost her hearing later in life and is living with dementia. However, it is imagined that there are effective communication strategies in place that have enabled Violet to hear what her carer is saying, i.e. the wearing of hearing aids if she has any hearing difficulties or Mary will speak up when she is talking. Additionally, it is assumed that it has been her choice specifically to have Mary coming into her home to support her. Both Mary and Violet use the same language. Violet’s carer does not see her as culturally different from herself, just older and living with the acquired disability of hearing loss.

However, this PhD concerns people, who like Laurie, are living with dementia as a Deaf person, someone who uses BSL, not English, and someone who has been part of a vibrant cultural community throughout all their lives: the Deaf community. As the author of this PhD, I share that language and culture, as I am Deaf too. Through this research study, we will explore together what living with dementia is like for a Deaf BSL

\(^3\) As shared in the Author Notes, the use of the capital D here for the word deaf signifies that Laurie is a member of a cultural, linguistic minority community called the Deaf community. The use of the big D defines this membership.
user, both from direct lived experiences and from the wider community. This is a vastly under-researched area. Almost no literature exists whether from the point of view of Deaf carers or from the point of view of Deaf people living with dementia (see Parker, Young and Rogers, 2010 as an exception). In this research study we will see/read the ‘voices’ (signs) of Deaf people living with dementia and will also investigate awareness and knowledge about dementia within the Deaf community.

1.1 The author’s position

After completing an undergraduate degree in Information Technology and Psychology in 1996, I followed a career in the field of Mental Health and Deafness, working mainly as an independent advocate with Deaf adults on acute and forensic wards. In my free time, I was an active campaigner for the recognition of BSL as a community language between 1997 and 2003 when finally this right was won.

A strong desire to create an evidence base for older Deaf people who are BSL users with mental health issues led me to start a new career as a research assistant at the University of Manchester in 2010 with the Deaf with Dementia project (which was funded by the Alzheimer’s Society) based within the Social Research with Deaf People Research Group (SORD) (www.manchester.ac.uk/sord).

I am Deaf, a BSL user and do not have dementia...yet. I was born into a generation where it has been predicted that by 2025, over 1.3 million people in the UK will be living with dementia (Lewis et al., 2014, p. 17). I may at some point in my life trajectory become part of this statistic.

The questions therefore in my mind, amongst many others, are:

- If I do develop dementia in my later years, who will support me in my everyday choices?
- Will my linguistic and cultural identity be supported in those choices and allowed to shape and guide them?
- How will I maintain my agency in the decisions that I make?
- If I choose to have carers, will they communicate with me in my everyday language, BSL, and if they do not, what will this mean for my life?

These highly personal questions consistently fuel my passion for positioning and supporting older Deaf people living with dementia and their carers to become full citizens in society. They also are at the heart of the research aims and research questions in this thesis.

Dementia and its diagnosis, treatment, prevention, care and support has become a priority internationally in recent years. Populations are growing older and staying alive for longer; thus, there is a justly anticipated increase in the incidence of dementia.
The first National Dementia Strategy, ‘Living Well with Dementia’, a strategic framework in England (Department of Health, 2009), in its aim to set a future agenda for dementia services, encouraged both healthcare and community professions to ensure that there is an earlier diagnosis of dementia, better awareness, improved treatment and enhanced support and care interventions, therefore enabling people to live well with dementia. However, in this strategy, there was a lack of clarity and emphasis around supporting people with dementia from minority communities. The Joseph Rowntree Foundation (JRF) report, ‘A stronger collective voice for people with dementia’ advocated the fact that minority communities were harder to reach (Williamson, 2012, p. 5.) and therefore were much less represented in mainstream policy documentation. To rectify these issues, there were subsequent actions taken to represent the views of minority communities, such as the Social Care Institute for Excellence (SCIE) research briefing in 2011 (Moriarty, Sharif and Robinson, 2011) and the All-Party Parliamentary Group (APPG) who launched the report, ‘Dementia does not discriminate’, in 2013 to explore further the unique experiences of black, Asian and minority ethnic communities (BAME) living with dementia. These reports were important, not just because they put the spotlight on communities who were not in the majority in the UK, but because they highlighted important differences and inequalities in living with dementia between some communities. For example, the APPG report (APPG, 2013) collated the evidence to show that some dementias disproportionately affect some ethnicities in England, such as Asian and Black Caribbean elders due to the higher prevalence of physical health issues. The JRF (2012) evidence review demonstrated that there was a limited or very low response from people in ‘seldom-heard’ communities (such as BAME) when surveying responses from established projects supporting people with dementia and their carers.

There is even less published information about people who are living with dementia that might also be experiencing additional issues, such as sight loss or hearing loss. Allan, Stapleton and McLean (2005) compiled a summary overview of the difficulties in communication for someone living with dementia and a hearing loss. Much more recently, SCIE Dementia Gateway (2014) has published specific pages online linked to dementia and hearing loss and a research review of the connections between dementia and sensory loss (Young, Waterman and Ferguson-Coleman, 2013). These documents all include within their purview Deaf people who use BSL as well, but this inclusion in itself will be discussed more in depth in Chapter 3. Furthermore, in May 2016, a report was published by the APPG ‘Dementia rarely travels alone’ (APPG, 2016), which is a report that summarises the prevalence of dementia as a condition with other comorbidities, such as diabetes. Within this report, on page 7, there is mention of hearing loss and how this impacts on communication difficulties. It needs to be acknowledged here that the majority of Deaf people would not regard themselves as having a hearing loss, as their cultural view of themselves as a linguistic minority in the UK is more likely to predominate. Yet, those reports and studies aimed at understanding better dementia within minority cultural-linguistic communities, such as the APPG report (2013), do not include Deaf people as there is no recognition of that cultural-linguistic status. Deaf people with dementia occupy this crossroads between disability and culture, sensory loss and linguistic identity in how they are written about and how policy treats them (Young and Temple, 2014). This intersection is not necessarily positive in practice, as this thesis will demonstrate.
In this research study, those very personal concerns I have described, the ways in which policy and practice intersect with the Deaf person’s linguistic and cultural positioning in society today will be translated into fundamental research questions which contribute to the small evidence based currently concerning Deaf people with dementia.

The two principal research aims of this doctoral study are:

- To explore the general Deaf community’s knowledge and understanding of dementia, its symptoms and impact on everyday lives.

- To explore the everyday experiences of living with dementia from the perspectives of Deaf BSL users with dementia and their care partners.

As a starting point, it is important to understand the landscape in which Deaf BSL users living with dementia and their families are situated; therefore, the next two chapters will focus on the formal literature review from which to value and evaluate these experiences.
2. Deafness and Dementia: Statistics

2.1 What does deafness and dementia mean in this context?

This section will outline some current definitions and statistics about people living with deafness and for people living with dementia. By the end of this chapter, the landscape in which this thesis is situated will be clearly laid out and a better understanding provided about which groups are being explored in this study.

2.2 Prevalence of deafness

Deafness is a condition where the person cannot hear. Levels of deafness can vary from being mild to profound. The most recent statistics available from Action on Hearing Loss (2015) states that there are more than 11 million people in the UK with a hearing loss, which equates to one in six of the UK’s population. The prevalence of hearing loss increases dramatically with age, for example Age UK (2015) states that 71.1% of over 70 year-olds and 41.7% of over 50 year-olds have some form of hearing loss.

However, within these figures, there are Deaf people who use British Sign Language (BSL). BSL is a language in its own right, with its own grammar, syntax and iconicity (Sutton-Spence and Woll, 1999). Deaf people do not start using BSL as a result of losing their hearing in later life. BSL users can be of all ages, from infants to the very oldest citizens in our society. In the UK, there are 87,000 Deaf BSL users (British Deaf Association, 2016a). Young, Ferguson-Coleman and Keady (2014a) offer a conservative estimate of there being 8,500 to 17,000 Deaf BSL users aged over 65 in the UK when measured against the general population (p. 40).

2.3 Prevalence of dementia

Dementia is a symptomatic condition that affects the brain. This can be caused by a series of small strokes, or by the onset of a disease, such as Alzheimer’s, which is the most common cause of dementia (Alzheimer’s Society, 2014). The symptoms can be loss of concentration, forgetfulness, changes in personality, and changes in language, difficulties with problem solving and with decision-making. According to the Alzheimer’s Society (2014), there are 850,000 people in the UK living with dementia, with only 44% receiving a formal diagnosis. The overall number of people being diagnosed with dementia increases each year, because i) the UK has an ageing population, due to people living longer, and ii) there is an increasing awareness about dementia through the use of mainstream and social media (Craig and Strivens, 2016).

Internationally, the global estimate is that there are 46 million people living with dementia worldwide with the majority of these people living in the developing world (Alzheimer’s Disease International, 2015, p. 24).

2.4 Prevalence of Deaf people and dementia
There are currently no confirmed statistics of how many Deaf BSL users there are in the UK who are living with dementia, mostly due to how difficult it is to pin down accurate numbers of how many Deaf BSL users currently reside in the UK. However, Young, Ferguson-Coleman and Keady (2014a) have offered a conservative estimate, based on earlier estimates of the older Deaf population in the UK, that 5% of 8,500-17,000 Deaf BSL users aged over 65 may be diagnosed with dementia. This is clearly a significant cause for concern.

2.5 What does it mean when someone is Deaf?

In the introductory chapter, you will have read the stories of Violet and Laurie. Violet is an older person who is living with dementia and has an acquired hearing loss, which means she has lost some hearing and as a result, has become deafened as she became older. Violet has learnt to hear her peers through the use of hearing aids, which may have been given to her by her local hearing clinic via the NHS (or purchased privately from Specsavers4).

Laurie, on the other hand, is also living with dementia and has been Deaf all his life. His mother had German measles when she was pregnant with him, which meant he was born deaf. Laurie attended a Deaf residential school in his youth and met other Deaf peers like him at this school. He learnt BSL here as this was taught in school and was the main form of communication for him and his peers.

Violet and Laurie have two very different experiences of being deaf. They both have a hearing ‘loss’ but will view this in two very different ways. Violet, as a predominantly hearing person, will view this reduction in her hearing as a ‘loss’ and seek out the necessary adjustments to resolve this. Laurie will have known no different, as he has been Deaf all of his life. He does not know what it is like to hear, and does not question what he is ‘missing’.

You will notice two words have been placed within quotation marks: ‘loss’ and ‘missing’. It is important to contextualise these two words within both the domains of deafness and of dementia. When hearing people think about becoming deaf in older age, they will perceive this, naturally, as a loss. They then will use this measurement to think about those who are born deaf and consider this group of people to have a loss, to be impaired and to be sensorially deprived.

In contrast, the Deaf person, who uses BSL as their first or preferred language, will see themselves as part of a specific minority with shared experiences of being Deaf in a mainstream hearing world. In this thesis, the use of the word Deaf, with a capital D will represent Deaf BSL users who consider themselves as members of a cultural and linguistic minority group (Woodward, 1975; Padden and Humphries, 1988).

4 Specsavers is a national opticians based in the UK which also sells ‘in-the-ear’ hearing aids [http://www.specsavers.co.uk/hearing](http://www.specsavers.co.uk/hearing)
Paradoxically, BSL use does not have a direct correlation with the degree of the person’s deafness; for example, not all BSL users are profoundly deaf, nor will all BSL users be Deaf people (Young and Temple, 2014). More on this will be discussed in Chapter 3.

In parallel, when a person is diagnosed with the onset of dementia, the mainstream society around them generally considers the person to be ‘lost’, or a ‘missing’ person, labelling them as lesser-abled citizens no longer able to make decisions for themselves. However, there has been a growing movement in the last twenty years of people living with dementia actively campaigning for recognition of their undiminished status as a person (Bartlett and O’Connor, 2007; 2010; Swaffer, 2014; 2015) even if they have experienced personal differences as a result of their dementia.

This research study will focus on the everyday experiences of Deaf people with dementia, as directly shared by them and their families; not on their hearing ‘loss’ nor on the ‘missing’ parts of their person. The formal literature review will draw upon these parallels, in that both groups are discriminated against for their perceived ‘losses’ and that there are activists within each minority group that retaliate against these preconceived erroneous assumptions.

The next chapter will explore mainstream and specialist literature that demonstrates the current thinking in both fields of dementia and Deafness and explore how these two worlds parallel each other.
3. Literature Review

3.1 Moment of reflexivity

As I reached this intersection of the thesis and began to compile this literature review, discussing the different components of the Deaf community and of people who live with dementia, it became more and more apparent to me that in writing about these particular groups of people, there appears to be an ethos in the written word of ‘them’ and ‘us’.

As a long-standing member (cultural insider) of the Deaf community (Jones and Pullen, 1992; Ladd, 2003; Young and Temple, 2014), and as a person who is not yet living with dementia, I feel uncomfortable in talking about, rather than with Deaf people, and about, rather than with people living with dementia. I would like to discourage the reader from assuming from my writing in this review that I share, or live by, the aforementioned ethos.

As a cultural insider I wish to declare my position, which is that the stories, heritage and culture of my community need to be shared; but direct ownership of these cannot be claimed as ‘my’ experiences. There are commonalities, but everyone has an individual experiential perspective, be that informed by the collective(s) to whom we belong or otherwise.

This literature review is about Deaf people and people living with dementia, but it is also about how literature currently represents that experience. I would like to reflect and represent both minority groups as valuable in their own right. This is why care will be taken to ensure that there is no mention of ‘them’ and ‘us’ throughout this review, with that terminology only being used to reflect the source language about Deaf people or people living with dementia. By the end of this review, the reader will have a better understanding and an appreciation of both minority groups, what they individually contribute to society and how they are both ‘othered’ (Doyle and Rubenstein, 2014; Young and Temple, 2014; Swaffer, 2015) by mainstream communities. The reader will also become aware of the societal barriers, which are in place, and the need to address those issues. This literature review has been presented in an alternative format owing to the paucity of literature available about Deaf people living with dementia. The aim of the review in its layout is to draw out comparisons and points of divergence from the literature on Deaf studies and dementia studies.

3.2 Definition of everyday lives

The focus of this thesis is firmly on everyday lives, not on disease, or conditions, or cures. It is very much about living with dementia within society, whether as a person with dementia or their care partner or a interested outsider. The term ‘everyday lives’ can be defined in a range of ways. If referring to Maslow’s (1943) Hierarchy of Needs, everyday life could be seen as those activities required to fulfill needs at different levels whether these are basic needs for food, warmth, shelter or at the highest level of need defined as ‘self-actualisation’. Everyday life is also closely linked to quality of life and how this is maintained, particularly for
people living with dementia (Robertson, 2014). Understanding and measuring what everyday lives mean to people with dementia is also closely linked to how they view and value their self (Keady, Williams and Hughes-Roberts, 2007) and their positioning in their world. Writers from a personhood perspective emphasise that once a person is diagnosed with dementia, the meaning of everyday life to them should remain consistent, along with their usual activities being maintained (Harman and Clare, 2006).

Wellbeing is also an important component of being part of society. The Care Act 2014 statutory guidance (Department of Health, 2016) discusses the role of the social worker in ensuring a person’s wellbeing is maintained. The Act stipulates that:

‘Care and support should put people in control of their care, with the support that they need to enhance their wellbeing and improve their connections to family, friends and community.’

(Department of Health, Care Act, 2016, 10.1)

These considerations, within the context of the thesis, should be explored from the viewpoints of the person living with dementia (with the awareness that there is stigma and exclusion as their condition is viewed in a negative light) and the Deaf person (where it is not always recognised that the Deaf person does not have access or information in their first language, BSL) – see section 3.26 for further discussion on these issues. Ultimately, the Deaf person with dementia’s personhood and sense of self should be placed at the centre of any person-centred planning processes that arise around their care needs. This, in turn, will contribute to the wellbeing and maintenance of people’s everyday lives.

Deaf people with dementia are a minority on two counts which is also a component of the everyday life focus of this thesis. Figure 1. on page 24 offers a visual representation of this positioning:
Figure 1 offers a visual representation of how this overall thesis is exploring a minority community within the background of a wider society. The main two overlapping sections across society demonstrate the co-existence of people living with dementia and the Deaf community. There is one tiny overlap between all sections which reflects the minority group of Deaf people living with dementia co-existing within the Deaf community and in society itself. We all co-exist within a wider community with our individual differences. However, as explained later on in section 3.5, Deaf people can be misunderstood and ostracised from society (Leigh, 2009) while hearing people with dementia can be stigmatised and misunderstood with evidence of their personhood being diminished (Kitwood, 1997; Swaffer, 2015).

3.3 The definition of identity

3.3.1 Introduction

This section will focus on the definition of identity from a culturally Deaf perspective and begin to explore how this relates to a focus on personhood in relation to Deaf people who have dementia. The focus of personhood within dementia care is about recognising, valuing and respecting a person’s identity. It is concerned both with allowing the person with dementia’s identity to be maintained after diagnosis and understanding how its expression might change. When we explore the term ‘personhood’ for people who are Deaf, the lens changes as there is a different journey towards the recognition and negotiation of one’s identity. It is important to acknowledge how identities have been superimposed upon Deaf people and how Deaf people are reclaiming their chosen identities positively.

We all have an identity; in fact, most of us have multiple identities due to the intersectionalities we face in our everyday lives (Sökefeld, 2001). For example, our gender, sexuality, culture, language and other facets of ‘who we are’ interact and intersect to make up our identity. The recognition of those multiple identities can happen at any stage of our lives, in that we may find that we belong somewhere; whether this is within our families or within our cultural groups or both. We are either not aware that we belong to this unit until we
recognise that we are the same as others, or others recognise us as being different from them (Brah and Phoenix, 2004; Howarth et al., 2014).

3.3.2 A journey towards a personal identity

As the identities of members of the Deaf community are being explored in this section (how they are formed and how they change), I will take a few moments to describe my own personal journey towards recognising my Deaf identity as it is today. This story may be shared with, or applicable to, other members of my community, the Deaf community, but each story remains individualised as each person's life experiences are different. The label that I have given myself and that others give me is that of a culturally Deaf person. My everyday interactions with people and within wider society remind me, and inform them, of this fact. However, I did not start out as a culturally Deaf person.

My parents are hearing. I attended a mainstream hearing primary school and a residential specialist deaf school, which had an oral communication policy, which promoted the use of speech, lip-reading and listening with radio aids as teaching methods. That placement was considered appropriate for me by my parents as its communication methods were the same as those used at home, namely the oral method, as the medical and educational establishments would describe it. Entering this school at age 11 introduced me to others, who were like me. This was a unique experience for me as up to that point, I had assumed that I was the only Deaf person in the world. This is not an uncommon assumption as is reported repeatedly by many Deaf people around the world (Freeman, Carbin and Boese, 1981; Padden and Humphries, 1988; Sheridan, 2001; Leigh, 2009). It was not until I met other d/Deaf people at boarding school at the age of 11 that I realised I had been missing part of me. The fact that there were other people like me was a revelation. Up until that point, I had assumed I was going to grow up to become a hearing person. Meeting those d/Deaf peers helped me to understand and value the fact that I could have a Deaf identity.

To this day, whenever I communicate with Deaf people in my own community, they choose to inform me from their interpretation of my lip-pattern that: a) I have good speech or b) I must be clever. I am also told that I ‘look hearing’ because of my clear lip-patterns. Such attributions between cultures are similar to that evidenced in the label of ‘Oreo’ given to African-Americans who follow ‘White’ rules (Leigh, 2009, p. 21) i.e. Black on the outside but White inside. By calling a Deaf person ‘hearing’, there is the direct attribution that they pay service to the concept of hearing ideologies and that these ideologies are the rulebook from which one wishes to live their life by (Padden and Humphries, 1988, p. 53). I might assert my identity as Deaf; others in the same community as me might attribute a different identity to me. This is not uncommon.

Deaf people, wittingly or unwittingly, will ascribe identities to one another, dependent on: educational opportunities; level of sign language skills; current employment; and social circles. An example of this

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5 The use of the 'little d' here for the word deaf represents the oral environment that I was within at this school.
attributed occurred in my late teenage years when I visited a well-known Deaf gathering that used to take place every two weeks in Covent Garden in London. I went into this group with very little sign language knowledge (due to my oral upbringing and my oral educational settings), but still assumed or felt that I belonged there. Yet, within minutes, I was told in no uncertain terms that I was ‘too oral’; ‘not signing well enough’; and ‘that I did not belong here’. This left me battling with my identity and resenting being a deaf person, because I did not fit into either world – the Deaf world rejected me because I was too oral and the hearing world could not include me because I was too deaf. Over time, I deliberately rectified this as I felt that this was my community, and I needed to prove to myself and others that I belonged in the Deaf community and that my true identity was that of a culturally Deaf person. Journeys like mine are not journeys into the Deaf world that hearing people might make, for example, when they learn to sign at level 1 BSL. This is a journey into valuing and understanding myself to reclaim who I am, after being told for many years who I should be. This process of ‘becoming’ is what is referred to as ‘Deafhood’ (Ladd, 2003).

As a Deaf woman, I have gone through a journey to recognise and validate my identity to be that of a culturally Deaf person. I was raised to speak, not to sign, as the doctors told my mother that sign language would isolate me from others (others being the mainstream hearing world). Despite being labelled an ‘oral success’ (by my schoolteachers and many audiologists/speech therapists) in terms of my speech development, I still struggled to understand the world around me and struggled to make myself understood. This is an experience that is shared by many of my peers.

Later on, in my late teenage years, I embraced sign language with a passion and felt I had found my people, my community. This was further reinforced in my twenties when, alongside other like-minded peers, I became involved in campaigning for BSL recognition with the Federation of Deaf People, as prior to 18th March 2003, the British Government did not recognise BSL as an indigenous language of the UK. Standing on Nelson’s Column in Trafalgar Square in London, in front of thousands of people who all wanted the same thing, for our language (BSL) to be recognised by the UK Government, which was a collective empowering process in itself (Breivik, 2005, p. 20), I thought, ‘Yes! This is me; this is where I belong’. This personal experience of metamorphosis is clearly summarised by Leigh (2009, p. 166), ‘(identities) will reframe themselves through rejection and acceptance from era to era and individual to individual’.

My identity, of course, is not just a Deaf identity. I am not just only Deaf. I am Deaf, and a woman, and a gay woman. However, who we are is often not seen when one feature of our identity predominates; an issue returned to later in section 3.19 when discussing dementia and Deaf people.

3.3.3 Deaf identities

I am not alone in my personal journey. The recognition of Deaf culture has led to members of the Deaf community feeling empowered and enabled to recognise that this forms part of their personal values. De Clerck (2010, p. 440) discusses how the Deaf community has evolved throughout history, by describing three stages of emancipation. The first stage is where Deaf people were seen as lesser citizens and forced to use
the oral method of communication; to speak in order to be like the majority or to fit in (Brennan, 1975; Lane 1984; Dimmock, 1993; Davis, 1995). The second stage is where signed languages start to become recognised as cultural, linguistic structures. This corresponds strongly to linguistic research, for example, that began to document signed languages as natural languages, not gestural systems (Stokoe, 1960; Sutton-Spence and Woll, 1999). In the third stage, which is the current day, we have Deaf community members who have grown up in a world of signed languages and see it as a natural mode of communication. Signed languages like BSL are now seen publicly in a whole variety of platforms such as on television, YouTube, and other web platforms. This is very different from the use of signed languages as underground or hidden languages and ones that might attract shame and stigma for their users, which is still within living memory (Padden and Humphries, 1988).

These different stages of recognition of Deaf people’s identities, language and culture have supported Deaf people’s progress throughout the decades, yet remain politically controversial when battling attitudes and awareness in the mainstream. An example of this would be how Deaf sign language users cannot learn their own language in school as a GCSE qualification, but other languages are taught, such as French or Spanish. This refusal to incorporate sign language in schools takes away from the potential development of many Deaf identities. Ladd (2003) argues that policies such as these, result in Deaf identities remaining quashed as a consequence of mainstream education and the maintained sole use of the oral method. However, Deaf community members do support younger members of the same community by being positive role models of Deaf identity and culture. Hauser et al. (2010) term this ‘resistant capital’ (p. 490). They draw upon the work of Bourdieu (1986) who uses ‘capital’ to imply the mutual recognition of collective group membership and hence ‘resistant capital’ is used to identify the resilience that is developed once the individual is aware of the member group to which they belong. Hauser et al. (2010) suggest that resistant capital acts to build Deaf people’s resilience against the wider world, which is seen as ‘phonocentric’. First argued by Derrida (1976) and later discussed by Bahan (2008), phonocentrism refers to a world where sound takes prominence and is seen as the norm.

Breivik (2005, p. 21) explains that Deaf individuals go through an ‘empowering master narrative that gradually has come to be an integral feature of deaf communities, which implies that deafness as a medical condition is replaced by an understanding of Deafhood as a cultural experience with a focus upon language minorities’. This definition also relates to a cultural world positioning where life experiences are shared with other people in the same community (in BSL, this would be signed YOU-ME-SAME⁶). As Padden and Humphries (1988, p. 44) stipulate, the community’s passion is linked to a shared desire to preserve their signed languages, developing policies for the education of Deaf children and maintaining socio-political contexts. These shared features are also part of what constitutes our identity. Cultural identities remain fluid while consistently embedded in social, historical, and political contexts (Howarth et al., 2014).

⁶ Using capital letters here is to signify the order in which this statement is signed by a Deaf BSL user. BSL grammar does not follow the same order as English grammar as it is a visual language.
Having shared life experiences, particularly of those that endure daily experiences with miscommunication, inaccessibility and misunderstandings (both ways) of Deaf people who use BSL, solidify the building of one’s identity. Each time there is shared recognition of one’s life experience, there is a mutual experiential understanding that we are in the same boat and this contributes to our wellbeing. This occurs because it contributes to reframing of the self as one who is not alone with these daily struggles. Furthermore, being a Deaf person that belongs to the Deaf community is described as being in our second home, which gives respite from living within the hearing mainstream community (Valentine and Skelton, 2007, p. 115). This exposure (Hauser et al., 2010, p. 489) enables Deaf people to develop a positive self-identity as they meet other Deaf role models who share the same language, share the same experiences and have the same recognition of the self, which legitimises identity.

3.3.4 Deaf identity and dementia – parallel struggles?

My personal journey to the realisation of my identity has contributed to my passion for advocating the support of the Deaf identities of many people in my community, particularly in situations where discrimination may occur against those who are experiencing mental health problems and those who are living with dementia.

If these experiences are compared to those who are showing signs of the onset of dementia and have their citizenship questioned, parallels can be drawn in how identities are attributed to those who do not fit in the boxes that mainstream society imposes upon them/us. However, the main difference in these experiences is that Deaf people have struggled with this identity attribution all their/our lives as the medical world, since our birth or in our developmental years, have strived to make us as ‘normal’ as possible and to fit in their mainstream (Lane, Hoffmeister and Bahan, 1996; Ladd, 2003). In contrast, people who develop dementia already have established identities (with which, of course, they may have had their own internal/external battles with over the years), which are then ignored/misunderstood by those around them, therefore diminishing their personhood, and in turn, their citizenship (Bond, Corner and Graham, 2004; Bartlett and O’Connor, 2007; Bartlett, 2014). Their experience of this ignorance is therefore a learning curve in how this can be challenged, whereas Deaf people may perhaps be more resilient or immune to these challenges, as they have occurred for much of their lifetime. The empirical work in this thesis will begin to explore those issues for the first time. The next section will explore the impact of both positively and negatively recognising personhood and citizenship for those who are living with dementia.

3.4 Dementia and its socio-cultural context

The previous section focussed on the shaping of one’s identity, how this defines someone as Deaf, and membership of the Deaf community within its own specific socio-cultural context, therefore this section will focus on the socio-cultural context that people with dementia live within, and how this concept is discussed in current literature. For clarification, for the Deaf community, the term socio-cultural context refers to the language, social bonds, history and culture of Deaf people (Lane 1992); it does not refer to a specific place or physical neighbourhood as it might do for a hearing person with dementia. In what follows, there will be a
deliberate omission about the medical perspective of dementia as there is a wide range of literature available on this topic that spans over many decades, as discussed in Chapter 2. This section will focus on personhood and citizenship because it has become such a crucial part of the emerging dementia movement. In a similar way to how the focus on Deaf cultural identity stands in opposition to a medicalised view of deafness, personhood and citizenship stand as a robust response to the mainstream assumption that people with dementia lose their self and their identities.

The research study which follows (see Chapter 4) specifically focuses on a subjective approach in finding out what Deaf people’s experiences are when living with dementia; an essentially social and person centred approach that aligns itself with Kitwood’s (1997) view that it is important to maintain focus on the person living with dementia rather than the person living with dementia. The key terms that will thread through this section are personhood and citizenship and these will be examined from several different theoretical perspectives.

3.5 ‘Othering’ and language use

As mentioned at the start of this literature review, the language employed in writing about dementia frequently implies a ‘them and us’ approach. It is important to understand and deconstruct the language currently used to talk about (and at times, with) people who have dementia. Dementia is indiscriminate in who is affected by this condition; but society’s negative understanding, cultural values and approach in how dementia is perceived and spoken about, is not. For example, terms such as ‘sufferer’, ‘victim’ and ‘the demented person’ create a distance between those who have dementia and those who do not because of the way in which they objectify the condition rather than reveal the person. They also emphasise the medical rather than social aspect of dementia. Prior to the Alzheimer’s Disease International Congress in Australia in 2009, people with dementia created their own charter of acceptable and unacceptable terms to use about them (Alzheimer’s Australia, 2009). In the acceptable box, words such as ‘dementia’, ‘condition’, ‘person with dementia’ and ‘changed behaviours’ (rather than ‘challenging behaviour’) were included. Unfortunately, an on-going campaign is still a necessity in order to encourage the use of the right language to describe people with dementia, as according to Swaffer (2014) negative language remains, with terms such as ‘sufferers’ and ‘victims’ being used at the Alzheimer’s Disease International Congress in Puerto Rico in 2014.

A similar dynamic of ‘othering’ is evident in reference to Deaf people (Ladd, 2003; Young and Temple, 2014). For example, children are divided into groups and named accordingly, based on how much they hear; with verbal and written reference to deaf children as ‘partials’ and ‘profounds’ (Harris and Beech, 1998). This process focuses on the aspect of ‘not hearing’, as opposed to the person as a whole. It contrasts with Deaf people’s own ways of describing each other, for example ‘fully Deaf’ (Padden and Humphries, 1988), which is a positive statement implying a person is fully embedded with Deaf culture, with a strong Deaf identity and is a fluent sign language user. It describes the person’s identity by their social context and embeddedness, not according to a feature of their physical state. In BSL, the person would sign ME-DEAF towards their mouth, which is pursed, with puffed cheeks and eyes cast downwards as a strong recognition, valuation and
positioning of their identity. A BSL version of this is available in Appendices (ii) V1. This is also reflective of the older generation, who would mouth ‘ME-EAF-UM’, (Appendices (ii) V2) meaning ‘I’m Deaf and dumb’, which is a phrase that was commonly used in their youth by people describing themselves as well as their membership of organisations that were established at that time, such as the British Deaf and Dumb Association. Using this signed phrase places the same value on ‘deaf and dumb’, such as how a gay person might (e.g. describing themselves as a ‘dyke’), or a Black person might use a colloquial phrase to reclaim their cultural and historical identity on their terms. Terms of abuse by others become instead terms of pride in the hands of those they were intended to diminish.

Returning to people with dementia, there is very little in the literature that is directly written or produced by people with dementia (Bryden, 2005; Johnson, 2010; Swaffer, 2014, 2015). There have been some successful examples of co-narrated stories (Shakespeare and Clare, 2005; Hellström, Nolan and Lundh, 2005; Keady, Williams and Hughes-Roberts, 2007; Benbow and Kingston, 2014) where stories are co-constructed by both the person with dementia and their carer(s). Swaffer (2014) states clearly that people with dementia should take individual ownership of their dementia and the decision-making processes that are part of their daily lives. In the main however, person-centred dementia literature showcases the experiences of people with dementia, as perceived by their family carers or by professional carers, rather than directly by the person with dementia. People with dementia are rarely given the opportunity to speak for themselves; organisations take the helm in speaking for them, not with them, and do not provide a platform from which they can represent themselves (Mittler, 2011; Swaffer, 2014, p. 712).

The author has noted, from personal attendance at conferences about living with dementia, that even where an intention to offer a campaigning platform in which to challenge stigma and perceptions of dementia is stated, it appears that people with dementia are not directly enabled, or empowered, to take centre stage by sharing their stories personally (witnessed as a verbal protest by a person who got up onto the stage to declare this fact). Small, tentative changes do seem to be afoot, however. In addition to Swaffer’s (2015) writing about how people with dementia should be at the forefront of the dementia movement, Bartlett (2014) also discusses the beginnings of a social movement where people with dementia are becoming active in advocating for their own rights; campaigning for their voices to be heard. The people Bartlett (2014) interviews, however, still elaborate upon experiences of being oppressed and express their self-doubt in relation to how their dementia is viewed by society and how ‘well’ they should be functioning in the eyes of others. Many described feeling guilty when functioning well because this challenges outsiders’ (outsiders: people who do not live with dementia) expectations and may not be a true reflection of the vast majority of people with dementia.

Similar experiences have happened to Deaf campaigning groups in a range of countries. Self-advocacy for rights based on cultural-linguistic identity have challenged the majority society’s view of Deaf people as those in need of support or care or lacking in capacity. Key examples include the Deaf President Now Campaign in Gallaudet University in the USA (Christiansen and Barnartt, 2003) and with the Federation of Deaf People (FDP) marches for BSL recognition as a community language and indigenous language of the UK (Bryan,
However, in so campaigning and becoming visible, it is the stronger and more empowered Deaf people who are seen and who may not be a true representation of the needs and social situation of the majority – see section 3.24 for a discussion about the choices that Deaf people do not have. As with any minority group, there are people who will be more prominent than others; there will be those who are more vocal/visual than others, and those who do not have the same vision as others. In the Deaf community, these similarities are found; but, in addition, the Deaf individuals who are not at the forefront of campaigning, or enabled to be explicit about their choices, would be labelled as ‘grassroots Deaf’. Being ‘grassroots Deaf’ can mean someone who has not had the same social, educational or employment opportunities as other Deaf people. One example of defining this label came from a focus group in Ferguson-Coleman, Young and Keady’s (2014a) paper where these members of the community are seen as having fewer opportunities, not having the same range of English skills as other Deaf people and needing that extra support to access and understand information in comparison with other Deaf people.

3.6 Stigma and dementia

As expressed in the initial discussion about the ethos of ‘them’ and ‘us’ (Kitwood, 1997) at the start of this literature review, stigma remains strongly associated with how people understand dementia and what it means to live well with dementia following diagnosis (Department of Health, 2015). Why is stigma important? Stigma is a social construct that is imperative for us to understand as it influences people’s behaviours, assumptions, language, emotions and perspectives about dementia. Goffman (1963) discusses how preconceptions that people have about others who are ‘different’ and not ‘normal’ contribute to creating a ‘spoiled identity’ in that people who do not fit in the box are somehow lesser citizens than those who do.

The fear that remains around dementia and living well with the condition continues to contribute to the direct or indirect dehumanisation of people who are living with dementia. Research studies have demonstrated that through these learned behaviours and anxieties, stigma then impacts on the choices and processes that a person goes through if they suspect the onset of dementia for themselves or for others (Blum, 1991; MacRae, 1999; Werner, 2005; Werner and Heinik, 2008). In this context, the definition of stigma is about interactions within the family unit and wider social contexts, rather than the ‘(in)visible disabilities’ that Goffman (1963) discusses in his book.

Once a person receives a diagnosis of dementia, it has been observed that they are spoken about in the past tense, as if their personality and values are immediately diminished and they have become victims of the condition (Kitwood, 1997; Link and Phelan, 2001; Bond, Corner and Graham, 2004; Swaffer, 2015). To elaborate on this further, Swaffer (2015) describes this as ‘Prescribed Disengagement™’: that once one receives a diagnosis of dementia, it is therefore deemed necessary to give up work, give up one’s social activities and so on. However, she reinforces in her paper the fact that people with dementia are individual agents who make their own decisions and choices, rather than being in a position where it is automatically assumed (through negative beliefs) they need 24-hour support and care. Additionally, she suggests that dementia organisations who work on behalf of people living with dementia need to become dementia-friendly
from the inside out, rather than purporting to be full supporters of this group; their language and attitudes
towards supporting people with dementia can at times reinforce the negative values that are held about
being less than capable while living with dementia. She also argues that the creation of dementia-friendly
communities is potentially the wrong approach to resolving stigma – instead, all communities should be
looking inside themselves to think about how they could become dementia-friendly, rather than dementia-
friendly communities being a separate entity. There is a difference between creating communities for people
with dementia and communities transforming to be inclusive, the consequences of which would be more
empowering for people with dementia. This is in many respects the same argument as that of the disability
movement - the desire to shift from the mind-set that there needs to be special places for disabled people to
live and work, to the restructuring of society so that it is accessible and inclusive for all, including disabled
people. In support of this philosophy, Sandblom (2014) implores in their presentation, ‘We need others to
enable us, not further disable us!’

3.7 Language and stigma

There is much debate about how dementia as a condition is described with negative language (Goffman,
1963; Corner and Bond, 2004; Devlin, MacAskill and Stead, 2007; Swaffer, 2014, 2015). Stigma will be
perpetuated if mainstream society continues to use negative terms such as ‘the dementia victim’, ‘the
dementia sufferer’, instead of using terms such as ‘living with dementia’, or ‘living well with dementia’. If
negative language is maintained, this then frames the person within a negative attribution, which excludes
them from the mainstream, as they do not ‘fit’ in the norm.

The use of negative language can also create a culture of fear to which people will respond with pre-
conceived assumptions (Sabat et al., 2011). The media plays an important part in conveying these negative
messages, with the use of sensationalist language to describe dementia (Devlin, MacAskill and Stead,
2007). Oftenmost, people will use language in the wrong context, for example, they will describe a person as
schizophrenic, rather than saying they are someone who has or lives with schizophrenia (Link and Phelan,
2001). In the field of dementia, Kitwood and Bredin (1992) termed this approach as malignant social
psychology, as people with dementia would then be perceived as less of a citizen than their peers and
unable to express their views or choices.

It is further argued that this language and behaviour subsequently creates an abyss of social distancing
between the general population and the person living with dementia (Sabat, 2003), therefore it is to be
expected that after diagnosis, stigma remains a key component of a person’s lived experience while living
with dementia (Milne, 2010). Jolley and Benbow (2000) have shown how social support networks can begin
to break down after diagnosis because of the stigma attached to the unknown elements of living with
dementia. This is an issue that is explored in this study in relation to Deaf people living with dementia and
their families and their wider social contexts (see Chapter 7).
3.8 Families and their response to living with dementia

There can be positive familial contributions to the management of stigma while living with dementia in mainstream society. The person’s carer may utilise scaffolding strategies to maintain the presence and contributions of their spouse or family member living with dementia by positively supporting their positioning by way of maintaining conversations and their presence in their relationships (Hellström, Nolan and Lundh, 2005; Hydén, 2011; Kindell et al., 2014). Goffman (1963) suggests that the closer the family member is, the less likely they are to stigmatise the person living with dementia, because their acceptance creates a protective circle. However, if the person’s symptoms of dementia have become more noticeable in social company, then the carer might decide to disclose their spouse or family member’s condition to the close members of the group (Blum, 1991). This action may be simply to inform the family of why the person is not responding to dialogue in the way they usually do, or to justify their family member’s right to express themselves in the way they wish, or finally, to acknowledge and respect that their behaviour is not within their usual habits (MacRae, 1999). The aim of this is not to disempower the person living with dementia, but to strengthen their societal relationships and enhance people's awareness and understanding of what otherwise could be misconstrued.

3.9 Living with dementia within different cultures

Goffman (1963) and Link and Phelan (2001) both discuss that stigma is not only associated with language and fear of the unknown; it can become a culturally embedded attitude and sets of assumptions, for example, the creation of stereotypes when a specific group becomes labelled rather than individuals and their behaviours. Within the parameters of understanding dementia and the stereotypes attached to living with the condition, there are some cultural restrictions. For instance, there are some community-cultural beliefs that perceive the person is being condemned by being diagnosed with dementia; some cultures believe that the onset of dementia is due to being a bad person in a previous life (Johl, Patterson and Pearson, 2014). There can also be ingrained cultural beliefs; for example, the Hindu population believing that dementia is a mental illness and has been imposed on oneself because of one’s aberrance in a previous life (Mackenzie, 2006) or that families should keep the issue within their own unit without taking outside help or support (McCabe, 2006). There may also be generational differences, particularly within minority ethnic communities, where in different political wars, army soldiers took part in ethnic cleansing and maintained culturally stigmatising behaviour (Mackenzie, 2006). Mackenzie (2006) suggests that the long-standing emotional issues arising from this historical maltreatment may contribute to one’s refusal to attend a GP appointment if they are worried about their memory and furthermore add to their refusal to access support locally. Stigma and related attitudes towards dementia may be borne out of lack of knowledge, lack of understanding, lack of empathy and generational experiences. A key issue in relation to stereotypes and stigma is how and why stereotypes may be maintained and what it is that breaks these; a point discussed later in relation specifically to the Deaf community and their attitudes towards dementia (see Chapter 5).
3.10 Parallels of stigma in the Deaf community

Stigma is not unique to dementia and is, indeed, not unique to the Deaf community. There is a stigma around being deaf or Deaf; having a hearing ‘problem’ is often portrayed as a loss or as an impairment. Being Deaf in a hearing world brings its own stigma, as Deaf people are seen as different from those who can hear; they are perceived to be lacking something (Lane, 1995). Furthermore, Deaf people who are not confident in their identity as a Deaf person will conceal their deafness, which then bolsters the stigmatisation of their ‘difference’ (Kent, Furlonger and Goodrick, 2001). Furthermore, if there are issues around communication, it is usually the Deaf person who is discredited, which is the equivalent to having a spoiled identity (Goffman, 1963), not the hearing person for misunderstanding what was said (Leigh, 2009).

Positively, on the other end of the social spectrum, Deaf sign language users have rallied against this stigma, by being proud of our language, our culture and celebrating our differences. Bauman and Murray (2009; 2014) have vigorously defended the Deaf community by reframing stigma into the concept of ‘Deaf Gain’. Deaf Gain draws attention to the unique contributions of Deaf people to society and human diversity through our visual orientation to the world, the advantages of our culture that enables easy communication across nations and even the physiological enhancements that we enjoy in having a wider field of vision than the spoken language users around us.

However, there are still practices of stigmatising behaviour that can occur within the Deaf community through lack of awareness of knowledge of different conditions. For example, the author has noted in her previous role as a mental health advocate that there can be internal community prejudices that are parallel to the hearing world. Within Deaf clubs, there have been clear actions of separating different groups of people, singling out those who are different from what is the (perceived) norm; in some clubs, there is a ‘mental health corner’ where local Deaf psychiatric patients will sit with their carers on an evening out (personal correspondence/experience). This is not noted in empirical literature, but is known and observed by those of us who attend Deaf clubs. From the perspective of stigma, as the Deaf people with mental health issues do not argue or challenge these actions, this then becomes ‘courtesy’ stigma; these people have internalised these external attitudes towards them and therefore believe that they ‘belonged’ to this corner due to the labels given to them by other members of the Deaf community (Goffman, 1963). However, to counteract this labelling and stigma behaviour, there are initiatives afoot that aim to educate and challenge these negative beliefs, such as Mental Health First Aid courses tailored specifically for Deaf BSL users (British Society for Mental Health and Deafness, 2016).

Despite the presence of stigma in the Deaf community, there is a scarcity of available published research that outlines this phenomenon in the Deaf community. This research study will explore the different personal experiences of Deaf people living with dementia, of their families and any direct/indirect stigma that has occurred (in Chapter 7).
3.11 The definition of personhood and dementia

In the field of dementia care, Kitwood (1997) argued for a move away from the negative homogeneity that people with dementia previously experienced and proposed the idea of personhood by introducing the concept that individualised biopsychosocial person-centred approaches with people with dementia were more appropriate and humane. This approach values the person regardless of their capacity or abilities. As introduced in his ground-breaking book, personhood can be defined as ‘a standing or status that is bestowed upon one human being by others, in the context of relationships and social being. It implies recognition, respect and trust (p. 8).

Furthermore, Sabat and Harré (1992) show how personhood can be inadvertently (or deliberately) not recognised in individuals when they are being supported. They discuss negative positioning where they state that the person with dementia is ‘malignantly positioned’ in measurement of their diminishing abilities, rather than being valued as a person in their own right. For example, Sabat, Napolitano and Fath (2004) discuss how a hired support worker chooses clothes for Mrs. E while she is at home, despite the fact that she is more than capable of making this decision by herself. Kelly (2010) observes that within a ward setting, no time is taken to sit with the person with dementia, to give them space and consider in their own time what they might want to share with the listener (p. 113). Another example of malignant positioning that has occurred very recently is as follows: a friend’s profoundly deaf father with dementia was positioned each day in a social lounge in a residential care home to sit next to the only deafblind resident in the home on the basis that they were similar and would feel comfortable together, instead of recognising they were the two people least likely to be able to communicate with each other. This decision also positioned their father away from anyone else whom he might have been able to lip-read (personal correspondence, 2016).

Taking a biographical approach in valuing people with dementia’s stories has been done by many researchers and campaigners (Clarke, Hanson and Ross, 2003; Hellström, Nolan and Lundh, 2005; Ward, Campbell and Keady, 2014). These approaches have contributed towards the consolidation of understanding personhood; the person’s self continues in some form that is recognisable, has value and is an expression of personal identity. Crucially, this work and others (Small et al., 1998; Caddell and Clare, 2010; Caddell and Clare, 2011; Angus and Bowen, 2011; Chaplin and Davidson, 2014) challenge the idea of dementia being defined by cognitive and behavioural changes alone, implying that the reduction in cognitive powers takes away the self because the ‘thinking self’ is no longer present.

Baldwin (2008) disputes some aspects of the personhood approach by questioning the effectiveness of Kitwood’s personhood principles. He points out that there is an assumption that a person’s identity is to be maintained as it was before they developed dementia. Rather, he puts forward that we should embrace the person as they are now and allow their self to flourish as it is, rather than trying to engage with who they used to be. Downs, Clare and Anderson (2008) outline that for a person with early-stage dementia, ‘the sense of continuity that characterises the experience of self is challenged and the nature of future experience of self becomes uncertain’ (p. 150). Additionally, Pearce, Clare and Pistrang (2002) explored...
sense of self through semi-structured interviews with 20 men and their wives. It was found that the men recognised their ‘previous’ self and were using coping strategies to develop a new ‘self’, whilst embracing their condition and valuing their existing skills.

Kontos (2004; 2005) pushes the personhood agenda further by challenging the dichotomy between the cognitive self and the embodied self, clearly advocating the non-verbal ways in which a person with dementia can demonstrate their selfhood through their facial expressions and/or body language. Her observations with a group of people in a residential unit clearly identify how people with dementia are able to be themselves, maintain their identity and offer their views through multiple modalities. This provides a valuable insight into how people with dementia can maintain their self through both verbal and non-verbal expression.

However, this work on the embodied self and non-verbal expression occurs in social contexts in which visual language has not been present in the histories of those people with dementia. The impact of dementia on lifelong users of a visual language such as BSL has not previously been considered in the literature on personhood (Young, Ferguson-Coleman and Keady, 2014b) and is a key consideration in this research study (see Chapter 4).

3.12 The Deaf community and the definition of personhood

Personhood is generally not a term that has been used within literature on Deaf people, Deaf culture and communities. Therefore, within this section, personhood will be considered in relation to supporting and developing Deaf identities, community, recognition of sign language and culture. Parallels will be drawn with the dementia movement in how Deaf people have been perceived as less than able to function as equals in society.

As a way of defining personhood, the work of Ladd (2003) is conceptual in how he presents ‘Deafhood’ as an alternative to this definition. This is where he positions the Deaf person as a member of a linguistic minority group, a sign language user, who is a visual being. Deaf people, he argues, view the world differently from their hearing counterparts who are ‘phonocentric’ (Derrida 1976; Corker, 2001; Bahan, 2008). Phonocentrism refers both to the notion that speech comes first or fundamentally to the aural orientation of people – sound and hearing take priority and is a fundamental orientation to the world. By contrast, it is the visual; movement and touch that forms the fundamental orientation of Deaf people (Bahan, 2008; Bauman and Murray, 2009; Hauser et al., 2010). Deafhood is also defined as a process of becoming, of owning that orientation and recognising, contributing and performing Deaf culture through everyday life. As Turner (1994) argues, culture is a verb, not a noun, therefore the ‘how’ of Deaf culture is of greater significance than the ‘what is’ Deaf culture (see also Young and Temple, 2014, Chapter 2). Ladd (2003) posits that hearing people (who exist and function in a phonocentric world) need to reconsider and reconstruct their beliefs and understanding of what constitutes a Deaf person in a Deaf world.
The repression of sign language from the late 19th Century onwards (Lane, 1984; Davis, 1995) led to the subsequent rise of oralism, where Deaf children were taught using the oral method in schools instead of in their native language, sign language. Up until that point, Deaf people were considered as full citizens of society, working as bankers, lawyers and bookkeepers, all educated and living with the use of sign language as their first language (Lane 1984; Dimmock, 1993; Davis, 1995). An educational congress held in Milan in 1880 changed this practice however, when those present decided that all Deaf children should be taught by the oral method and that sign language should be banished (International Conference on the Education for the Deaf, 1880). This decision then exacerbated negative societal perceptions of Deaf sign language users, as Turner (2009) observes, in that it was erroneously stated ‘everyone knew that signing was not really language’ (p. 244).

Emery (2007) describes how the criteria for full citizenship have a phonocentric requirement; all people must ‘speak’ the language they know so that they can participate fully in society. A key example of the phonocentric dominance in definitions of citizenship in the early 20th Century is evident in approaches to social welfare amongst Deaf people in the UK. These were led by missioners, who were predominantly hearing people, who could sign, who saw it as their duty, within a Christian tradition, to bring the ‘word’ of God to Deaf people who could not hear and could not speak it (Ladd, 2003). This justification became the basis for a process of social welfare ‘for’ Deaf people, that created dependency on those who could hear and speak to sort out all aspects of Deaf people’s lives, including employment and marriage (Ladd, 2003) and engendering an internalised oppression that ‘hearing people know best’ (Corker, 1994; Ladd, 2003; Leigh, 2009). For example, Griggs (1998) observed a real-life scenario where a Deaf man wrote down all the appropriate answers on a separate piece of paper for his application for housing benefit, believing that the official form could only be correctly completed by the hearing support worker. However, Emery (2007) later argues that sign language and English should, and can, both be learnt simultaneously so that the Deaf child (and later, adult) can be an active social citizen on their terms, in their own native language. This will be further discussed in Chapter 8.

3.13 Citizenship

As the argument for personhood has developed into a political concept (Bartlett and O’Connor, 2010; Bartlett, 2014) for people becoming full citizens, it is important to understand the concept of citizenship first. Citizenship is a ‘status afforded to a person to bolster their rights to access health and social services in the country that they are situated within, while they are being socially active and connected to other citizens’ (Brannelly, 2011). Marshall (1949, reprinted 2006) originally defined the term citizenship as comprising of three basic rights; that is, civil rights towards one another, political rights and social citizenship. For the purposes of this literature review, social citizenship will be the main focus because this highlights the welfare entitlements of people, such as being able to access social services and support if one is unemployed, disabled or elderly. Social citizenship also embraces the notion of our citizenship rights being reinforced by each other through community obligation and shared benefit. This focus on social citizenship in turn will
highlight how people, whether they are Deaf, or whether they have dementia, are to maintain their agency and autonomy.

3.14 Citizenship and dementia

Bartlett and O’Connor (2007) state that the concept of personhood needs to shift towards a citizenship approach, which allows the narrative identity of the person with dementia to maintain their agency and presence in society, rather than just being enabled to express their views. In this sense, agency implies having the rights to decide, the ability to actively influence a situation and the recognition of someone who can and does influence their environment. Bartlett and O’Connor (2010) later argue further how people living with dementia should be recognised as political citizens in their own right; rather than just being enabled and supported using the personhood approach advocated by Kitwood (1997). Being positioned as political citizens in this context advocates that people with dementia can act with agency and autonomy in making their own decisions and choices within their lives. There is no assumption that the onset of dementia influences these decision-making processes or makes them by definition unable to make their own choices. Baldwin (2008) adds that personhood, citizenship and narrative opportunities should all be allowed to co-exist together to allow the person to be a full participant in society with political and agential positioning. In other words, all three bolster participation, which is the overriding principle.

In 2012, the UK’s Prime Minister, David Cameron, launched the first Prime Minister’s Challenge on Dementia, whereby the three main priorities were for: driving improvements in health and social care; creating dementia-friendly communities; and better research in dementia (Department of Health, 2012). Cameron further stated, ‘...as a society, we must make sure that people with dementia, their carers and families can be active citizens with the potential to live well with dementia at every stage of the condition’ (Department of Health, 2012, p. 12). This is the first time that people with dementia are referred to as ‘citizens’ at this level, which shows the (slowly) changing landscape in approaching positive conceptual developments in dementia care.

3.15 Supporting agency within relational contexts

Research on agency and personhood and the relationship between both in respect to people with dementia has taken a strongly relational turn with the work of Bartlett and O’Connor (2007) and Brannelly (2016), for example. Ratner (2000, p. 442) defines relational agency as a social construct, an action that can only occur when there is social interaction between two individuals or within a collective. In other words, to see agency amongst people with dementia then people have to be seen within social and communicative contexts in which there are opportunities to relate to each other. The implication is that agency as a facet of the individual, devoid of social context, is difficult to identify for someone with dementia. Ratner (2000) states that when someone expresses their view or opinion to another, this demonstrates and positions their social identity through representing themselves within and to their individual world around them.
Personhood relates to agency through an emphasis on situating the person with dementia within a social world, not in an isolated position cut off from the world around them (Kitwood, 1997). As explored by Sabat and Harré (1992), Brooker (2006), Keady et al (2007), and Bartlett and O'Connor (2010), supporting a person’s agency emphasises the maintenance of the sense of self and the importance of giving space and opportunity to maintain identity in as many areas of their lives as possible. Relational agency assumes personhood in this sense, and personhood is enacted through opportunities to demonstrate agency within a social world.

Sabat, Napolitano and Fath (2004), in a study of older people accessing day-care services, describes an older woman who is portrayed by her husband as being meek and passive and he has to undertake all the work at their home. However, the staff that support this same person at their local day centre describe her as a different person who mucks in and helps with everyday activities with the other residents. The woman’s agency is supported and/or relinquished depending on which environment she is within at the time and those she relates to in that environment. Her personhood is seen or obscured through the impact of a social environment enabling or denying agential acts and choices. To further elaborate the argument that a person can make agential choices, Jaworska (1999) observes, ‘the person thinks she is correct in wanting what she wants; achieving what she wants is tied up with her sense of self-worth; and the importance of achieving what she wants is, for her, independent of her own experience’ (p. 116).

It has been argued that the person living with dementia cannot maintain their agency alone. It is a supportive and collaborative environment that enables the person to make decisions and retain their identity; context is vital, so is communication. Sabat and Harré (1992), for example, state that the person enters ‘social space’ only in so far as it is recognised, responded to and confirmed in the actions of others’ (p. 446). Jaworska (1999) adds, ‘to properly respect the autonomy of many an Alzheimer’s patient, one must do quite a bit to enhance her autonomy. One must help the person no longer able to do so on her own to lead her life according to her remaining values, to the extent that this is still feasible’ (p. 133). Kitwood (1997) and Harris and Keady (2009) affirm that the person living with dementia needs to be bolstered by an environment that provides both love and belongingness, which fosters the possibilities in which the person with dementia can maintain their agency and the choices they make on a daily basis. What the authors have in common is the observation that if there is no supportive or engaged environment, then the person with dementia’s personhood is diminished and their agency relinquished.

Hulko (2004) posits that individuals do live with multiple identities and positions within society, (for example, being Deaf and Black), which can define different forms of oppression experienced by those who are denied their rights and responsibilities as citizens (p.238). Bond, Corner and Graham (2004) discuss how the social positioning and social inclusion of a person living with dementia can challenge their capacity to respond or make choices with agency. They remark, ‘their experience of intersectionality militates against acting with agency and denies them cognitive citizenship’ (Bond, Corner and Graham, 2004, p. 233). The lack of direct support and lack of positive attitude from society negates and denies the person with dementia’s opportunity to maintain their multiple identities.
A more recent example of how people living with dementia can make and carry out their own agential choices, which reflect their embedded identities, would be to consider the work of Dr. Ann Johnson and Mike Howorth from Greater Manchester, UK. They are both living with dementia and have been heavily involved in providing dementia awareness training to clinicians and nurses, which is a positive demonstration of how they have maintained their multiple identities in pursuing their teaching interests during their retirement. Mike Howorth left early retirement to return to a part-time post with the Open Doors Network in Salford (in the North-West of the UK) because he believed, with his diagnosis of Alzheimer’s Disease, and the support of his wife as he discussed these decisions with her, he was in a perfect position to talk about his experiences and support the wellbeing of other people who had recently received the same diagnosis. Additionally, by taking on this role, Mike was showing the mainstream population that people with dementia can maintain fulfilling lives as well as take on new challenges and published articles to this effect (Howorth, et al., 2012; Ward et al., 2012). Dr. Johnson (2010) has written about her personal experience but also has challenged thinking around the discourse used about people living with dementia (Sabat et al., 2011) while maintaining her lecturing and advisory role in presenting and writing about her diagnosis. However, Dr. Johnson has recently made her own agential choices in asking a close friend to travel with her to events so that she can continue to offer presentations. These two examples show how each person identified their scaffolding needs; they were clear on which individuals would support them in unique tasks that were important to them. When a person with dementia receives support from their spouse, family member, their carer or their friend, this is a mutual arrangement that enables the person with dementia to maintain their agency and their choices. Scaffolding can occur deliberately, or indirectly.

Informal discussions with like-minded peers in the Deaf community have explored whether Deaf people with dementia have been given any opportunities to maintain their agency and presence in the here and now. One significant anecdote (between the author and a friend) stands out in defining how scaffolding agential choices might work for a Deaf person. The story was as follows: A Deaf woman who was recently diagnosed with dementia agreed with her friend that if she had started to repeat a story or funny tale in company, that this friend would gently rub her arm (without saying anything) as an indicator that she had already shared this information. This was a gentle, mutual and supportive agreement between two Deaf friends, which became an effective coping strategy for the Deaf person with dementia so that they did not feel embarrassed while socialising within the wider community. The physical action of rubbing one’s arm would be defined as scaffolding, as this action enabled the Deaf person with dementia to remain authentic within their small community. It supported the maintenance of their identity within social communication. This will be further discussed in Chapter 7, when we explore further potential physical and kinaesthetic components of offering scaffolding for the Deaf person with dementia within the social world.

3.16 Definitions of agency versus resilience

While exploring the concept of agency and its definition for this review, it has become apparent that the realisation of agency is not the only component that supports the individual in representing their self. While
considering the Deaf community’s approach to dealing with everyday barriers, their agency is compromised by the society they live within; but they remain as members of this oppressive environment through necessity and lived experiences. If their agency is not fully realised, the maintenance of their self could be better labelled as resilience or toughness (Dienstbier, 1989; Seery, 2011). Deaf peoples’ toughness as they face a lifetime adversity in being valued and recognised as Deaf individuals is an on-going process as Deaf people will shrug their shoulders, brush it off and think ‘that’s what it’s like being in a hearing world’ because they have not experienced an alternative reality. However, Young et al. (2011) articulate that Deaf people have a ‘navigation of experience’, which enables them (us) to continue with their/our lives through lived experiences and maintain their/our resilience as a life-long attribute. Deaf people are not bouncing back from a one-off adverse event in their/our lives; being Deaf is something that is a constant and an identity, which is only challenged by those who are not in the know.

In relation to Deaf people with dementia therefore, this life-long experience raises an important question. Is Deaf people’s response to dementia (including their personhood and agency) enhanced in a positive way because they have been used to experiences in the face of which they must maintain their resilience? Or does that life-long experience of oppression and inequities imply in the face of dementia there are no resources left with which to resist and respond? There is no evidence on which to draw on in answering this question because there are very few publications that directly explore older Deaf people’s life experiences and still fewer that might be linked to health and healthcare (Pullen and Kyle, 1997; Witte and Kuzel, 2000; Margellos-Anast, Estarziau and Kaufman, 2006; McKee et al., 2011; Young, 2013). The study by Witte and Kuzel (2000) is a good example of the question raised above, be it in the broader domain of health care in general. They identified through two focus groups that the Deaf population are tolerant and accepting of their difficulties in accessing healthcare services. One way of interpreting this finding is that it demonstrates that this population maintain their resilience and toughness in knowing that healthcare service access is consistently problematic, but yet choosing to tolerate and accept this as part of their interactional environment. Another way of interpreting it is that this population have so internalised their oppression that they simply accept a lack of access to healthcare services as normal and there is nothing to be challenged.

The next few paragraphs will consider literature that explores how social citizenship in the Deaf community is an on-going issue, with evident layers of convergence with the denied citizenship of people who have dementia.

3.17 Citizenship and the Deaf community

This section will explore the different avenues in which Deaf people have struggled and campaigned for the right to be seen and accepted as full citizens. In sign language (BSL), the sign for citizenship is PERSON-RIGHT, towards their chest, as if they are being ‘given’ the right to be themselves (Appendices (ii) V3). Translated simply, this means ‘human right give’. Another sign given to citizenship is PERSON-POWER (Appendices (ii) V4). The sign for power in BSL, in this context, is one of political activism, which is another
meaningful way to demonstrate this community’s views about how they are valued (or indeed de-valued) by the mainstream.

3.18 How does one achieve full citizenship status?

Citizenship is an assumed status that each person can take for granted while they are alive. As a full citizen, a parent might expect that their child will have rights that are met, for example, by attending nursery/school; accessing education in their native language; choosing which school to attend, and so on. Parents will act as political citizens for their child(ren) if these specific requirements are not met. This example is replicated in other areas of life, such as accessing health care or achieving gainful employment. However, as a Deaf individual, access to full citizenship is denied at each stage of life. For example, the parents of Deaf children of whom 95% are hearing with no familial deafness (Mitchell and Karchmer, 2004) have to consider choices that are not automatically granted. The discourse in the UK might be one of informed choice (Young et al., 2006), but in reality not all potential choices are available, such as intensive BSL for the child and family, or the best school to suit the particular needs and strengths of each Deaf child because of financial and ideological constraints. As the Deaf child matures into a young Deaf adult, their choices for accessing further and higher education are limited (Young et al., 2015) and employment opportunities are few and far between in the mainstream hearing population (Winn, 2007; Young et al., 2015). Health inequalities are common (as covered in section 3.21) and daily frustrations at being Deaf are an on-going thread for the person who is being denied full citizenship.

There are obvious parallels in relation to people with dementia whose citizenship status becomes problematic in the eyes of many, not simply because their capacity and capability might be questioned (as happens in the case of many Deaf people too), but because their choices become limited. As discussed previously, (see section 3.19), the recognition of a person with dementia’s agency may be denied and/or the social contexts, physical environments and forms of communication that might scaffold that agency may not be available. Hence, the ability to exercise choices as a full citizen becomes constrained, and some choices simply do not exist anymore for someone with the label of ‘dementia’.

3.19 Political citizenship as a Deaf person

Throughout recent decades, Deaf sign language users have campaigned for the right to be heard as equals in society through their own language through politically minded activist groups, such as the National Union for the Deaf (NUD), which ran from 1976 to 1986; the Federation of Deaf People (FDP), which ran from 1997 to 2004; and the Deaf Liberation Front (DLF), which was set up so that direct action could be achieved, ran from 2001 to 2003 (Beschizza, Dodds and Don, 2015). The Deaf community were able to show their pride in their language by taking to the streets to march for its recognition. On 18th March 2003, the Department of Work and Pensions within the UK Government recognised BSL as a community language. This was perceived by the Deaf community as a huge step forward with an initial one-off investment of £1.5 million made by the UK Government to enable the growth of BSL within mainstream society.
However, recent political changes within the UK Government have meant differing views on the provision of support for BSL as a mainstream language; Deaf people as citizens who use BSL as their first language are being re-evaluated as lesser than their peers, which perpetuates and maintains the ‘them and us’ philosophy (Emery, 2009) that has been discussed in previous sections. Legislation in the UK is variable in its approach, and how it is understood, to supporting the recognition of Deaf people and their language. There is the Equality Act (2010) that supersedes the Disability Discrimination Act (1995), which positions Deaf sign language users into the category of disability (not as a culturally linguistic group). However, the equality duty that public sector organisations have to implement to show their responsibilities under the Equality Act (2010) does, in fact, demonstrate awareness of Deaf sign language users. Furthermore, there are positive examples of councils and public services working with their local and national Deaf organisations to adopt BSL Charters which signify their intention to improve access to services for Deaf people (British Deaf Association, 2016b).

Members of the Deaf community are showing resilience by facing the mainstream society and fighting for their rights to become equal citizens in society with access to BSL as their first language. Deaf people have engineered their own opportunities to access information. For example, the London Deaf Video Project (LDVP) was set up in 1985 in response to the mass translation of welfare benefit information leaflets into community languages, but not into BSL. The LDVP translated those leaflets into BSL so that that Deaf people had the same access to the welfare benefits information being distributed (Collins, 1989). In the last year, Scotland has just passed the BSL Act (Scotland) in October 2015 which signifies a positive change in the thinking of the mainstream community about sign language users and our rights to live as full citizens in mainstream society. It places specific duties on public services to respond to and plan for the rights of BSL users in the delivery of services, including education.

Members of the Deaf community have pooled together their resources to develop collective agency, by sharing their experiences via the Limping Chicken website (www.limpingchicken.com) thus striving to challenge attitudes and discriminatory practice. This demonstrates how the individual can make agential choices for themselves and also become agents through the shared (collective) experiences and learned strategies of others. The Limping Chicken is a very popular online forum that provides Deaf sign language users with the opportunity to either blog (or vlog, which is a video log) their everyday experiences. The forum has reported that there were over 1 million hits in a period of 20 months (Swinbourne, 2013a) which demonstrates its versatility and acceptance by the Deaf community. However, via this online forum, the Deaf community are consistently sharing stories of how their Access to Work funding is being reduced or denied. Deaf sign language users are now being perceived as being too expensive to support within the workplace,

7 Access to Work is a UK Government initiative in which the Deaf person in employment can receive funding support for their communication and environmental needs, which allows full participation on a daily basis. https://www.gov.uk/access-to-work/overview
with evidence of Access to Work advisors being inconsiderate in their assessments (Limping Chicken, June 2016). One campaigner, Dodds (2014), labels this activity as epistemic injustice as the Access to Work advisors are blatantly devaluing the Deaf sign language user’s knowledge, particularly of their personal experiences and cultural status. This, in itself, is a support group activity to debrief and share communal exasperation with discriminatory activity.

The development of dementia user groups in the hearing world such as the EDUCATE (Early Dementia Users Co-operative Aiming to Educate) group based in Stockport (in Greater Manchester) and the ACE group (a support group for those who have younger onset dementia) in Rhyl (in North Wales) are similar attempts at collective agency in the face of social discrimination and the need to fight back to change the image of how people with dementia are seen in order to secure better rights of recognition (Davies-Quarrell et al., 2010). However, these support groups for hearing people with dementia clearly evidence that the appropriate connections are there locally; while for the Deaf community, being geographically dispersed, these connections are made via social media networks as it is easier to reach one another through this medium.

There is a history of oppression that stems from being in a minority group as a Deaf person; there are narratives continuously shared about how hearing people wittingly or unwittingly oppress Deaf sign language users because they do not know sign language and they do not understand Deaf culture. It is a known fact that hearing people will ask, or force, the Deaf person to mould themselves into an accessible vehicle; for example asking them to communicate via pen and paper when English is not their first language (personal correspondence) or speaking loudly at them thinking their communication method is appropriate for the Deaf person (Swinbourne, 2013b). Assumptions about Deaf sign language users are regularly imposed on us/them, which in turn, inadvertently challenges our/their agency because we/they are not able to communicate directly in our/their own language.

In contrast to the positive activism discussed earlier within this section, there are many examples shared in the Deaf community of being unheard or not listened to, particularly within healthcare services (SignHealth, 2014). Deaf people feel that their stories are ignored or their questions go unanswered because, in the eyes of unaware hearing professionals who do not use sign language themselves, Deaf people cannot be knowers of their own ill-health issues because this has not been communicated clearly in their language. Instances of epistemic injustice are common for those who exist within this community and parallels can be drawn with people who live with dementia in that their views and opinions are dismissed and they are interpreted as not being ‘knowers’ of their personal health concerns due to their memory issues. This, in turn, denies them full citizenship.

There is a paucity of literature that demonstrates the socio-cultural opportunities (or lack of) that the older Deaf person living with dementia might exist within. There is one book (Conrad, 2004) which describes the author’s experience of supporting her Deaf mother while she lived with dementia, and there are two research articles that portray the stories that Deaf people living with dementia and their families have shared (Parker,
Internationally, there has been one paper published in Finland by a Child of Deaf Adult(s) (CODA) discussing changes in communication with their Deaf parent (Rantapää and Pekkala, 2014). This paper is written from the perspective of a hearing child, discussing their observations of the changes in communication that their parent presents while living with dementia, and does not offer direct input from the Deaf parent themselves. The findings section of this thesis will highlight individual examples of how Deaf people living with dementia might express their agency.

Deaf people who have been discriminated against, or oppressed for all of their lives, will always know they have a label. They will always experience how hearing people (with no knowledge of BSL) will put up a language barrier; ‘I cannot communicate with this person’ (therefore creating the untold assumption) they are less of a person because the Deaf person’s values or opinions are not heard or understood. So, taking the above into consideration, in theory, if a Deaf person living with dementia is approached by a hearing person (whether this is on the street, in a nursing home or by a service provider), that same automatic ignorance of their selfhood may remain, regardless of whether there is any additional recognition of any cognitive issues the Deaf person may be living with. The Deaf person with dementia may well not notice this disregard as an additional oppression, as they may be already acclimatised to this response as an experiential way of living.

This has been further elaborated in Hunt, Oram and Young’s (2011) commissioned review where the researchers met, in a care home, with a Deaf resident who was perceived by the predominantly hearing care staff to be living with the early stages of dementia. It soon became quickly apparent that this person did not have any symptoms of dementia and was thirsty for communication in their first language, BSL. It was determined that there could possibly be deterioration in their communication, as there were very few opportunities for formal or social interactions in their native language, BSL. However, positively, Hulko’s (2009) argument that, ‘older people with dementia who have experienced discrimination or disadvantage in their lives prior to developing dementia, on the basis of racialization, gender expression, ethnic group membership, and/or socio-economic status, are able to apply this resilience to their lives with dementia’ (p. 141) really contributes to the concept that the Deaf person living with dementia will continue with their innate toughness and resilience and carry out their daily lives as only they know how. However there is little research evidence to support this hypothesis and the data from this study (see Chapters 5 and 7) make an additional contribution to this area of work.

3.20 Making health-related choices

This section will focus on health issues that are experienced by Deaf BSL users. Whereas personhood and identity have previously been discussed in relation to this group, how Deaf people are able to or are supported to make decisions about their future remains little touched upon. The current climate for healthcare provision will be highlighted first so the general picture of barriers to making health related choices could be seen before focusing on those in relation to Deaf people with dementia and their families.

3.21 Why are health inequalities important to us?
Marmot (2010) states that ‘health inequalities are not inevitable and can be significantly reduced. They stem from avoidable inequalities in society: of income, education, employment and neighbourhood circumstances. Inequalities present before birth set the scene for poorer health and other outcomes accumulating throughout the life course’ (p.36). Health inequalities can impact on the full continuum of receiving health and social care at all levels. Positioned on the continuum are issues such as access to GPs; access to hospitals; access to information treatment; support and fundamentally, outcomes.

Within England, there is the Health and Social Care Act (2012) which supersedes the National Health Service Act (2006) with a statement that declares action will be taken to ‘reduce inequalities between patients with respect to their ability to access health services, reduce inequalities between patients with respect to the outcomes achieved for them by the provision of health services and in exercising functions in relation to the health service, the Secretary of State must have regard to the need to reduce inequalities between the people of England with respect to the benefits that they can obtain from the health service’ (part 1C). In addition, the Department of Health have developed the Equality Objectives Action Plan (2012), which stipulates their intention to ensure that dignity is a priority for the older members of the population.

Although the document’s stated aim is to reduce inequalities within the health service (Equality Objectives Action Plan, 2012), there is no mention of actions or targets in relation to this aim, except for one point regarding an appropriate percentage of Disabled senior staff being recruited into the Civil Service. Given the document’s aim and scope, one would have expected targets and actions working towards reducing the acknowledged inequalities within the health service.

The National Institute for Health and Care Excellence (NICE) (2012) have guidelines on tackling health inequalities using the Equality Act (2010) as their reference point. They created a conceptual framework diagram (p.25) of what they consider to be the priorities (see Figure 2) for all populations.
Figure 2 incorporates all potential aspects of one’s life-course and how health inequalities might occur in one, or all, of each segment and how different levels of public service have to take responsibility for their actions in reducing these inequalities.

However, this diagram is very striking in how it could be translated to the Deaf life experience. The same headings and the same positioning have an impact on Deaf people’s daily experiences. For example, the Deaf community can, at times, be at the mercy of organisations that make decisions on their behalf but do not always represent all views of that community. Some Deaf community organisations have altered their priorities in order to target and support specific sectors within the Deaf community. For example, Action on Hearing Loss, previously called the Royal National Institute for the Deaf, rebranded themselves at the cost of nearly £250,000 because the organisation was becoming very aware that they did not represent all sectors of the Deaf community; they reshaped their focus to people who are hard of hearing and/or older people who experience a hearing loss. Similarly, Sign Charity rebranded itself as ‘SignHealth, the health charity for Deaf people’ as it recognised that there were health inequalities across all aspects of health, not just mental health.

3.22 Health inequalities and the Deaf community

When the phrase health inequalities is used in this context, it is understood to mean that Deaf BSL users have difficulties in health care provision as well as experiencing differences in health outcomes in comparison with the general population. There has been an exponential growth in research and publication of articles or reports that identify and discuss the huge difficulties that the Deaf population face in accessing health and/or social care in the UK (and indeed, internationally) in the last 20 years (Ubido, Huntington and Warburton, 2002; Sign Health, 2008; 2014; Alexander, Ladd and Powell, 2012; Kritzinger, et al., 2014; Emond et al., 2015).

Access difficulties in relation to communication and language occur at different points in the patient journey. For example, at first point of contact there is evidence that interpreters are not consistently booked for health appointments although this has been challenged with a recent publication (NHS England, 2015, draft); there are examples shared in the literature about the consequences of the lack of provision of interpreters in mainstream healthcare (Alexander, Ladd and Powell, 2012; Lowrie, 2014; SignHealth, 2014). Without interpreters being present at the health appointment, the patients’ agency and autonomy in sharing information about their condition and the decision-making processes are severely impacted. This discriminatory practice is not restricted to the UK, for example, a Deaf man was refused access to sign language interpreters by three different hospitals in the USA (Boniello, 2014). A report launched in Victoria, Australia (Lowrie, 2014) demonstrates parallel barriers to accessing sign language interpreters in primary healthcare settings. Seventy-two participants were interviewed and represented in a case study approach
where experiences of serious adverse events were shared, such as the Deafblind patient left under general anaesthetic for a longer time than would be usual because nursing staff could not find an interpreter to communicate with them, and the demand that a mother-to-be provided letters from both her obstetrician and a psychologist to ‘prove’ (quotation marks my own) that she needed a sign language interpreter for her baby’s birth.

Indeed, there are difficulties in booking appointments in the first instance, as most GP surgeries now ask patients to phone in on the day to secure an appointment via a telephone queuing system (Barnsley Clinical Commissioning Group, 2014). Ironically, by carrying out this literature review and reading about limited options for Deaf people to access their GP surgeries, I found out that I could register with my local practice online. This has never been communicated to me directly, but as a Deaf sign language user who cannot use the telephone; this has made a huge difference in being freely able to book GP appointments online. While these appointments appear to be for routine discussions only, as the first appointment offered at first view was for in a month’s time, and while clearly not appropriate for emergencies, it has offered me a choice which is something that I thought was not an option previously.

Additionally, there are some individual pockets of good practice, where doctors’ surgeries offer their Deaf patients the opportunity to send a fax or a text message (Pal, 2003). There is also evidence of GPs using texts to inform their patients of their blood test results with beneficial consequences, including saving money on the costs of a face-to-face appointment with the GP (Akunjee and Akunjee, 2015). However, there is very little evidence that this practice is being implemented for Deaf sign language users, with inconsistencies being reported, with media reporting of a Deaf woman being unable to use their GP’s new triage system (Qaiser, 2014).

GP practices are often not aware of how to book a BSL interpreter and may refer the request to their contracted generic spoken language agency, who themselves may not be aware of how to book BSL interpreters for health-related appointments. Online newspaper articles both in the UK and internationally portray stories of Deaf people’s misdiagnosis, lack of understanding around being told about their health condition, not knowing what to do about it, not knowing or understanding what their treatment is and even, in the most extreme cases, agreeing to operations without knowing what the procedure would be. Similar experiences span across a range of mainstream healthcare providers, in that these establishments do not provide services that are accessible in BSL (Urquhart, 2013; Swinbourne, 2014).

Additionally, via the Limping Chicken vlog website mentioned in section 3.19, negative health experiences have been posted by Deaf and hearing people who are all distressed about common themes; such as having no sign language interpreters present at appointments. A hearing child of a Deaf parent, Dixon (2013) shares his story about having to interpret for his father and tell him directly that he was going to die, ‘Matt walked into the cancer centre that day wanting to play a supportive role but instead had no option but to face his dad and tell him that his fight against cancer was over’. If a qualified sign language interpreter had been present at that appointment, Dixon would have been able to be there as his father’s son and support him in
that familial role, rather than being on the other side of the table breaking the news to him in an interpreting role. Additionally, on the vlog, a Deaf sign language user, Gurney (2013) also shares his story about going for an operation where he had no idea what was happening, ‘I trusted them medically, but I didn’t know what would be done. Would my appendix be removed? Or cleaned up? I understood that it would be keyhole surgery and I agreed and signed the form, mainly because I just wanted the pain to stop’. The concerns highlighted by the community in these general online forums have also been shared with the author in personal interactions, highlighting the issues which Deaf people currently face when attending pre-booked appointments at hospitals. For example, an older Deaf person described how she turned up for a long-standing appointment, only to find an interpreter had not been booked, despite the person’s case notes clearly stating they were Deaf. The Deaf person then had to wait in reception for three hours until an interpreter was found. When they asked why the interpreter had not been booked in advance, the response was, ‘we wanted to wait to see if you would turn up for the appointment first’. This is a key issue for many Deaf people; they trust the medical staff’s expertise and accept their own lack of knowledge. They accept a lack of information and the professional’s inability to communicate (due to having no interpreter) or fully answer their questions and so accept a lower level of understanding about their health care.

Predominantly, the Deaf community retains a surprising level of tolerance about these health inequalities, viewing them as part of a life-long experience in which they/we are aware there will be communication breakdowns. This is commonly illustrated through Deaf humour, where jokes are shared about hearing people’s lack of awareness. The Deaf Comedians (a popular group of Deaf men and women who toured the UK in the late 1980s) would often act out a sketch demonstrating a patient attending their local Accident and Emergency (A&E) department with a broken leg, only for the doctor to constantly address them from behind their back (literally), showing interest only in discussing their hearing loss as opposed to their actual health condition.

Despite this humorous position, the situations in which Deaf people find themselves when they attend A&E and GP surgeries are highlighted in review articles such as (Reeves et al., 2002; SignHealth 2008; 2014; Ringham, 2013). They investigate the negative experiences of Deaf people attending their GPs and A&E services; communication is always a struggle in that Deaf people do not understand the health professionals they are talking to, they do not understand the medication they are being given (with examples of people ingesting medications that were meant for external use only or being given the wrong medication as they could not describe their condition in their own language) and they are apathetic about attending the GP in the first place and not dealing with their illness at the onset. Conversely, Reeves et al. (2002) found 68% of managers of A&E departments did not believe that they had issues with communicating with Deaf people, stating that they knew how to book BSL interpreters. Just 14% had evaluated the effectiveness of their service provision for Deaf people. There has been increased publicity around these issues (Ringham, 2013; SignHealth, 2014) with suggested recommendations for positive action to offer resolution to these daily barriers (NHS Practice Management Network, 2009; Ringham, 2013) but it appears that Deaf sign language users are still experiencing consistent difficulties in accessing primary healthcare provision. Within tertiary
mental health service provision there are specialist services for Deaf sign language users, however there are still no specific specialist services within primary care.

The Towards Equity and Access report (TEA) in 2005 specifically ring-fenced funding for Deaf sign language users and for improving barriers to their mental health care and provision. Each Primary Care Trust (there were 304 NHS trusts in the UK at the time of publication) was instructed to spend this money on improving access to their services. Some services simply purchased a textphone (a device that enables deaf people to type directly to one another when making a phone call) so that Deaf people could ring them directly, whereas, much more positively, in South Yorkshire, the PCT developed a specialist mental health worker role that offered support to Deaf sign language users in the region. There have been individual efforts made to address this imbalance though, with for example, the provision of BSL Improving Access to Psychological Therapies (IAPT) which is a direct therapeutic programme, called BSL Healthy Minds based within SignHealth, with qualified Psychological Wellbeing Practitioners (PWPs) who are fluent in BSL and work with Deaf BSL users who are experiencing anxiety and depression (SignHealth, 2016). This is provided in the North-West and South-East of England with inconsistent coverage across the UK as there are no concrete funding arrangements.

In addition, mainstream nursing practitioners have published articles about their experiences and have suggested practical ways forward for communicating with Deaf people (Berry and Stewart, 2006; Royal College of Nursing, 2007; Sporek, 2014). Berry and Stewart created guidelines for front-line staff to carry out a communication assessment with the Deaf patient; a crucial activity as the receptionist in the GP surgery is often the first person that the Deaf patient makes contact with. In addition, they offer guidelines on how to work with a sign language interpreter. In contrast, the Royal College of Nursing (2007) gives guidelines on what needs to be considered for a deaf pregnant woman in hospital. They inform the reader that the deaf person will have deaf aids at home (without going into detail on what deaf aids actually are, and the term itself is extremely archaic) and suggest that they bring to the hospital their own textphone or to use TextDirect (a relay telephony system to communicate with hearing people and vice versa) so they can communicate with relatives. They have evidently not considered whether these phones would be compatible with the NHS telephone systems.

As Deaf people have difficulties in accessing information about health conditions, this can often be reflected in their lack of knowledge of how to sign the actual symptom or issue that they are experiencing. They may not know how symptoms may be grouped together to name a condition, and they may not have come across the English word that would be used to describe their symptom(s) so this could mean they would not know the appropriate sign for it. McEwen and Anton-Culver (1988) found that just 50% of their Deaf participants could understand health-related words and signs. Major et al (2012) explored this phenomenon and acknowledge the coping mechanisms that Deaf Auslan (Australian sign language) users adopt, including the

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8 SignHealth is a charity that supports Deaf people who are BSL users in all aspects of their health. [www.signhealth.org.uk](http://www.signhealth.org.uk)
use of finger-spelling and nonce signs\(^9\). For example, the nonce signs in this case were, instead of finger-spelling cholesterol each time the word was said, the first two letters would be used C-H, after the initial first full spelling of the word in the sign language alphabet. Johnston and Napier (2010) developed a medical signs facility online where people could ‘bank’ their known sign(s) for medical terminology in order to offer a new way forward in adopting healthcare related signs. This evidence relates to the research question, namely there is little evidence of the Deaf community’s knowledge about dementia, there are very few signs used to describe dementia and if one has dementia, how would they wish this to be signed by themselves or other people? These issues are explored with the Deaf community later in this thesis (see Chapter 5).

3.23 Making choices for the future

When the FDP were campaigning for BSL recognition during 1998-2003, we were not just campaigning for the recognition of our community language; we were also campaigning for new opportunities for Deaf people to be able to make autonomous choices, primarily in relation to education, health and social care. Evidence of this wider scope remains in paper copies of the FDP’s written material at that time (FDP, 1999; 2000). The FDP argued that if education, health or social care is not accessible in one’s own language, then how can a person make fully informed choices or understand what is available? Informed choice and autonomous decision-making are key principles in health and social care more generally (Jepson et al., 2005; Abhyankar et al., 2016). As discussed previously, the lack of accessible and intelligible services in BSL is a key source of subsequent health inequalities in terms of patient/user outcomes - including life expectancy.

Having restricted access, choice, language barriers and limited opportunities to experience autonomous decision making are, of course, not just restricted to Deaf people’s access to health services. These are, in many cases, life-long experiences starting in early childhood. Such experiences can create an internalised oppression, in which there is no expectation that choices are or should be available, and a passive acceptance of poor access to services. Previous sections have outlined how Deaf peoples’ language choices were taken out of their hands; how they were forced to follow the method of communication preferred by mainstream society – the spoken method. By denying access to sign language (and as a consequence imposing a language system which was difficult to understand, thus impeding potential abilities to consider information independently and autonomously), the opportunity to voice one’s opinion or exercise one’s choice was also removed. Deaf children were not able to choose an education system for themselves (as is the same for most children); this decision was made by their parents and the professionals around them (Gregory and Knight, 1998; Wilkens and Hehir, 2008). Deaf adults were severely restricted in the employment opportunities they were able to pursue, as these opportunities were few and far between. As a result of this reduction in autonomy through an insufficient grasp of (any) language, Deaf people were often only offered manual work, due to low expectations of their abilities (Punch, Hyde and Power, 2007).

\(^9\) Nonce is a description used within the study of linguistics for the occasional use of a word (or in this case, a sign).
mainstream culture of restricted choice making may have impacted on the potential processes that may happen when a Deaf person becomes older and begins to consider their options within health and residential care.

A direct observation by the author was made whilst travelling to various Deaf clubs across the Midlands and North-East to recruit for this study. The initial aim of recruiting people directly into the study had to be changed in the face of a widespread uncertainty from the older Deaf people who sought information and advice from the author – as a fellow sign language user. The majority of older Deaf people had little or no understanding of the choices available to them should their health status change, or how much it might cost, or if any of the necessary information was available in their own language. This is further evidenced by Hunt, Oram and Young (2011)’s findings in their report into residential care choices by older Deaf people in Wales.

It is necessary to outline what is meant by the word access in this context. A person cannot value information or services without first being given access to them. Access here means full and genuine understanding and engagement in the person’s native or preferred language and in such a way that they can absorb the message or options or knowledge to fit into their worldview and life experiences. Superficial attempts to provide information without ensuring the person has obtained and retained what is being said, is not true access. Access is the basis of informed decision making.

Equally, for Deaf people in particular, the concept of full and complete understanding and access may itself be outside their life experiences to date and cannot be assumed to be a constant – if frustrating – goal. Although there are also some Deaf people who do understand and value and strive for this access in their daily lives, the Deaf community is a diverse group of people and experiences. It is, therefore, imperative that information or services need to be understood and received in one’s native or preferred language (Ferguson-Coleman, Keady and Young, 2014). More recently, individual projects have begun in supporting Deaf people to access the services available to them in their local areas. An example of successful information sharing for Deaf BSL users is Deaf Health Champions (a three-year partnership between UK Council on Deafness, Sign Health, Manchester Deaf Centre, Merseyside Society for Deaf People and Deaf Vision Cumbria). This is a regional awareness-raising group based in the North-West of England, which has representative officers who go out and train local Deaf community members to become volunteer Health Champions to help bridge the gaps between Deaf communities and their local health authorities. Another example is the ‘Our Health in Your Hands’ (www.ohyh.org.uk) campaign which offers support for Deaf people wishing to make complaints about the service they have received. Internationally, the National Center for Deaf Health Research in Rochester, US, has developed an evidence base as well implementing health programmes such as weight-loss programmes that support Deaf people to lose weight but also collecting data in parallel to this work (Barnett et al., 2011; Mathos and Pollard, 2016).

3.24 Redressing the balance

There are online resources such as the ‘My life, my health’ campaign (NDCS, 2016) which supports young Deaf people to access healthcare services. Media programmes such as See Hear (on BBC 2) and the BSL
Zone (an online media resource) have focussed on a variety of different health-related case studies in order to make information accessible to the signing Deaf community.

The BSL Zone transmitted an online documentary called ‘Who Cares’ in 2013 (Arnold, 2013) which focussed on older Deaf people’s residential choices and the clear limitations there were around these opportunities. Additionally, there are BSL videos on mainstream health organisations’ websites such as Diabetes UK (Diabetes UK, 2016) and the British Heart Foundation with a series of information videos in BSL (British Heart Foundation, 2016). In the last 12 months, there has been a proliferation of BSL videos created by the British Deaf Association (BDA, 2016c) and by the Alzheimer’s Society to share information about dementia (Alzheimer’s Society, 2014). While these information videos are excellent, there is still an underlying assumption that the average Deaf person will understand what dementia is already before watching them, and they also imply that specific cultural and linguistic tailored services for Deaf people living with dementia and their families are present, when, in fact, there are no such available care pathways after their diagnosis.

3.25 Older Deaf people and making choices

Whilst there are now movements afoot to make sure that the Deaf population in the UK is better equipped to access health care services, there is very little evidence of how the older Deaf population specifically is being supported within these initiatives. There are very few research articles that show evidence of older Deaf people being directly asked about their preferences for future care. Hunt, Oram and Young (2011) carried out a pioneering study (funded by the Welsh Assembly) by asking older Deaf people living in Wales about their preferences for residential care. 32 people participated in focus groups, six stakeholders were interviewed and seven face-to-face interviews with older Deaf people were carried out. The most fundamental priority was that communication in their own language, BSL, should be available; they were worried that they would not have access to this on a daily basis, even adding that they did not want interpreters present but direct sign language communication, preferably with Deaf staff. Another priority was having access to their local Deaf community (including community activities such as attending Deaf church), which was inhibited by their current facilities, with one participant explaining that the residential unit could not allow their staff time to take the participant to their local Deaf club, which in turn would have been a violation of the necessary maintenance of their Deaf identity.

More recently, with the focus being on dementia, Ferguson-Coleman, Young and Keady (2014b) completed a qualitative study with three focus groups asking them about their knowledge and preferences for support should they develop dementia. Young, Ferguson-Coleman and Keady (2014b) also discussed two case studies of Deaf people living with dementia where the individuals could give clear evidence of autonomy and agency in that they did not wish to be supported by hearing professionals who cannot use sign language. These papers reported from one aspect of the Alzheimer’s Society funded research study from which the data in this thesis also derives.
In Scotland, the Royal Bank of Scotland Centre for the Older Person’s Agenda (RBS COPA) funded a report into older Deaf people’s health and social care preferences, highlighting the current difficulties that they were experiencing while accessing those services (Donaldson and Cook, 2007). A small-scale qualitative study, with 18 older Deaf people (aged over 65) within 4 focus groups, found common themes of Deaf people not understanding what their GP was discussing with them; the experiences that Deaf people have when accessing mainstream services and communication breakdowns with staff, with one participant describing how they just received a ‘thumbs-up’ gesture from a nurse, only to find out from their family later that they’d nearly died on the operating table. The summary recommends that there should be specialist services available for this minority group but no plan or action for the translation of this recommendation into practice occurred. Donaldson and Cook (2007) made an interesting criticism themselves while carrying out this work; they recognised that they are both hearing non-sign language users who used hearing BSL/English interpreters and Deaf relay interpreters to ‘Deaf-proof’ their interactions with the Deaf people in their focus groups. They recognised in their recommendations that in future consultations with Deaf BSL users, Deaf researchers should be included from the onset.

In other areas of the UK, a review commissioned by the Royal Association for Deaf People (a Deaf charity based in the South-East of England, UK), explored social care and older Deaf people’s provision/support in England (Young, 2014). This review was carried out into this population in England, offering, for the first time, a statistical overview of the Deaf community’s ageing population. The report ends with six deliberately open-ended questions to make service providers consider this specific population and how they would tailor their services accordingly.

The six questions (Young, 2014a, p. 26) are as follows:

1. In what ways do the characteristics of the population of older Deaf people obscure need, hide strengths and hinder effective service provision within the domains of activity?
2. To what extent do the characteristics of health and social care provision in the mainstream facilitate or deny equitable access to effective social care services for older Deaf people?
3. Do we know from older Deaf people themselves, their definitions of desired outcomes which support their aspirations, goals and priorities?
4. What might facilitate or hinder the achievement of outcomes, which are valued by older Deaf people?
5. How does the minority cultural-linguistic status of Deaf people impact on the execution of core principles within the provision of social care for them?
6. On an individual basis, how should Deaf people’s language, culture and values shape the services to which they are entitled?

Young’s (2014) questions are appropriate for service providers to consider this specific cultural and linguistic community and their needs. However, with relation to these six questions, this research study is uniquely positioned to ask Deaf community members directly what their views are about mainstream and specialist service provision (see Chapter 5 and 7).
3.26 Summary

Within this literature review, there has been an exploration of the world seen through ‘Deaf eyes’, in particular through the experiences of the author and other Deaf people who belong to the same community. The concepts of identities and personhood have been discussed, showing many similarities between how a hearing person with dementia and a Deaf person within mainstream society may be stigmatised and labelled as being ‘different’.

There has been an extensive consideration of potential access issues faced by Deaf sign language users on their journey to being healthy beings; as well as the possibilities of being able to live well with dementia. There is a paucity of information about dementia in BSL, and even with the available existing information, it is clear to see that it may not be fully understood.

Chapter 4 will explore the methodologies that underpin the research aims outlined in Chapter 1. Also in Chapter 4, the methods employed to collect the views of the Deaf community and Deaf people living with dementia will be considered in depth.
4. Methodology and Method

This chapter will focus on the underpinning methodologies that have influenced this research study’s design and execution. Additionally, the methods, through which the research data were generated, will be discussed in detail.

4.1 Research aims and objectives

Overall, this research study is exploring the concept of living with dementia as a Deaf BSL user. In order to address this issue, two studies were carried out as each study explored this central concern in a different way.

The first study10 (henceforth Study 1) was concerned with understanding dementia from the perspective of Deaf people who do not have dementia themselves and do not have direct contact with dementia as carers. The research aims of this study were:

1. To explore knowledge of dementia and its symptoms;
2. To explore knowledge about mainstream service providers and where to go for support; and
3. To identify accessible information preferences.

The second study (henceforth Study 2) explored the lived experience of Deaf people who have dementia and Deaf and hearing family members who were their carers.

The research aims of this study were:

1. To explore everyday experiences of living with dementia as a Deaf BSL user; and
2. To discuss experiences of current service provision.

The combined studies were designed to meet the overall objectives of:

1. Enhancing understanding of the Deaf community’s knowledge of dementia;
2. Understanding the everyday lives of Deaf people living with dementia and their carers; and
3. To consider future dementia-related service provision for this cultural and linguistic minority group.

Section 4.2 explains the ontological and epistemological assumptions that influenced the design of the two studies.

10 The data collection from which the studies draw upon are part of the Deaf with Dementia Project. This was funded by the Alzheimer’s Society, grant number 119 (2010-2013).
4.2 The ontological perspective of being a Deaf person: a social constructionist approach

Both studies begin from a social constructionist perspective. That is to say, it assumes that there is not a fixed reality that can be measured, assessed, and understood through a set of rules or approaches that can capture it objectively and are devoid of interaction within it (Berger and Luckmann, 1991). Rather, reality is represented as an individual or collective truth that stems from people’s lived experiences (Hammersley, 1992). These lived experiences are not just those that are personally and directly experienced, but also those which are prevalent in society, might be indirectly experienced in attitudes to and representations of different groups and in how people ‘talk’ about that reality (Young and Collin, 2004). It is imperative that those realities are shared in the person’s own language (Spradley, 1979) so that their stories are heard directly from them.

Social constructivism was an appropriate basis upon which to undertake these studies, because Deaf people, Deaf people with dementia, and the carers of Deaf people with dementia were being asked about their individual and collective realities and it was important to capture their worldviews as interpreted by them and through the ways in which they chose to represent them to others. It was important to value what was meaningful, how they made sense of what was happening and what differences (from the hearing mainstream) might be apparent from a cultural point of view from two different perspectives as Deaf people and as Deaf people experiencing dementia.

There is previous research knowledge of the Deaf community and the different life experiences Deaf people have on a daily basis in comparison with hearing people (see Chapter 3), but there is a paucity of publications relating to the lived experience of dementia through a Deaf person’s ontological positioning in the world. Ontology refers to ‘being’ in the world; how and what we experience because of who we are and our relationship with what is around us (Guba and Lincoln, 1994). The reality of being Deaf with dementia as known by those living it has so far been unrecorded and therefore largely unrecognised and is without meaning for others. It is also largely unrecognised in any recent work that has taken place on Deaf ontology (Bauman and Murray, 2009; 2014; Leigh, 2009; McIlroy and Storbeck, 2011) which, whilst focussing on having visual identities, signed languages, perception and community, has not considered these implications for dementia, or even ageing more generally.

Living as a Deaf person in a hearing world can bring many challenges. As outlined in Chapter 3, this is part of every Deaf person’s ontological reality. However, Deaf people have developed coping strategies, for example by learning from each other about how to deal with routine barriers, particularly when communicating with hearing people who do not sign. A shared experience can be, for example, the feeling of becoming ‘wrong-footed’ while trying to communicate with hearing people who do not use BSL. In this context being wrong-footed is an experience in which the Deaf person feels like they are floundering because they have not understood and might feel that they have missed out, which can bring on feelings of anxiety and low self-worth.
There are different coping mechanisms used to deal with these discrepancies in daily communication, for example, they might be deflected with humour; both through the written word (Padden and Humphries, 1988; Holcomb, Holcomb and Holcomb, 1994) and demonstrated visually through performance and roadshows (BSL Zone, 2014; Smith, 2016). In these visual ways and shared experiences, Deaf people acquire effective coping strategies, which enable being part of being in the world.

However, not all humorous strategies can be positively employed. Common responses to misunderstandings by Deaf people might be to ignore the occurrence with a shrug of the shoulders but also deflect, such as saying phrases like ‘well you know’ to cover up lack of knowledge or understanding (instead of asking for clarification or asking what was meant). In addition, there are different views about hearing people depending on which generation you were born in. On the one hand, if you are an older Deaf person, the prevalent attitude tends to be ‘hearing people know best’ (Griggs, 1998). On the other hand, if you are a younger person, common experiences include hearing people deferring to other hearing people who are present in the dialogue, even when you know that because you are a Deaf person, it is in fact you who knows best. For example, as a new Deaf mum, your hearing partner will be consulted (rather than you as the new mum), as they are perceived to know best, hearing professionals will talk to them instead of you (Jackson, 2011). If you are a Deaf parent with a hearing child, medical or educational professionals will talk directly to the hearing child, even asking them to interpret dialogue, which is more prevalent in health-related scenarios (SignHealth, 2014).

4.3 Representation of Deaf people with dementia in research

Lived experiences of people with dementia have become a growing body of research in recent years (Goldsmith, 1996; Kitwood, 1997; Harris and Keady, 2004; Harman and Clare, 2006; Bartlett and O'Connor, 2007; Hulko, 2009; Ward et al., 2012; Swaffer, 2015). It is argued that the person with dementia remains as a person with his or her own values and opinions, not someone who is seen as ‘missing’ (Sabat and Harré, 1992). As discussed in Chapter 3, the person living with dementia should be positioned within society as an equal citizen, and not seen as less than such (Swaffer, 2014; 2015). It is, therefore, appropriate and valid that the person living with dementia has the right to share their lived experience as they see it, and not just through the eyes of their carers or their service providers, regardless of whether they are inhibited by the onset of dementia and its impact on their sense of self (Mental Health Foundation, 2015).

However, there is a paucity of literature that endeavours to value and understand the lived experience that has been shared directly from Deaf people living with dementia. There is literature that has been presented from the carers' perspective (Conrad, 2004; Parker, Young and Rogers, 2010; Rantapää and Pekkala, 2014). It is, therefore, a significant step forward in dementia research studies to show considered thought to these values in recognising the uniqueness of each Deaf person with dementia's interpretation of the world they exist within as they begin to live with dementia. This thesis will offer an exploration of the meaning behind, and within, personal stories from a culturally Deaf perspective, valuing how some meanings are
created and maintained, such as those associated with the experience of dementia for Deaf people and their families.

The knowledge we have about Deaf culture and daily experiences of being Deaf in a hearing world directly influenced the ontological basis of Study 2. It begins from, and is grounded in, the Deaf person with dementia’s worldview and nowhere else, particularly as this viewpoint has never been researched previously. Furthermore, a key design element of Study 2 was to ensure that the primary focus remained on the perceptions, insights and understandings directly shared by the Deaf person with dementia and their families. This approach did not exclude any hearing close family members, as their contributions were equally valuable, but their lived experiences will be different to the Deaf person with dementia despite the insider experience that is communally shared within each family. This tension between what is known through the Deaf person with dementia’s contributions and how those around the person enable and to some extent share those contributions is explicitly addressed in how the data are analysed (see below in section 4.10). However, during Study 2, no interviews were held with mainstream hearing professionals who had no prior knowledge of working with Deaf people. They were not included as it was felt that their viewpoint on providing a service to Deaf people with dementia and their families would take away from the richness of the actual lived experiences that were being explored. The intention was to privilege the Deaf person’s experience throughout.

4.4 Construction of knowledge through a Deaf window

At this point, it is important to clarify that emphasis is being given to Deaf epistemologies in this thesis (Ladd, 2003; Young and Temple, 2014). Firstly, it is necessary to clarify what epistemology means in this context. Epistemology refers to knowledge, rather than to being, and the study of that knowledge. It concerns what counts as knowledge, who generates that knowledge, whether some knowledge is more accepted than others, exploring how new knowledge is constructed, who has the right to be a knower and how to know who the knowers are (Guba and Lincoln, 1994, p. 108).

In the broader academic world, Deaf epistemology, or epistemologies, is a relatively new area of enquiry. Young and Temple (2014) state that d/Deaf epistemologies focus on multiple truths, and that the personal is political (p. 40). For example, we know Deaf people approach the world differently; they use a visual language; are visual learners; visual communicators; and visual knowers (Bauman and Murray 2009; 2014; Young and Temple, 2014). We are aware that new information for Deaf people is processed through a different knowledge base, as most new information is not given via a visual medium i.e. in a signed language. This therefore means the way in which dementia might become known by Deaf people and how that knowledge is expressed is likely to be different from what the hearing ‘knowers’ would know, or do not know, about dementia. Study 1, which gathers information and knowledge about dementia in discussion with Deaf people who do not have dementia, is founded on this recognition of the value and significance of Deaf epistemologies. If we use a hearing magnifying glass (Temple and Young, 2004, p. 169), the power imbalance of hearing parameters are imposed on what the Deaf person has missed; misinterpreted, does not
know or does not understand, rather than what they may uniquely see, appreciate and express. As Paul and Moores (2010) posit, there are potentially multiple perspectives that result from multiple epistemologies and this relies on the individual and collective realities through which we become knowers: our ontologies and epistemologies are inextricably linked (p. 422). It is, therefore, imperative to understand Deaf people’s knowledge and understanding of dementia via Study 1, as their prepositioned Deaf ontologies and epistemologies will have an impact on how this information and knowledge about dementia is acquired and maintained.

Hulko (2004, p. 273) shares the concept of intersectionality where a person can have multiple identities, for example, a person living with dementia also belonging to a marginalised group. This potentially demonstrates how there can be multiple epistemologies for a Deaf person who has dementia, as there are two entities contributing to and being interpreted within one person’s identity. For instance, within this research study, the marginalised group is the Deaf community and Study 2 focuses on the Deaf person, whose perceived identity by others is one of marginalisation and who is living with dementia, which is also a source of marginalisation in the mainstream. Both features intersect to form the experience studied, but also to form others’ attitudes and perceptions toward this specific intersectionality.

As Study 2 is generating new data from the Deaf person with dementia’s worldview (as well as their carers), there is therefore an assumption that the information they share within the study is valid and legitimate; this stems from the core belief that they are the ‘experts’ on their own experiences. It cannot be questioned why they would not know best, as who would ‘know’ better than someone who is living each day with dementia? Epistemological privilege (Griffith, 1998) will be positioned firmly with the Deaf people with dementia’s shared life stories. The assumption on which the design of Study 2 is based is that what they do know is unknown, so this information needs to be shared by them with us in order to understand what is known, assumed or unknown in their reality (Baldwin, 2008; Clare, Rowlands and Quin, 2008; Beard, Knauss and Moyer, 2009).

The research study also assumes that it is important to value this information and how it is presented, as this will inform wider knowledge of how to support a Deaf person living with dementia. At the same time, I am aware that in the sharing of any knowledge, which is reality of personal/collective truth, the act of sharing and communicating will involve some choices of personal representation – not just what the reality is, but how an individual might want that reality to be known to the other. This is also an aspect of Deaf epistemology as knowledge sharing is strongly influenced by whom the recipient of the information is, as in Study 1, Deaf people are being asked about what they know about dementia and what forms of support there is available for Deaf people if they develop dementia. Furthermore, Study 1 is asking how Deaf people wish to receive new information about dementia and what the best ways are in how this would be an effective process. In this respect, having a Deaf researcher present to generate this new knowledge was paramount to this development. Literature has discussed how this cultural positioning, Deaf to Deaf, allows participants to feel at ease while sharing their knowledge with someone they can trust, someone they know will hold what they say to its’ true value, rather than decimating it with inappropriate questioning due to lack of cultural appreciation (Young and Ackerman, 2001; Ladd, 2003; Emery, 2007; Young and Temple, 2014).
4.5 Strengthening validity

When conducting interviews with Deaf people (with or without dementia), having a Deaf researcher as an interviewer, or focus group facilitator, can offer many benefits. One of those benefits is that there may be a strengthening of positioning for the Deaf person being interviewed or participating in a group, in that they may recognise that they are discussing their issues with another Deaf person, not with a hearing person where some imbalances of power might come into play. For example, a Deaf person might have to change their linguistic register while signing, in order to be understood by the hearing interviewer, thus the research encounter becomes a cross-cultural one, one of which a Deaf person might not have a positive experience of in previous situations. A Deaf researcher interacting with a Deaf participant enables full recognition as an individual with his or her own opinion from a shared set of cultural knowledge and shared language. It was anticipated that a Deaf person discussing their opinions in their own language directly with a peer would mean that their thought processes were not being challenged linguistically – there is no interruption for clarification because the language has not been understood - and also that these thoughts would be enabled to come to life via the medium of BSL. As Young and Ackerman (2001) remark, ‘…we were seeking to construct epistemological validity by placing a marginalised language and oppressed cultural perspective at the very centre of knowledge construction’ (p. 186).

Having a Deaf researcher present also allows for direct peer-to-peer communication, which reduces the opportunity to detract from the issues being shared, as well as ensuring that the topics are transparently discussed. The focus remains constant, rather than potential erroneous focus being placed on issues that the participants may not consider as important. For example, a hearing researcher might ask questions relating to the persons' physical deafness rather than their lived experience. In addition, implicit trust would be invested in the researcher as being a member of their community; meaning, it would be safe to share their worldview without being objectified. The participants would be aware that they do not need to explain themselves; they do not have to sign slower because they are talking to a hearing person who does not share the same language to a fluent level. There would also be an assumed confidence in the researcher that no irrelevant questions would be asked; such as being asked about one’s deafness and how one can acquire better hearing, when one actually just wants to talk about one’s broken leg (a common example used in Deaf humour (personal correspondence).

A common criticism of the claims to validity being strengthened in qualitative work by the insider status of the researcher is that this same status can give rise to complicity. In other words, failing to challenge or expand on a person’s contribution because it is just assumed to be shared and therefore correct. In this study, as previously stated, the design assumes an unconditional positive regard (Rogers, 1961) for whatever it is that the Deaf person with dementia chooses to contribute; this is different from the assumed negative impact of the cultural insider status of the researcher. The second common criticism is that just because a researcher may be an insider by one standard (language and culture) this does not necessarily mean she is a good representative for that community. All communities are highly diverse and anyone may be an insider by one
set of criteria and an outside by another (Threadgold, 2000; Leigh, 2009). Knowing who the researcher is, therefore, becomes important and how they are present in the data is also important.

Harding (1987, p. 9) states the researcher must be visible, with historically concrete ideas, which allows the newly generated data to be scrutinised as clearly as possible. With this need for clarity and visibility in mind, the Deaf researcher’s identity and their use of BSL as their preferred language was a vital component to the study design and throughout this thesis, the ‘I’ of the researcher and her identity is foregrounded. It added a reassurance for the participants that the researcher was one of their own and that person could empathise with their social, historical and cultural positioning. However, perceived insider status of the researcher does not necessarily guarantee a greater or better degree of ‘truth’ in how data are interpreted, but it does provide a transparent framework for understanding what it is that has influenced the generation of the data and, later, how it is analysed and interpreted (see Chapters 5 and 7). There is not an absolute claim to representativeness of the researcher on behalf of the Deaf community; as not all Deaf people are the same and, indeed, a ‘different kind of Deaf person’ might have influenced the data and in its interpretation differently (Young and Ackerman, 2001). There will always be different interpretations of the data from whoever is generating or analysing it. Instead, the claim made with regard to insider status and validity is that my identity as a researcher and as a Deaf person is one which positively enables the sharing of Deaf perceptions (as in the focus group discussions in Study 1) and those of the lived experience of being Deaf with dementia (in Study 2), with as few barriers as possible. It is one that builds trust and it is one that guarantees a level of authenticity in how the data might subsequently be interpreted. A reflexive commentary is available in Chapter 3, from page 21 onwards.

4.6 Methods

4.6.1 Frame of reference for choice of methods

In the dementia field, person-centred approaches to eliciting the views and experiences of those living with dementia have snowballed in the last two decades (see Chapter 3). It was previously erroneously assumed that people living with dementia would not be capable of reflecting on, or expressing their views about their personal experiences. More often than not, it would be their families and/or professionals in their orbit that would be approached to speak on their behalf. Proactive practitioners and researchers such as Goldsmith (1996), Kitwood (1997), Keady, Williams and Hughes-Roberts (2007), Scholl and Sabat (2008) all have strenuously argued against this approach and in support of the sustained communicative capabilities of those with dementia to determine how they should be known by others and to contribute first hand to an understanding of what it is to live with dementia. Their work emphasises a holistic approach to communication and interaction encompassing both the verbal and the non-verbal. It is also important to consider the impact of communication for people with advanced dementia and how it is framed through the engaged body and the sensing body, which emphasises the multi-sensory experience of being a person (Kontos, 2005, 2012; Hydén and Örluv, 2009; Ward and Campbell, 2013).
Within the field of gerontology and Deaf people, there is a paucity of evidence of direct interviews being conducted with older Deaf people specifically for research purposes. Those of significance include: Tidball (1990) who interviewed older Deaf people about their coping strategies in the aging process; Werngren-Elgström, Dehlin and Iwarsson (2003) who interviewed older Deaf adults about their perceived wellbeing; and, more recently, Hunt, Oram and Young (2011) and Willoughby (2014) who asked older Deaf people about their preferred residential care options.

In summary, there have, however, been no previous studies that have sought to elicit directly the personal experiences and perspectives of Deaf people with dementia, thus older Deaf people living with dementia have been doubly marginalised in not being given the opportunity to share their stories in the mainstream, both on account of being Deaf and on account of living with dementia.

The two studies in this work, therefore, sought to maximise opportunities for Deaf people’s involvement in generating knowledge about dementia through their highly specific cultural lens. It did so in two ways. Firstly, by engaging diverse members of the Deaf community without dementia, but for whom the topic was still nonetheless of relevance (Study 1) and secondly, by engaging Deaf people who were living with dementia and their care partners (Study 2). To this end, two principal methods of data generation were chosen, which were semi-structured interviews and focus groups.

4.6.2 Study 1 – Focus groups with the Deaf community

In Study 1, members of the Deaf community who did not have dementia and who were not carers of people with dementia were invited to participate in focus groups to discuss their knowledge, thoughts and awareness about dementia and associated services. Focus groups are a method in which information is discussed within a small group of people who are either anonymous or known to each other. They are usually brought together because they have a shared commonality, for example, being mothers, bereavement, social workers and so on. As Silverman (2006, p. 181) elaborates, focus groups give us a frame in which to observe participants’ knowledge and beliefs about a particular subject. Halcomb et al. (2007, p. 1009) argue that focus groups are a relevant method in which to find out what is known and what is valuable about it for the participants involved.

Within Study 1, it was necessary to ascertain the levels of knowledge and understanding about dementia in the generic Deaf community. As previously discussed (Chapter 3 section 3.26) these were likely to be very low but it had not previously been investigated or recorded directly. It was felt that interviews would be too time-consuming and that the way in which these data were generated should be in a supportive, information-sharing manner. In addition, Gibbs (1997) describes how the social setting of the focus group enables the participants to share their views, but also to clarify the opinions shared by other people within the same group. This allows for clarification and for articulating in more depth issues that may otherwise have just been one-off statements. It was, therefore, decided that focus groups were the best method in which to understand what was known, and what was not known, about dementia from the perspective of Deaf
community members. It was also important that the participants felt at ease with one another while sharing new information with a researcher.

Balch and Mertens (1999, p. 271) describe how their focus groups became a forum in which Deaf participants felt that they were able to share information about issues that were of a sensitive nature. They also found that other Deaf participants were keen to support one another within this environment, particularly when rephrasing questions and supporting mutual understanding. In the focus groups that were conducted for Study 1, this behaviour occurred on more than one occasion; participants would clarify the questions asked, tell one another what another person had said if they had missed it and also re-establish ground rules when they felt that a participant was flouting boundaries already agreed upon.

One limitation of using focus groups is that the group as a whole becomes party to sensitive and confidential information that is being shared. The information shared is no longer anonymous as the group has heard/seen it (Gibbs, 1997). This would be particularly all the more contentious for the Deaf community members as the community is a small one and members of the focus group would be more likely to be known to one another. However, as the topic was about generic knowledge of dementia and identification of services known to the community, it was felt that the information shared was not anticipated to be of a sensitive or damaging nature.

4.6.3 Study 2: Deaf people living with dementia via interviews

In Study 2, Deaf people with dementia were interviewed directly. Silverman (2006, p. 132) elaborates that interviews offer the researcher a window into enabling participants to offer their own narrative of their individual social world. Interviews afford the opportunity to access the participant’s worldview, their individual truths which give us a deep mutual understanding of their social worlds (Charmaz, 1995, p. 54, cited in Miller and Glassner, 2011). They also offer the potential to explore both verbal and non-verbal responses, particularly while being conducted face-to-face. Silverman (2006, p. 144) adds that such interviews offer illumination into individual perspectives that are based on cultural resources.

There are different examples of interview styles that can be used, such as structured, semi-structured or open-ended. Semi-structured interviews, and how they are structured with the guidance of topical questions, offer a more flexible and relaxed approach in asking people with dementia (and their families) about their views and opinions (see Pearce, Clare and Pistrang, 2002; Katsuno, 2005; Preston, Marshall and Bucks, 2007; Mazaheri et al., 2013; Kindell et al., 2014) as they are not being bombarded with questions that need to be answered, instead, being given space and time to consider their stories and what they wish to share with the researcher at that point. Focus groups have been held with people with dementia previously (see, for example, Innes, Kelly and Dincarslan, 2011; Law, Russ and Connelly, 2014), but the focus has not been directly on the person’s narrative of their day-to-day lives, but rather on their experience of the services around them. There is a distinct possibility that if Deaf people with dementia and their families were invited to a focus group discussion, the potential intensity of relating their personal journeys would be lost, as well as
the opportunity to have the focus directly upon their unique and valuable experiences being diluted. It was, therefore, determined that qualitative semi-structured interviews were the best platform for generating new data from this specific group.

As Deaf people were at a stage in their lives where they had experienced the onset of dementia, it was felt a face-to-face dialogue with family/carer support structures already in place was the most appropriate method to elicit their stories. Using semi-structured interviews would offer a prime opportunity for a safe space, ideally at the person’s home, within which the Deaf person with dementia and their family could share their worldviews and experiences. Additionally, as Morgan et al. (2013) summarise in their paper, the structure of the interview is dyadic, where two participants have been brought together at the same time to share the same story but with both their input. However, as a researcher and by being present and contributing to the dialogue, I added to the dyadic structure and made it a triadic one (as discussed by Adams and Gardiner, 2005), with the awareness that my role was to ensure that the participants were able to share their stories about living with dementia, both from the perspective of the Deaf person and from their carers’ perspective. Semi-structured interviews were considered to be the most effective way in which to enter into dialogue with the participants, as it was important that their stories were led by their experiences, rather than eliciting yes-no responses.

4.7 Method Study 1

4.7.1 Approach to data collection

In order to investigate the research aims of the study, it was determined that focus groups would be an effective way to explore the understanding of dementia within the Deaf community. As previously discussed, focus groups are a method where researchers generate qualitative data by engaging participants into a discussion guided by a particular theme, in this case, dementia and the Deaf community. The researcher acts as a moderator by posing questions, managing the flow of the dialogue and encouraging all participants to join in (Wilkinson, 2004, p. 187). Focus groups are a naturalistic way of being involved with participants; there is no formal interview taking place and dialogue can be guided and shaped in many ways, such as enabling the group members to engage in story-telling and humour. The researcher, in the role of being a facilitator, must prepare a schedule to ensure that the session flows, to ensure that participants do not go off on a tangent and to ensure that data collection is achieved.

4.7.2 Sampling

As it was a focus group setting, it was important that the potential participants felt that they could choose for themselves whether they wished to be included or not. Convenience sampling did not occur even though the proximity of the community could have lent itself well to this method, as the groups were based in one geographical area. It was important that the findings were representative of the community being asked the research question (Robson, 2002, p. 265). Purposive sampling is a flexible method in which the researcher
ensured that the potential participants were informed about the study first (through presentations and face-to-face information sharing discussions) and their interest in this topic (dementia) would enable them to come forward to take part. In addition, the potential participants were informed that the focus groups were being facilitated by a Deaf researcher using BSL, which would potentially alleviate any concerns about communication, and having to explain themselves (as discussed earlier in section 4.5). The participants were recruited within one region in England, due to the organisation of the focus groups being held in one Deaf centre that kindly allowed for a room to be used for the study. It was anticipated that the participants would fit into three categories and participants were allocated to each group accordingly:

a) Older people specifically aged over 60;

b) Well-educated Deaf people, with no age limit (but over 18 and under 60);

c) Deaf club members, with no age limit (but over 18 and under 60).

The term 'well-educated' was introduced at this stage to ensure that there was a diverse sample of Deaf community members that attended the three groups. It was intended to define people who were current professionals who were in employment or retired professional Deaf people. These three categories were defined by the need to explore different demographic groups’ understanding of dementia within the same community. Each participant that decided to attend the focus group chose to attend of her or his own accord, which meant the sample was self-selecting.

4.7.3 Ethical approval

Formal ethical approval for this data collection was sought from the University of Manchester Research Ethics Committee. As there were no recruitment routes via the NHS, it was appropriate to put an application through the University, rather than through the National Research Ethics System (NRES). Full approval was granted before recruitment and full data collection took place. The approval reference number was Project Ref 10397 and is in place for five years (2011-2016). See Appendix A for approval letter.

4.7.4 Recruitment

To recruit for these groups, a recruitment advert (see Appendix B) with videos in BSL and English copies of the information sheet (see Appendix C) and the consent form (see Appendix D) were made available on the study’s website (www.manchester.ac.uk/deafwithdementia) at the start of the recruitment process. In addition, the researcher arranged personal visits to four Deaf centres in the South-East of England, where Deaf people regularly meet each week so they can participate in social activities, such as bingo and to have a cooked lunch. These Deaf centres were managed by the Royal Association for Deaf people (RAD); they were partners within the whole Deaf with Dementia project therefore these visits were arranged with the support of staff from RAD. An informal 10-minute presentation in BSL (with no interpreter present, as it was assumed that most audience members were Deaf BSL users) was given in one club before lunchtime. At the other three Deaf centres, the researcher mingled with smaller groups and explained why they were
visiting their club. Recruitment advertisements, information sheets and DVDs of BSL translations of the leaflets, information sheets and consent forms were left with different individuals. In addition, one person from a Deaf centre emailed the English versions of the documents to their friends who were not present that week at the bingo. One community officer in another Deaf centre carried out face-to-face recruitment using the study’s recruitment advertisement and website address to ask people to express their interest in joining the focus groups.

This face-to-face recruitment strategy was also employed to ensure the building of trust in the researcher, as they would not have been a familiar face to many of the participants, due to living in a different geographical location. Deaf people like to ‘know’ who people are before they get involved in events or discussions; simply so that they can validate the person as being Deaf and a fluent BSL user and not someone who has come to practise their novice BSL skills ‘on them’ (Stone and West, 2012, p. 647).

Once these visits had taken place, participants then made direct contact with the researcher to confirm their interest in attending the workshops and once their demographic information was received, they were allocated to one of the three groups which are further described in section 4.7.5. In one case, the participant was not able to attend on the selected date and therefore attended a different group as it suited their availability. Their demographic characteristics did not have an adverse impact on the alternative group dynamic. In one group, one participant turned up on the day without having informed the researcher or the Deaf club community officer. As it was not clear whether they had accessed the information about the focus group, the researcher spent some time with the participant beforehand to ensure they fully understood the aims of the discussion.

4.7.5 The sample

The consent sheet for each participant did not ask for demographic data; however, this information was given in an informal format to the researcher so that the participants could be allocated to the appropriate focus group.

Fourteen men and 12 women participated, all of whom were BSL users who identified as culturally Deaf. Twenty-five people described themselves as White British, and one described themselves as British Muslim.

There were three separate groups:

1) Older Deaf people over the age 60 who did not have a diagnosis of dementia (n=11);
2) Deaf people working in professional roles, not necessarily in connection with service delivery or dementia, aged 18 to 60 and who had good educational and vocational qualifications as judged by their current employment status (n=6); and
3) Any members of Deaf clubs aged between 18 and 60 (n=9).
4.7.6 Consent

All participants identified as culturally Deaf, were over 18 years of age, fluent BSL users and were able to give informed consent (after clarification with the researcher) for their full participation.

On the day, participants were given an information sheet and consent form before they participated in the focus group, regardless of whether they had already accessed this information prior to attending the session. At the beginning of each focus group, all the participants were reminded that the data was being audio-recorded and it was checked that their consent for their information, to be recorded in this way within the study, remained in place.

4.7.7 Data collection

A room at a Deaf centre based in the South-East of England with convenient links to local transport was booked (with the support of the local Deaf organisation) and hot refreshments and cold food were made available. The sessions were organised at appropriate times to suit the participants to ensure the focus groups were as accessible as possible.

The seating in each room was laid out in a horseshoe shape with the researcher sitting by a flip-chart board with a written welcome, a blank sheet for ground rules and the main questions for the session written out in capitals as a reference point. This seating arrangement was done in a culturally Deaf way, as each participant needed to be facing each other so that communication could be facilitated effectively and smoothly. A computer room was made available at the venue so that the BSL DVDs of the information sheet and consent forms could be watched before the sessions commenced.

Each participant was greeted on arrival and offered a hot drink, before being asked to watch the videos. Once the videos had been watched, the participant then met the researcher to go through the consent form face-to-face. Any points in the video that were not understood were clarified before the participant signed their name on the consent form. This was done because there are typical examples of Deaf people using the ‘nodding head’ syndrome where they will pretend they have understood something and will not ask for clarification if they have not understood. In addition, there was a pre-instilled level of trust in the researcher because they were Deaf themselves and participants therefore made an unstated assumption that whatever was happening that day, their involvement would be ‘alright’ because in theory, Deaf people would not harm other Deaf people.

Due to this cultural awareness, the researcher confirmed with each participant their satisfaction in understanding the information on the DVD and ensured that the main issues concerning consent, confidentiality, anonymity and data use were re-explained again in BSL prior to data collection to ensure that participants had the opportunity to clarify any concerns before signing the written English version of the consent form.
Indeed, some participants stated they had watched the videos in BSL via the website and again via the DVD; however, when it came to signing the written English consent form, there was still some confusion about the statements they had to agree to. Only when it was explained in ‘real-time’ BSL and examples were given, did the participants fully understand the aims of the focus group and were happy to be involved.

There were some participants who did not understand the function of the focus group; this is quite common in the Deaf community when members have not been encouraged to offer their views within this type of setting (Hawcroft, Peckford and Thomson, 1994, p. 41). These particular participants came to the group thinking they were coming to learn about dementia and how they could help themselves to not have dementia. Time was spent directly with these individuals, before the focus group commenced, to ensure that they understood the aims and expected outputs of the focus group with the clear explanation was given that this was not a specific training forum. This will be further discussed in Chapter 5, section 5.3.

4.7.8 Working with BSL/English Interpreters

While planning how to capture data from the focus groups, several avenues were considered. The most obvious method would have been to use video cameras, as BSL is a visual language and this would mean that the research data would be captured at source. However, this would have meant the use of at least four or five video cameras being used simultaneously in one setting as it was anticipated that there would be a maximum of 15 participants in each session. The video camera can only film up to three people in one frame; particularly in ensuring what is being signed is captured in its entirety. It was felt that having this many video cameras positioned in the room would be invasive, as opposed to conducive to a positive discussion process, and was not a viable option due to the time constraints of the study.

The researcher was a Deaf BSL user, which meant that recording data via note form while watching the discussions was not an option. As soon as eye contact is broken, this would deter the participants from feeling ‘heard’ and feeling involved in the discussion. This would also have had an impact on the flow of the session and the participants’ desire to contribute. It was therefore decided that using BSL interpreters to voice over the discussion and to audio-record this data would be the most viable option. This decision was made with the conscious knowledge that contemporaneous notes would be written by the researcher after each discussion to ensure key comments or descriptions were not lost in translation.

The researcher was conscious that the BSL interpreters would not necessarily voice over in detail the specific features of a Deaf person’s imaginative or creative sign that they might use to try and describe the concept of dementia. Within those instances, during the event, the researcher would pause the proceedings for a short time to describe in detail the actual signs that were used, so this uniqueness was not lost due to the lack of video recordings.
Two BSL/English interpreters were given a copy of the topic guide (see Appendix E) prior to the focus group and on the day itself and positioned to the left of the researcher, facing the horseshoe shape. They were not seated within the horseshoe seating arrangement as they then could not be falsely perceived as being part of the focus group with their own views and opinions. They could see each BSL user’s hands and faces. They were positioned near an electricity point, as the Dictaphone being used to record their voice-over needed to be plugged in due to an inconsistent battery life. The researcher held a preparatory discussion with each pair of interpreters, as there were six different interpreters booked, about the identification of different speakers. It was agreed that the interpreters would not identify the group members by their names for confidentiality reasons, but would use ‘he...’ or ‘she...’ as a prompt that there was a new speaker. There was a suggestion that the use of numbers would be ideal, but it was felt for the over 60’s group that it would be inappropriate as this action could potentially evoke negative memories from their boarding-school days where they were allocated and known by numbers, not their names (Hunt, Oram and Young, 2011, p. 13).

4.7.9 The focus group discussion

The participants were asked to sit wherever they preferred, depending on communication preferences. Some had specific communication needs (i.e. there were some Deaf people with Usher Syndrome\(^\text{11}\) so they positioned themselves where they could access all the information being signed. The researcher explained the aims of the group, explaining why the interpreters were present and then encouraged the participants to comment as they wished. They were asked to raise their hands to indicate their intention to say something so that people could see who was signing and for ease of voice-over for the BSL/English interpreters. Each group lasted for a maximum of two hours, with one break after 45 minutes of dialogue for something to eat and drink. The participants returned to their seats after a break of 30 minutes and were happy to continue the discussion.

The focus groups offered the opportunity for a group of Deaf community members to discuss their understanding and knowledge of dementia collectively. It was therefore decided that having the group together was also a viable process in which to assess the accessibility of mainstream websites sharing information about dementia. The Alzheimer’s Society website (www.alzheimers.org.uk) was chosen for this purpose as the original research project was funded by this charity.

At the end of each session, the participants were therefore encouraged to explore the Alzheimer’s Society website in order to give verbal feedback on its accessibility, how easy it was to navigate and whether the information was easy to understand. An interesting observation was that immediately, the participants in the over 60’s group offered to start working in pairs, which had not initially been considered by the researcher. This did not happen in the other groups, but they initiated this activity while discussing the preparation for

\(^{11}\) Usher syndrome is a condition where a person can have both deafness and retinitis pigmentosa, which causes a range of difficulties with vision and blindness. There are approximately 9,750 people who live with Usher Syndrome in the UK (https://www.sense.org.uk/content/usher-syndrome).
researching the website. Perhaps the pairing-up for the over 60’s group was an innate response to approaching a novel situation (reviewing the website); or maybe this is something that already naturally happened within this group because of their familiarity with one another; or how they may have previously approached other group work in other environments.

When the website had been explored and discussed together, the participants were thanked for their time and willingness to participate. It was explained that their views would all be put together into a report that would be submitted to the Alzheimer’s Society and that they would receive a copy of this report in 12 months’ time. It was also explained that the researcher would be happy to travel to different Deaf clubs to explain what was found out in the research process.

4.7.10 Analysis

Thematic analysis was used to analyse the data collected from the groups. Thematic analysis is a flexible method from which common themes in the data are elicited, as Braun and Clarke (2006) state that ‘thematic analysis can be an essentialist or realist method, which reports experiences, meanings and the reality of participants, or it can be a constructionist method, which examines the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society’ (p. 81). This approach offers a foundation in which the study will be able to demonstrate Deaf BSL users’ realities and how this has an impact on their understanding of dementia. This is different from Interpretative Phenomenological Analysis (IPA), where Smith, Flowers and Larkin (2009) that the individual’s world-view, their lived experience and how they make sense of their world from a homogenous sample of participants (that is, they all share similar life experiences (in this case, Deaf people with dementia and their carers) is explored by the researcher. Within IPA, themes are elicited by reading the transcripts several times and attempting to present real-life experiences rather than interpretations/assumptions made by the researcher from the focus group data as a whole.

4.7.11 Transcription and translation

In this context, there are multiple modalities of how the data were captured, recorded and analysed: the data were originally signed in BSL by the participants, which were then voice-overed by BSL/English interpreters. The BSL/English interpreters each would have their own individual interpretation based on their own frame of reference, which would influence their lexical choices in translating what the Deaf participants signed. The data then were then transcribed into written English by an independent transcriber who typed the notes verbatim and finally read by the Deaf researcher who was the original facilitator of the focus groups. As Temple and Young (2004, p. 164) clarify, it is important to demonstrate the transparency of the translation

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12 This report was a summary report with initial findings for the Alzheimer’s Society upon completion of the Deaf with Dementia Project. [https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1129](https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1129) A full analysis of these findings has been done within this thesis.
process taken for the focus group findings; as at each stage, the contributions made (the Deaf facilitator, the interpreters and the transcriber) will all have contributed to the sharing of new knowledge from the Deaf BSL users in the focus groups. Interpreters will have voice-over their understanding of what the Deaf focus group members have signed; but this understanding stems from the interpreters’ world-view, not the Deaf person’s (Young and Temple, 2014, p. 141).

The Deaf researcher, however, wrote contemporaneous field notes after each focus group and began analysis on the transcripts typed from the audio-recordings as soon as possible to ensure her memory was fresh in recalling who said which statement and to check any information that may have been erroneously voice-overed by the BSL/English interpreters present. A hearing colleague, who has worked with the researcher for many years, typed the transcripts verbatim from the audio recordings. The transcriber listened to how the BSL/English interpreters reflected the researcher in their voice-over and having an established working relationship with them, this was another way of checking that the BSL/English interpreters’ lexical choices for the researcher were appropriate.

While considering conventions for these transcripts, there was some consciousness of potential barriers to forming a full transcript. There are no names mentioned in each group except for that of the researcher (to maintain confidentiality in a small community) so as far as the transcriber is concerned, all they could hear was one of two voices voicing over what a Deaf person was signing. It was difficult to deduce from the audiotape whether it was a new person speaking (even though the BSL/English interpreters were previously instructed to use pronouns to notify the transcriber of a change in speaker), so the scripts were read over and over again by the researcher in order to recall who was speaking. Drawings were made in field notes of who was sitting where in order to aid this recall of who said which comment.

As the interpreters were voice-overing from BSL to English, there is no visual information that would be found on video recordings, where body language and non-verbal communication indicators would be picked up. There were no verbal nuances, no pauses, no umms and ahhs, apart from what the interpreters would use as processing fillers while translating the information from BSL to English, that a researcher would normally listen to on an audiotape.

There were concerns about the consistency in the quality of the voiceovering process by interpreters within the discussion, especially as there were six different BSL/English interpreters working within this process all with different value bases and therefore different lexical choices. In addition, there were a few concerns about the lexical choices that were made to describe different views about dementia – did they actually reflect the BSL presentation that was used to express that particular view? We all have our own interpretations of what someone has signed and what they meant by it; in addition, we need to remember Deaf people will uniquely use a combination of signs where there is not one sole lexical choice that would match it perfectly. While the focus groups were running, if the researcher felt that the BSL/English interpreters were unlikely to be voicing over the hand shapes or the specific signs chosen by the participants
to describe a concept, the researcher interjected in their dialogue to ensure that a clear description was recorded on the audio-tape of not just what was signed, but how it was signed too.

There were also occasions where non-verbal communication was used, for example, in the researcher’s notes, there were times when participants offered their assent by using ‘lots of nods of assent or acquiescence’, which were not voiceovered by the interpreters. One convention was established within the scripts, which is that the transcriber attempted to separate dialogue by typing ‘interviewer’ or, ‘interviewee’. However, because of the difficulties in voiceovering outlined above, the researcher checked these data to check that this was truly the case. As Stone and West (2012, p. 649) acknowledge, it is important to reflect on how the Deaf researcher needs to be transparent in demonstrating the fluidity of how the participants are fairly and clearly represented.

4.7.12 Coding the data

Initially, ten overarching themes were devised in line with the research questions and discussed with the research supervisors. These were reviewed and reduced to three main themes with sub-themes while coding the data. NVivo 9 software (QSR, 2012) was used to code the data; this is effective qualitative data management software that enables the researcher to tag the qualitative data as it is being read. Any personal notes and comments were written onto the printed copies of the transcribed data during the coding process.

The initial ten themes were:

1. Information
2. Dementia knowledge
3. Support
4. Expectations
5. ‘Deaf way’
6. Accessibility
7. Checking knowledge
8. Deaf versus hearing issues
9. Uncertainty
10. Clarification

After re-reading the written data at least five times, discussing with the supervisory team, and in writing the analysis, it was determined that the main themes for the analysis would be (i) dementia knowledge, (ii) information about dementia and (iii) support. It was determined that the other categories, upon re-reading, were sub-themes of the three main themes.

4.8 Method Study 2
4.8.1 Sampling

The formal inclusion criteria for the interviews were that the Deaf person living with dementia would be aged 55 years and over; Deaf BSL users and have received a diagnosis of dementia by their GP/Consultant/Memory Clinic. All participants were self-selecting; each set made direct contact either via their primary carer or via a close family member. Each Deaf person living with dementia (and their carers) were assessed for their capacity to consent to be part of this study following the Mental Capacity Act (2005) (NHS Choices, 2016).

4.8.2 Recruitment

There were two recruitment routes designed to maximise potential involvement in Study 2. The first recruitment route was to distribute information packs via a local specialist mental health unit in the North-West of the UK. A nominated clinician was asked to consider their caseload and to distribute our information packs accordingly (see Appendix F). I was verbally advised by the unit that there was a very low intake of either inpatients or outpatients with a formal diagnosis of dementia.

Study 2 was also registered via the clinical route on the Dementias and Neurodegenerative Diseases Research Network (DeNDRon) portfolio; face-to-face meetings were held with their clinical officer based in the North-West of the UK who subsequently distributed the information to their mainstream contacts across the UK. Eleven written responses were sent directly to the officer, where it was clearly indicated there were difficulties in identifying Deaf BSL users on clinical services’ caseloads, particularly as this communication preference is not formally recorded on service users’ case notes.

For the second recruitment route, which utilised the Deaf community networks, recruitment advertisement posters (see Appendix G) were distributed to over 50 Deaf clubs in the UK via post and via email. Community presentations were given in 20 Deaf clubs or Deaf professional support groups to aid recruitment. This was the more successful route with all of our referrals being received via this method.

4.8.3 The sample

Six sets of families were recruited; one set withdrew before the pre-meeting took place and one set withdrew from the study before the second interview took place. One other meeting was completed with a carer and their parent, but it was felt that this parent living with dementia did not meet the criteria for capacity, as outlined in the Mental Capacity Act (2005) (NHS Choices, 2016).

13 More information about this network can be found here: https://www.crn.nihr.ac.uk/dementia/
Four Deaf people living with dementia and five carers were interviewed; of which three were Deaf BSL users and one was a hard of hearing BSL user. No BSL interpreters were present at the interviews as the research is a fluent Deaf BSL user. All the participants’ capacity to consent and participate within the interview was checked by the researcher within pre-discussions that took place before the interview formally started.

The four families were:

1. A Deaf woman (79) living with her deaf daughter;
2. A Deaf woman (86) with her hearing daughter who lived nearby;
3. A Deaf man (84) living with his Deaf wife; and
4. A Deaf man (87) living with his Deaf wife and his Deaf daughter (who lived away from the family home but visited regularly).

All participants were White British. Three carers identified as Deaf BSL users and two carers identified as native sign language users, one carer was hearing and one carer was hard of hearing.

4.8.4 The interviews

Two consecutive interviews with each family took place within 6-12 weeks, dependent on the Deaf person with dementia and their carers’ availability. The interviews were at the Deaf person with dementia’s normal place of residence, and usually held within the Deaf person with dementia’s favoured location in their home e.g. lounge, conservatory etc.

Each carer explained how they had checked with their spouse or parent beforehand that they were happy for the researcher to visit. The study was explained to all parties present with the opportunity to ask any questions. The information sheet (see Appendix H and I) was shared in real-time BSL (as all participants explained that they did not particularly enjoy watching the DVD beforehand on their DVD player or on their laptops – they all preferred receiving the information in real-time with the opportunity to clarify). The consent form (see Appendix J and K) was also shared in real-time BSL, with the participants being informed that this would be done again when the video camera was switched on.

4.8.5 Ethical Approval

The ethical application for Study 2 was submitted online via the Integrated Research Application System. Subsequently, the National Research Ethics Service Committee North West - Greater Manchester South gave ethical approval for the interviews. The acceptance code was 11/NW/0669 (see Appendix L for approval letter).

4.8.6 Consent
As interviews were being conducted with Deaf people living with dementia and their carers, it was paramount that clear consent was given for participating in interviews. Dewing (2007, p. 15) describes a method called process consent, which ensures that the researcher maintains the participants’ personhood and agency in their decision-making, recognises that their consent is context-specific and re-checks that their consent is still valid throughout the research process.

In addition, there are issues with consent-taking for Deaf people (which is also apparent in Study 1), where there may be episodes of Deaf people just nodding their heads to offer consent but without fully understanding what is about to occur. This can occur for many reasons regardless of whether the information has been provided in BSL both prior to and the giving of consent. As I am Deaf, the fact that I belong to the same community confirms my validity and trustworthiness and therefore the participants feel safe.

These hurdles were carefully considered before the context-specific process consent was developed for the interviews. It was paramount that all participants (both the Deaf person with dementia and their carers) understood and expressed their clear intent to participate in the study. It was clear that a one-off giving of consent would not at all be sufficient for these interviews. It was, therefore, agreed that consent would be established by:

1. Sending information sheets and consent forms in BSL and English directly to both the Deaf person living dementia and their carer before they met with the researcher;
2. Organising pre-discussions before the interviews so that there was sufficient time for discussion about the information sheets and consent forms before the actual data were collated;
3. Videoing the consent given by the participants in both BSL and English;
4. Checking in throughout the interview with the participants that they were happy to continue throughout the interview;
5. Checking at the end of the first interview with the participants that they were happy for the researcher to return for the second interview;
6. At the second interview, before the discussion was re-commenced, reminding the participant of their right to stop at any time, asking if they had any questions and also checking they were happy to continue our discussion.

Each process of gaining consent before the actual formal consent (the signed English signature on the ethics committee approved form) was given took up to 20-30 minutes on average, with one participant taking 45 minutes to be completely happy with understanding what was happening. Separate consent was agreed with each carer after the Deaf person living with dementia’s consent had been confirmed. Each carer was happy with the statements on their consent form and did not ask for any clarification.

Once the information had all been clarified and the consent received in both BSL and by means of receiving the participants’ written signatures, the interviews then commenced. Each interview took up to one and a
half hours; with a 10-15 minute break for those who wished for a drink or comfort break. Each participant was thanked for their time.

One issue around consent that became apparent in two or three interviews was the prompt, ‘Anything you want to ask before we move on’, or ‘Is there anything else you’d like to ask me?’ This prompt is usually seen in business meetings, academic dialogue and within more formal settings. From the Deaf person’s perspective, in using BSL, this is a very ‘hearing way’ in how to ask a question when wishing to check with someone if they have anything to add. However, within the consent process, it was agreed that it would be an informal way of checking-in with the participant, a concrete method in ensuring informed consent was still present, and gaining a further level of affirmation during process consent (Dewing, 2007).

Ethically, it is important to clarify that the person with dementia has understood what the researcher is asking and is able to interact in return. However, asking Deaf participants, particularly those living with dementia, if they were happy to continue with the interview (at the second time of meeting) and if they had any further questions (of clarification or other) created confusion and encouraged them to start telling their stories instead of responding directly to the question. They were not interrupted at the point of telling their stories, but the question was repeated when they had finished. In one interview, one Deaf carer interrupted their Deaf parent and clarifies, ‘no, she wants check you happy ok carry on?’ (written exactly as it was signed). It is possible there was a perception that this question proffered a platform where the Deaf participant felt that they could finally share their personal stories with the researcher, having had no opportunity to discuss these issues in their native language and home environment. A topic guide was used to facilitate questioning throughout our dialogue (see Appendix M).

4.8.7 Data Capture

All the interviews were video-recorded via videotape. These data were then uploaded to a remote secure server, within 24 hours of the interview taking place. Each participant (both the Deaf person living with dementia and their carers) gave his or her clear signed (BSL) and signed (written) consent for the video camera to be switched on during the interview and for the interview to be recorded.

4.8.8 Transcription and translation issues

It was agreed within the supervisory team that the source data would be analysed without translating and writing a full transcript of the videotapes. This was because BSL was the only language in which the Deaf person with dementia and their families’ unique concepts and perspectives were captured, thus there were no interpretations of what the participants were signing. However, in order to make notes in relation to the video recordings, it was sometimes necessary to transcribe what was said, adding a written description of what was visually represented in the video, for example, body language, facial expressions, how something was signed, the space in which it was signed and so on. If a literal translation had taken place without
regarding the importance of those issues, there would have been a great loss in fully capturing and valuing what was being shared with the researcher.

One example of the importance of using video to analyse the source language was watching how one gentleman signed a series of signs very succinctly within a space of two to three seconds, but yet conveyed in depth his feelings and emotions about the onset of dementia (see Chapter 7, Section 7.3.3). If this had been just translated from BSL to English, each of the signs would have been difficult to pick up and to interpret in sequence, therefore by putting this message into words; the depth and impact of the message would have been lost.

However, as the author of this thesis, I am conscious that there are limitations to producing a doctoral thesis in a visual language. My preferred language is BSL and I work within a bi-lingual medium, which is both BSL and English. There are no current opportunities within academia to submit a PhD that has been signed in a visual language. It has therefore been decided that the data will be represented and discussed in written English with some independent confidential recorded replications of what was signed for the reader to be able to watch examples of what was captured. I will sign this replication to video camera, as I am the only person to have access to this video data, along with my supervisors and as the researcher; I had a key role in capturing this information and therefore have the privilege of sharing it with the reader.

4.9 Analysis

4.9.1 Narrative methodological approaches

Narratives are an important process in how people position themselves in their sociocultural worlds (Baldwin, 2008). By using dialogue, body language and self-expression, the person then represents their own agential choices and opinions, individually and collectively. Baldwin (2008) argues that by sharing their lived experiences, people with dementia are demonstrating a collaborative effort in representing their agency throughout the narrative process. Moreover, sharing stories about lived experiences is a form of positive social action for a person with dementia, as they are then positioning themselves as a narrative and as a political citizen (Bartlett and O’Connor, 2010) rather than the perception that their dialogue is unworthy of exploration as previously discussed in Chapter 3. The linking of narrative with citizenship is also important because it establishes the process of storytelling one’s life as a legitimate basis on which to have one’s rights recognised. If we ourselves do not tell our stories, or support others in talking about their lives, then we are suppressing the means through which our identities can be recognised or in how our culture finds expression. Narrating within such cultural contexts therefore becomes a powerful expression of the right to be part of society, hence validating one’s citizenship. It is also understood that people’s narratives may not always be concrete, hard, cold facts, but instead the consistent re-telling of memories or interpretations of events that have been internally processed by the storyteller(s) and therefore undergone transformation as a result of the telling (Riessman, 2008).
Narrative as a process is important in any culture but in some, the enacting and expression of identity and culture through narrative is more strongly an artefact of that culture than others. For example, recording narratives is an important part of retaining historical roots in society and therefore citizenship (Spradley, 1979; Christiansen and Barnartt, 1995; Ladd, 2003; Bauman and Murray, 2009; West, 2011). This demonstrates how recording Deaf people with dementia’s narratives in a visual context contribute to the landscape of Deaf history. Deaf communities throughout the world express storytelling and narrative as fundamentally constitutive of culture (Rathmann, Mann and Morgan, 2007; Bahan, 2008). Narrative analysis was therefore chosen as the most appropriate structure to approach the elicitation of data in the context of Deaf people with dementia because it is a familiar medium that establishes social positioning, expresses identity and demonstrates culture.

In the context of Study 2, the key event in the change in social positioning (Ryan, Bannister and Anas, 2009) for the Deaf people in this context is the diagnosis of dementia and the impact that this has had on the Deaf person and their lives. Furthermore, the triadic encounter of the researcher with both participants is a Deaf to Deaf encounter (see Ladd, 2003; Sutton-Spence, 2010; Lane, Pillard and Hedberg, 2010) in which storytelling from one person to the other is a habitual social practice using visual language resources (Young and Temple, 2014). This is important because as Surr (2006) comments, the relationship between researcher and participants is not just the vehicle for elicitation of communication, its nature is also a contributor what is expressed or shared within the narrative structures and how it is expressed. Being a Deaf researcher (as explained earlier in this chapter) will have had an impact on the content and context of the narratives within each interview.

4.9.2 Which narrative approach will be used for analysis?

Interpretive Phenomenological Analysis (Smith, Flowers and Larkin, 2009) was originally identified as the primary analysis method for these data because the study was exploring the lived experiences of Deaf people living with dementia and their carers. Deaf sign language users living with dementia and their carers have many stories to share, but within the context of how this was shared, in their first language, BSL, it was important also to record the idiosyncrasies of their communication and any underlying messages being conveyed that would not be picked up via direct transcription from BSL to English. However, while the researcher and the supervisory team were discussing the content of the interviews, it became clear that the dialogic narratives shared between the researcher and participants were equally important in their structure and their embodiment rather than their content or implied meaning alone (Kontos, 2004; 2005). In a visual language, the how of the narrative is especially important because of the ways in which the language utilises space, movement, eye gaze, facial expression, touch and deliberate positioning of the body (Perniss, Thompson and Vigliocco, 2010; Vinson et al., 2015). Embodiment has semantic intent in a signed language. For example, if someone leans forward or backwards when telling an element of their story, this has semantic implications beyond those that might be inferred in a spoken language. In leaning away, someone can grammatically indicate additional layers of meaning such as reluctance or distaste or fear (Morgan and Woll, 2007; Bahan, 2008). Narrative analysis therefore offers more possibilities of capturing these subtleties.
than IPA would, as IPA has a greater reliance on the interpretation of another’s underlying meaning making but this is often divorced from the broader contexts in which that expression is formed. IPA does not yet offer a socio-cultural context, (Todorova, 2011) which, if in place, would allow for the Deaf person to be understood in their unique environment. Using IPA for Study 2 would not offer the best representation of the participants’ viewpoints on living with dementia, as they are sharing these experiences in a visual language, which adds a unique dimension. The embodiment of these views would be lost in the literal interpretation of the participants’ statements, as well as the narrative structure within the triad that is potentially scaffolding the dialogue (Young and Temple, 2014).

Furthermore, Riessman (2008) discusses four different ways in which to analyse narrative data –thematic, structural, visual and dialogic. Dialogical narrative analysis allows the data to be explored from an observational and a thematic perspective, watching and understanding how the story(ies) were co-produced between the participants, using both signed and non-verbal positions (Bruner, 1987). As the data are being explored from both the perspectives of what has been signed and how it has been signed, it was decided that a dialogical narrative analysis framework (Riessman, 2008) as well as a case study approach, where the participants’ backgrounds, positioning in the interview and relationships will be portrayed, would be the two most appropriate methods to analyse the interview data. Using the dialogical analysis approach gives the stories of both the person living with dementia and their carers the opportunity to be analysed with additional interpretations of the wider social context. This would mean the interview data would be intertwined and represent lived experiences using a holistic case-study approach where the triad (the Deaf person with dementia, their carer and the researcher) would be contextualised appropriately (Yin, 1989). For each set of interviews, as previously explained, in section 4.9.4, there were two consecutive interviews carried out with four Deaf people living with dementia and their carer(s) within the space of three months. These will be kept as a whole narrative unit following a chronological timeline, starting with the first interview, reflections and then the second interview.

By using a dialogic narrative approach, additional considerations will need to be made about the data and their modality. BSL is not just composed of the use of sign language through the hands; there are also additional gestures, facial expressions, body language, body positioning, touch and movement. Therefore, in using this type of analysis, it is necessary to consider what was said, but also how the participant(s) represented themselves in a holistic way.

Using the case study approach initially to introduce each family unit will allow the participants’ different day-to-day experiences to be presented to the reader. This will be done in such a way that the reader will understand why it is important that something was said and how it was said within the context of their individual and wider social relationships. Following on from the case study approach, storied stories (McCormack, 2002) have been utilised as a method of analysis and data presentation to further introduce the research participants and their unique life perspectives. It was felt that if the participants’ stories were just replicated as they were signed, that there might be a loss in cultural translation and representation of their meaning (Young, Ferguson-Coleman and Keady, 2014b). It is therefore anticipated that by using the storied
stories approach, the significance of the cultural relevance, i.e. the Deaf perspective of each personal story, will become clearer and easier to understand for the reader. This was because data presentation through storied stories allows for commentary on those data as they are presented and close engagement with the ‘feel’ of what is being shared through how the narrative structure of the storied story progresses.

4.9.3 Coding the data

The video data from all the interviews were uploaded into NVivo 9, QSR International's qualitative data management software package (QSR, 2012) which meant that the data were kept at their source language, BSL. Each interview was given an appropriate numerical identifier in order to preserve anonymity.

While re-watching the video data, it became apparent that there were two different ways in how to represent the data during analysis. It was necessary to recognise the participant’s views in what was said, not only with what they were sharing about their everyday lives, but also consideration was needed about how statements were made and how participants were non-verbally supported during the interviews. Therefore, this led to a decision that the video data would be represented in two ways; thematic analysis and situational analysis. The thematic analysis will explore the dialogue shared with the participants about their everyday lives and experiences. The situational analysis will explore how the participants maintained their presence, how their carers offered scaffolding and the non-verbal communication that enabled their participation in dialogue together. By using these approaches, the video data has been firstly given the opportunity to be presented as facts, and secondly, the opportunity to offer a visually meaningful picture of how the participants presented themselves during the interviews.

Each interview was watched at least five times before any written notes were made to highlight the different themes that were coming to the surface. The written notes were tagged alongside each video and given specific time-tags, so that the exact note could match the exact moment that a signed or non-verbal occurrence was recorded.

The initial themes were shared with the supervisory team to develop critical dialogue and to consider the appropriateness of these overarching themes. The supervisory team also watched chunks of the video data with the researcher after discussing the initial themes. A BSL interpreter was present at this time to voice-over the signed dialogue between the researcher and the participants on the screen, as well as to build up depth to the themes with the researcher present.

4.9.4 Analysis Framework

Table 1 outlines a summary of the analytical approaches undertaken across the data set in Chapter 7.
### How data are represented

<table>
<thead>
<tr>
<th>Unit of Analysis</th>
<th>Attention to Context</th>
</tr>
</thead>
<tbody>
<tr>
<td>Storied Stories</td>
<td>Personal, everyday experiences; Societal; community-based</td>
</tr>
<tr>
<td>Themes</td>
<td>Personal, everyday experiences; Societal; community-based</td>
</tr>
<tr>
<td>Situational Analysis</td>
<td>Non-verbal communication; situational contexts; everyday experiences; scaffolding opportunities</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Storied Stories</th>
<th>Storied stories - one from each interview; attention paid to participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Themes</td>
<td>Thematic analysis – overarching themes that were pulled from the data</td>
</tr>
<tr>
<td>Situational Analysis</td>
<td>Situational analysis – overarching perspectives pulled from the data</td>
</tr>
</tbody>
</table>

#### Table 1: Analysis Framework

**Themes for thematic analysis**

1. Personal every-day experiences
2. Events leading up to diagnosis
3. The process of diagnosis
4. Support of family members
5. Support from Deaf community
6. Accessing services/external support

**Contextual dialogue**

1. Expectations
2. Stigma
3. Recognition
4. Acceptance from/of others

**Situational analysis**

1. Assertion of agency
2. Carer scaffolding
3. Maintenance of presence in conversation
4. Empowering one another in dialogue
5. Meaningful non-verbal components
By taking this three layered approach, incorporating the case study approach, storied stories, thematic and situational analysis, the holistic approach to the whole unit of the Deaf person living with dementia and their carers has been upheld (Riessman, 2008).

4.10 The impact of collecting data from a qualitative research perspective

4.10.1 Reflexivity

As a Deaf researcher, there is always potential for personal experiences to influence the collection and interpretation of data, however, reflexive practice was undertaken (Denzin and Lincoln, 1998; Young and Temple, 2014) to support the researcher in avoiding bias. These experiential issues meant that I had to constantly reflect on my own positioning during the process of data collection in order to remain transparent while generating new findings. Examples of reflective practice included taking contemporaneous field notes after each interaction with the participants to demonstrate reflexivity and thought processes that occurred during or afterwards. Face-to-face supervision was also held with the research team after each focus group (as it was after the individual interviews in Study 2) had taken place in order to debrief and to discuss any concerns or new thoughts the data generation process has provoked (LeCompte and Goetz, 1982).

4.10.2 Reliability and validity

Each focus group was audio recorded and each interview was video-recorded. These recordings bolster the evidence in how the researcher collated the data and provide proof that the researcher has not presupposed information or added their own viewpoint (Strauss and Corbin, 1998). These recordings also provide a concrete validation of the research process that has taken place with its time sensitivity and being as close to the data as possible (Hammersley, 1992).

The methodological triangulation through the use of recorded video and audio data, contemporaneous field notes and face-to-face supervision with the supervisory team has all added to the strength and the transparency of the sole researcher and, in turn, the validity of the data.

4.10.3 Generalisability

The issues discussed in the focus groups are to some extent generalisable to the wider Deaf community, as the views and opinions shared within these groups may reflect the overall views and experiences of the Deaf community as a whole because of the common shared experiences discussed earlier throughout Chapter 3.

However, a potential limitation is that the geographical presentation of personal experiences (as in accessing services) may not be as generalisable. The Deaf community population is diverse across the UK, where there are much smaller pockets of community members with perhaps less opportunity to access local Deaf community services, compared to the central location of the focus groups.
Furthermore, the interviews were held with Deaf people living with dementia and their carers within the sampling frame of their diagnosis occurring within the past three years. This purposive sampling frame meant that their everyday experiences and experiences of service provision were within a time-specific context (Guba and Lincoln, 1994). However, if this research were to take place again in the future, the views and experiences are highly likely to be similar in the context of being Deaf and living with dementia in a mainstream hearing society.

4.10.4 Conclusion

This chapter has discussed the strengths and limitations of collating data within a small community. The methods of data collection for both studies have been described in detail while recognising the sensitive approaches needed while working with Deaf BSL users.

Chapter 5 will explore in depth the findings of the focus groups with members of the Deaf community who did not have dementia. Chapter 6 is an addendum for a Deaf carer’s story of supporting his hearing mother, while Chapter 7 will focus on the interviews with Deaf people living with dementia and their carers.
5. Findings – Focus Groups – Thematic Analysis

5.1 Introduction

This chapter will present the views of 26 Deaf BSL users who have shared their understanding and thoughts about dementia. As previously stated in Chapter 4, there were three focus groups, which were run at the same venue. All the participants were Deaf BSL users and the aim when recruiting participants had been to focus on those who did not have direct experience of living with, or caring for, a person living with dementia. In reality, out of the 26 members, only two people had some experience, and that experience was minimal.

This section addresses three overarching themes: knowledge of dementia, information about dementia and support for living with dementia, which have been established from participants’ feedback. These three themes emerged as important in the Deaf community’s experience, because, firstly, it is possible not to have any information at all, or to hold information without completely understanding it. Secondly, personal knowledge can lead to understanding without the provision of external (or third party) accessible information. Thirdly, access to mainstream support services can be problematic for Deaf BSL users (see Chapter 3, section 3.25 for further discussion). For a community whose experience of access to information is fragile, and who have few possibilities to discuss topics with knowledgeable others in their own preferred first language, the relationship between information, knowledge and support is particularly important in this new topic area of dementia.

5.2 Introduction to the focus group members

In the first group, there were 11 participants aged 60 and over; the second consisted of six participants between 18 and 60 years and the third, nine participants between 18 and 60 years. In some respects these groups were derived from different populations within the Deaf community. The first group consisted exclusively of retired Deaf people, the second group was made up of a mixture of general Deaf community members where the afternoon timing did not preclude them from attending, and therefore there were some members who worked part time/flexible hours or did not work at all. The third group were of working age and included some professionals [see Methods in Chapter 4 for further details of recruitment]. There were 14 men and 12 women and all were Deaf BSL users.

The members of each group were positioned in a horseshoe shape (as explained in Chapter 4) for ease of communication and face-to-face access to each other’s signed dialogue. Each group met once for about two hours with a 15-minute break after an hour of discussion. Most participants already knew one another, from either being part of the same Deaf club, or being part of the same Deaf community networks or through their work.

Table 2 illustrates the arrangement of each group and their members. All names are fictitious in order to preserve confidentiality.
5.3. Cultural Reflexivity

Deaf culture (as discussed in Chapter 3) refers to many characteristic behaviours, preferences, attitudes and features of identity that are seen through how Deaf people interact with each other (Padden and Humphries, 1988). It is a living expression, which refers to shared ways of being, rather than a label of identity. In this regard, it is important to share some unique cultural differences in hosting these focus groups. Upon arrival, in Group 1, some participants were sitting in their chairs holding print outs of what they had researched the previous night about dementia. I, as the facilitator, had to ask these specific participants to place such papers on the floor, as their mode of communication was hampered; they were not able to sign while holding the paper. Group 1 participants had arrived expecting to be ‘trained’ in/about dementia, rather than directly participate, in the discussion. They had, therefore, printed out the papers to aid their perceived training opportunity. They had this perception despite the participant information sheets in BSL and English being clear about the purpose of the group.

All participants from across the three groups came with expectations of the group, which were derived, in part, from their life experiences as predominantly seekers and receivers of information, rather than co-producers of knowledge. This is understandable given that access to information cannot be casually assumed to be within the individual’s control, but, instead, is regularly perceived as problematic and likely to involve overcoming barriers and obstacles to acquire knowledge derived from it. To explain further, a hearing person can usually assume that if they do not know about something, they can easily ask another
(hearing) person and be understood, or they can look it up and will understand at a first read through what is written. This is not an axiomatic assumption for many Deaf people. Therefore, there is a lifetime of assuming that information has to be deliberately imparted and that one is more often a recipient than an active participant. The lack of information available in BSL for autonomous consultation also contributes to this expectation (see Chapter 3 for further discussion).

When the focus groups commenced, the participants all started discussing issues around dementia as they sat down. At this point, I was keen to state that this group was ‘not like being back at school’. I wish to develop this point further as it is important in a culturally Deaf context. I was unsure as to whether or not this would be a common statement for a facilitator to make, but in this context it was important because many Deaf people strongly associate the imparting and receiving of information with their school experiences. Unfortunately, not all school experiences for Deaf people are positive, and negative memories can be carried forward throughout the life trajectory. Moreover, a possibility existed that the participants might interpret the group discussions as a ‘test’ of knowledge, or a situation in which one might be revealed as ‘stupid’ or ‘ignorant’. This is because the acquisition of knowledge in a group setting outside of a school context can be a rare event, particularly for older Deaf people. By making the ‘not like school’ statement I was also attempting to show that I respected the group as individuals in the ‘here and now’. Also, from my insider perspective, I was aware that the group situation might be unfamiliar for some participants as there are not many opportunities in Deaf people’s lives to participate, and contribute to data collection, especially in an equal group environment, i.e. conducted only in BSL for Deaf participants (Young et al., 2016). So this statement was also offering reassurance that group participants were not being expected to ‘perform’ or that they would ‘make any wrong statements’ in our discussion.

I needed to ensure that the group were comfortable with the use of interpreters, while also establishing communication rules, such as raising hands when a participant was ready to say something. I was very conscious at this point that in a way I was controlling the flow of information and I was unclear as to whether this would be a similar dynamic in a hearing-led group that was being audiotaped. This structured method in managing the focus group was important, as it was imperative for the interpreters to voice over everything that was presented throughout the session as things that had been signed could otherwise be missed (or not described clearly) and, therefore, not recorded. In fact, in the interest of capturing everything on the audio recording, there were moments through the focus groups where I would chip in, using my voice and signing at the same time, to describe particular signs that I thought were rich in their information, such as the person signing their conceptual understanding of the development of dementia (see Chapter 4, section 4.7.8. for further details).
5.4 Presentation of focus group themes and sub-themes in tabular format

<table>
<thead>
<tr>
<th>Main Themes</th>
<th>1: Dementia Knowledge</th>
<th>2: Dementia Information</th>
<th>3: Dementia Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub themes</td>
<td>The origins of dementia</td>
<td>Information and its meaningfulness</td>
<td>The identification of support</td>
</tr>
<tr>
<td></td>
<td>Dementia and symptoms</td>
<td>Information and the process of receiving it</td>
<td>Where to go for support if you’re worried about memory issues</td>
</tr>
<tr>
<td></td>
<td>A signed representation of the development of dementia</td>
<td>Information and professionals</td>
<td>Service expectations</td>
</tr>
<tr>
<td></td>
<td>How do hearing professionals efficiently diagnose dementia if you are Deaf?</td>
<td>Dementia Information via the Alzheimer’s Society website</td>
<td>Service design and limitations</td>
</tr>
<tr>
<td></td>
<td>Dementia and Alzheimer’s</td>
<td>Dementia and communication</td>
<td></td>
</tr>
</tbody>
</table>

Table 3: Presentation of focus group themes and sub-themes in tabular format

5.5 Dementia Knowledge

This section will highlight what the focus groups revealed about Deaf people’s understanding of dementia, before progressing in later sections to consider what might influence their knowledge, including access to information.

5.5.1 The origins of dementia

The participants expressed several theories about the origins of dementia and how it progressed. Overall, there was not a great deal of certainty and participants were quite open about how unsure they were. The following suggestions were offered more as speculation for discussion rather than the passing on of clear knowledge within the group. Participants from all the focus groups introduced a potential link between dementia and nerve cells within the brain. For example, George (G1) and James (G1) had direct dialogue clarifying with one another where they were exchanging ideas about what they thought dementia was.
George stated that the progression of dementia was due to the ‘loss of nerve cells in the brain’ while James wanted to clarify whether ‘George meant that the ‘nerve cells are gone’ in their entirety. In the original BSL, the difference between these two statements were whether ‘gone’ implied ‘wiped out totally’ or ‘gone’ implied a gradual loss bit by bit, hence the need for clarification. James explained that he thought, ‘just a few nerve cells were left and that they slowly fade away’.

Later on in the same focus group, Norah (G1) added that she thought, ‘some brain cells die quicker than others which is the early start of dementia’. In a visual language such as BSL, these conceptual distinctions are easy to produce and see because they relate to the precision with which the language represents ideas; in this example, the difference would not just be in the movement that represents ‘gone’, but in the speed of that movement that communicates its gradual or absolute nature.

Another theory of the origins of dementia was that it was genetic and inherited. This was only mentioned in one of the focus groups. However, what exactly being genetic implied was itself not clear, beyond the idea that it meant within the body. For example, Mark (G1), whilst linking dementia with something inherited within the brain, thought that the mechanism for it becoming manifest was to do with the brain becoming worn out. He said:

‘It is difficult to say whether (or not) dementia is genetic, it’s related to the brain, isn’t it? And I think it’s just a matter of the brain reaching a point where it can’t go on any longer.’

Fred (G1) understood the idea in terms of the brain being unable to cope any longer, ‘I think, obviously, the brain has a kind of overload; it could be related to that’. In other words, it was thought that ‘genetics’ meant in some way that a person’s brain was not as strong or robust as might be expected. The extent to which the implied weakness would be passed on and how deterministic that might be was a cause for concern. It led Annie (G1) to speculate if a person’s ‘mum had dementia would it mean they would follow in her footsteps?’

Alternative theories generated by the focus groups about the origins of dementia centred on whether it was a side effect of other health problems. For example, Jackie (G2) explained that she thought the onset of dementia could be to do with the levels of cholesterol in the body, ‘it blocks your arteries and that can cause you to be forgetful’.

Susie (G2) was concerned that ‘if we were to smoke a lot, would it affect the brain in that way?’ Seeing dementia as a side effect of other problems inevitably led to discussion about whether they would potentially receive health advice linked to dementia like they have linked to other common health conditions. Jackie also suggested that if a person is overweight, the doctor would ask them to adjust their diet and that the same principle of adjustment could be applied to the onset of dementia:
‘If someone is having problems with their memory, does the doctor give them recommendations of how to help or do they say “You have dementia” and that’s it?’

This comment betrays a wider assumption within the group, which was even if the actual origins of dementia were not clear, it could be identified and steps could be taken to prevent its onset or slow down its effects. This should be understood also in the wider context of Deaf people struggling to acquire health related information in a form that is accessible and intelligible to them, as discussed in Chapter 3.

5.5.2 Dementia and symptoms

There were concerns about how to prepare oneself for dementia, in light of there being little information out there in BSL, few forums for discussion and, in the view of many participants, nobody from within the Deaf community really advocating for Deaf people with dementia.

Participants were also concerned with understanding symptoms and what they looked like. This is important in the Deaf community because as I outlined in Chapter 4, the visual recognition of symptoms are key for those who communicate in a visual language and are visually orientated people in a broader sense. Stephen (G1) queried for example, ‘if there was a person wearing funny coloured clothes, bright yellow socks and boots with a funny hat, with a strange smell about them, does that mean they have dementia?’

Mark (G1) explained that he had looked dementia up the day before coming to the focus group in what he described as a ‘very good medical book’. It transpired later on in the group discussion that the very good medical book was a copy of Reader’s Digest\(^\text{14}\); this was evidently a trusted source of information for Mark. He did not explain why, but it might be speculated that, because it is seen as a publication with straightforward explanations that are clearly expressed, it is therefore potentially accessible for someone for whom English is a second and less strong language than their first. Or it might be regarded in this way because of its reputation as a publication series many people enjoy. Nonetheless, it was not a medical book despite Mark’s assigning it as such. Annie (G1) herself came to the focus group with a pile of papers that she had printed out from the Internet. For both, the impetus of the discussion group had led them to search for information, which they would not otherwise have done. However, both sources of information were not fully accessible nor necessarily accurate or helpful. Indeed, Annie further explained that she felt she had a good command of the English language, but was worried that this skill might change with the onset of dementia.

Participants were generally clear that dementia is a progressive disease that does not improve. Symptoms they described included ‘a loss of memory’, ‘absent-mindedness’, and ‘repetitiveness’. People living with dementia were described as being ‘slower’. Kim (G2) stated that living with dementia could go on for ‘maybe

\(^{14}\) Readers Digest is a monthly subscription magazine, which summarises interesting headlines, news and articles in one issue from around the world. Their website is [http://www.readersdigest.co.uk](http://www.readersdigest.co.uk)
fifteen to twenty years at the same level. Sometimes it gets worse, sometimes it gets better, and it can fluctuate.’

The majority of the participants’ shared knowledge about how dementia manifests itself appeared to be from personal encounters and experiences, not necessarily from meeting someone or looking after someone with dementia, rather than from having read about dementia. In this respect, participants drew on their observations and interactions with hearing people as well as with Deaf people. They did not make a clear distinction between how dementia is manifest in hearing people and how it manifests in Deaf people. There was strong agreement that people with dementia become repetitive and have the potential to forget what they were saying halfway through a sentence. In addition, Susie (G2) described a story in which their Deaf family member would start reading a page and by the time they’d got to the bottom of the page, they would forget what they were reading, adding that people living with dementia can forget what time it is. In this discussion, Lisa (G2) was also concerned that Deaf people with dementia would struggle with their tinnitus symptoms while managing their memory loss too.

Participants described a person with dementia as potentially having risky behaviours, such as leaving the gas cooker on, forgetting to turn off the fire, or displaying volatility with their frustrations in not being understood. In addition, several participants referred to people with dementia displaying the same ‘problems’ as those with mental health issues. Mark (G1) outlined how there are Deaf people in the community ‘who are involved in drugs, you know, cannabis smoking, and I think that can affect your memory, that could bring on dementia’. Furthermore, Clare (G2) described how ‘dementia is like cancer. You can’t stop it. You can’t prevent it from happening. You can keep active but you will still have that dementia, its wear and tear’.

However, there was a good awareness of celebrities who were living with dementia and participants looked up to them as positive examples of being able to do so. Stephen (G1) commented:

‘You can carry on with your life when you have dementia; look at Terry Pratchett\(^\text{15}\): he is still writing and he’s keeping on going’.

Clare (G2) thought that regardless of one’s intelligence and how well one’s brain is used, dementia can still develop:

‘Look at Iris Murdoch\(^\text{16}\) for example, she was an incredibly intelligent woman, however, as she became older, her brain started to slow down and not be so good’.

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\(^{15}\) Terry Pratchett (1948-2015) was the author of the famous Discworld novels. He was diagnosed with early-onset Alzheimer’s in 2007.

\(^{16}\) Iris Murdoch (1919-1999) was a famous philosopher and author in the UK. She was diagnosed with Alzheimer’s in 1997.
It is interesting to note that the participants offered examples of famous hearing people living with dementia; it appears there were no parallel examples of famous (or, even, not famous) Deaf people living with dementia that could be named.

5.5.3 A signed representation of the development of dementia

In addition to the visual environments that are the natural requirements of the Deaf community, it was also felt that Deaf people’s memory banks would be of a different format to hearing people’s; two participants argued that Deaf people have a better photographic memory because Deaf people ‘use their eyes and don’t rely on listening’. They also used the example that Deaf people are more likely to pass their driving tests first time because of the enhanced acuity of their peripheral vision.

A fascinating query was raised where Bert (G1) wondered if the Deaf person living with dementia would have a different memory base to refer to, as he anticipated that the Deaf person’s photographic memory would bring a different ‘variety’ of memory compared to a hearing person’s memory base. Bert queried:

‘I’m wondering if you have a photographic memory (whether you’re Deaf or hearing), and things come flashing back to you’.

Once again, this was a strongly visual-based understanding of memory and by extension, of the concept of dementia. This statement begins to demonstrate a different orientation that Deaf people may commonly have, that shows their thinking about dementia and its likely effects. Mark (G1) exemplified this conceptual thinking too. He attempted to create a new concept in BSL, in which he understood dementia to take over the memory bank in the brain. He used two hands, each clenched into a fist. The first hand is the brain, as it is when one is born, slowly unclenching as it ‘expands’ with new knowledge. The second hand, in turn, represents dementia progressing as time goes on (with the first hand returning to its clenched shape and thus, to the original state of the brain as when one is a child). Through this visual image represented in Appendices (ii) V5, Mark was emphasising his personal understanding of how dementia affects one’s memories, in that learnt or current information is slowly eroded by dementia eclipsing these memories.

5.5.4 How do hearing professionals efficiently diagnose dementia if you are Deaf?

Vineet (G3) stressed how difficult it would be for hearing professionals to make a clear diagnosis of a Deaf BSL user’s symptoms and stated there was potential for misdiagnosis to take place due to their potential lack of understanding of Deaf culture (as discussed in Chapter 3) as well as their lack of fluency in BSL. It was felt that hearing professionals need to consider the visual ways in which Deaf people communicate. For example, maintained eye contact is imperative while talking to a Deaf person, thus, hearing professionals who do not have this awareness would not look for changes in Deaf people’s routine eye contact behaviours, but other Deaf people would notice this quickly and question it.
It was agreed that whilst the diagnosis of dementia would be the same for both hearing and Deaf people, professionals might be able to identify the onset much more easily if it were happening to a hearing person. The issue here was not so much being hearing or being Deaf, but rather one of familiarity. This could work in two ways. Being Deaf within a small community might mean that a friend’s symptoms could not be spotted because of the closeness of the friendship and the familiarity with each other as Deaf friends. For example, Annie (G1) had recently met with some of her long-standing Deaf friends and together they had started using old signs from when they had been at school together. This seemed natural at the time, but now Annie was worried about whether it was indicative of a regression linked with the onset of dementia. In this respect, there was discussion around the possibility that a hearing person might ‘see’ the symptoms of dementia more easily because their vision was not clouded by familiarity. On the other hand, Ursula (G1) pointed out that ‘as a Deaf person in the community, you’d notice it (more) because of your friendship and the closeness of the Deaf community’. A hearing person unconnected with the Deaf community might not notice that anything was different or had changed and might simply attribute the behaviour to that person being ‘deaf’. Annie (G1) also queried the potential changes in characteristics for someone who might have dementia:

‘You need to look at the person and whether they’re losing their personality: if that person has gone, how would they be able to get themselves back?’

One or two participants in the group were worried about the performance of their own memories – it appeared that this concern was flagged up because of the topic of the focus group and not an actual underlying concern that they’d been worried about for some time. For example, Owen (G3) explained that he went to children’s parties regularly and commented that ‘the next time I go to see them again, I’ve forgotten their names and it’s embarrassing. I have to ask...as I constantly forget.’ This comment signifies the lack of confidence there is generally about the specific identification of ‘normal’ ageing processes and the onset of dementia.

As a Deaf person, Bert (G1) felt that being Deaf meant that Deaf people had to deal with a lot of stress in their lives; Bert asserted this was stress arising from common everyday frustrations associated with communication and access. Thus, he wondered if there was more likelihood of being diagnosed with dementia sooner as a Deaf person who has a lifelong experience of such stress. Bert thought that hearing people’s lives were more ‘stress-free’ and they were, therefore, less susceptible to developing the signs and symptoms of dementia. For example, Bert suggested that vicars are less likely to be diagnosed with dementia as their jobs are calm and have a routine. This is a good example of how Deaf people, like everyone else, will begin from what they know as ‘normal’ and compare it with the normal of the ‘other’, but also make a judgement about whether that alternative experience is better or worse than their own. Hearing people, on the other hand, are unlikely to consider how being hearing and having easy access to knowledge and information reduces the risk of acquiring dementia because barriers to knowledge and information access are not usually of significant meaning throughout their lives.
5.5.5 Defining dementia and Alzheimer's

Within all the focus groups, answers to the question ‘what is the difference between dementia and Alzheimer’s?’ were consistent; very few people were able to describe each noun and its meaning. Susie (G2) asked, ‘where the words dementia and Alzheimer’s came from, were they medical words?’ Kim (G2) responded with the suggestion that ‘dementia is a progressive disability that has come up over the years; I think Alzheimer’s leads to death’. Clare (G2) thought, ‘Alzheimer’s was worse; it’s when you don’t recognise people’. Jackie (G2) added, ‘dementia was perhaps less serious, you just forget stuff, but I think Alzheimer’s is much worse, much more progressed’. Confusion over the precise meaning of terms associated with dementia is not exclusive to Deaf people; in fact, it is a common experience of many people in society encountering dementia for the first time. However, these sorts of exchanges between these Deaf participants should be understood in the context of awareness that Deaf people face barriers when trying to access information and acquire new knowledge, which in turn would lead to a greater understanding. There is a scarcity of information available in BSL that caters for Deaf cultural preferences, with English as a second language (see Chapter 3, section 3.26). Being present in these specific focus groups afforded these participants the opportunity to begin to exchange information with one another and be understood in their queries to one another about the topic of dementia.

Clare and Jackie were challenged by Lisa (G2) who had personal experience of caring for someone with dementia; Lisa stated, ‘my mother did recognise me up until the end when she passed away...I’m thinking she just suffered from dementia’. Lisa said the sign for both dementia and Alzheimer’s was the same, but ‘talking about the differences, with Alzheimer’s, it’s an illness, and dementia is a condition (of Alzheimer’s)’.

These exchanges demonstrated the importance to the group of being precise and accurate about words in English; they wanted to know exactly what the difference was or how these two words were related. They agreed that the BSL sign for dementia did not make a distinction between the words dementia and Alzheimer’s, which was a concern, but equally there could be no sign ‘made’ until there was clarity about the similarity or difference in the concepts, thus, naturally, such a difference in how it was signed would emerge.

5.5.6 Dementia and communication

There was a particularly striking assumption made about language and dementia. Some participants indicated that having dementia would not affect a Deaf person’s sign language production, stating that dementia only affects the short-term memory and a person would have sign language memories embedded in their long-term memory. Vineet (G3) queried ‘whether people with either Alzheimer’s or dementia forget sign language or whether they forget to know how to sign’. This distinction between forgetting a specific language rather than forgetting how to use the language perhaps has its origins in the high value Deaf people place on their signed languages throughout the world as something defining of culture and unique to Deaf heritage. How could the language be forgotten? But forgetting how to use it may be more understandable.
There was a range of personal experiences described by the Deaf participants; experiences with both hearing and Deaf people living with dementia. There were no obvious discrepancies within those scenarios; a common element was tolerance in how they handled the person’s differences. Lisa (G2) outlined how she had tolerated their mother’s language towards her and her siblings, ‘you just have to accept that that’s the way she is, you can’t take her seriously, don’t worry about it, you have to let it go’. However, there was some anxiety around how to respond to the repetitiveness of a person with dementia; the participants described feeling incompetent in how to react to a person living with dementia; whether to respond as if it was new information or whether to respond with ‘yes, you have told me that before’. There were no relatable or accessible advice models available on which to draw to reach a conclusion on what might be the ‘right’ thing to do.

5.6 Information about dementia

The two Prime Ministers’ Dementia Challenges (Department of Health 2012; 2015) have emphasised that good quality information about dementia is a priority in being able to live well with dementia. These challenges further stipulate that policy makers and service providers should consider that ‘the needs of some groups (e.g. those with a learning disability and dementia, younger people with dementia, those from minority ethnic groups, or those from rural, island or traveller communities) may be different from those of the majority population, and may require specifically tailored approaches’ (Department of Health, 2012, p.28).

This section will explore how ‘tailored approaches’ could be applied to information about dementia for Deaf people; how it should be presented, accessed and used, and also what information Deaf people themselves might want. Within the focus groups, whilst discussing issues connected with information access, participants commented on two distinct aspects: information and its meaningfulness; and information and the process of receiving it. These two aspects will be explored further.

5.6.1 Information and its meaningfulness

As outlined in Chapter 3, through the widespread lack of appropriately delivered education, many Deaf people struggle with understanding written information. This, paired with a lower than average ‘fund of knowledge’, due to the lack of appropriate education and the lack of environmental learning processes (Pollard and Barnett, 2009), creates an immediate barrier to the necessary cognitive processes needed to ‘understand’ information.

Moreover, if a Deaf person states ‘I need accessible information’, it may be a natural assumption that they will understand information that has simply been translated from English to BSL. However, as the research process of the focus group itself demonstrated, providing a BSL version of something (in this case a participant information sheet) simply translated from the English version, does not automatically provide a platform whereby the Deaf person has ‘full access’ to what has been given to them. Information does not
ensure understanding; translation does not ensure full access to knowledge. In this study, the researcher provided the focus group with a BSL DVD explaining about the study and what was involved in taking part. The focus group participants immediately assumed that it was a training DVD and the researcher was asked in person to clarify the points made by the presenter on the DVD; ironically, it was the same researcher/facilitator providing both sets of information.

Participants identified that accessing information on the Internet did not necessarily give all the answers and that identifying the right information was crucial; Tim (G1) stated, ‘you could be given so much information about dementia but you’re never too sure of what it actually means to you... you could misinterpret it or misdiagnose’.

These comments reflect the educational disparity that exists within the small Deaf community and the strong knowledge/awareness that members have a lack of opportunities and a concern that they may misunderstand.

There is also a desire to ensure that other Deaf people have their particular needs met. Tim offered, ‘I’d like it so that Deaf people can understand through sign language...or an in easy, readable format...we do have different needs’. The Deaf community’s language, communication and environments are all preferred via a visual medium or in accessible plain English formats.

This dialogue continued with the suggestion that case studies are used whereby Deaf people are signing about their personal experiences ‘so you can put yourself in their shoes.’ James (G1) added that the use of role-play in explaining scenarios to the Deaf community was crucial and indeed preferred:

‘You need a drama of someone asking what dementia is and then an answer, I think role play is really useful’.

Within Deaf culture, the visual representation of information is imperative as well as the use of anecdotal experiences. Deaf people are passionate about storytelling, sharing examples and watching stories being dramatised physically. This is a cultural norm and a preferred means of acquiring knowledge and understanding.

5.6.2 Information and the process of receiving it

This heading explores how the participants felt that information should be provided in BSL at ‘their level’. It was made clear that information solely translated from English to BSL alone is simply not enough for the Deaf recipient. It is imperative to consider the content of information provided and how information is given.

As explained earlier in this section, Bert (G1) explained how he had referred to ‘Reader’s Digest’ to glean information for the workshop and his name for this source of information was ‘the medical book’. This
reflects different facets of understanding information; firstly, the medical summaries found in these types of media are written at an appropriate level of English that makes it comprehensible for this participant; secondly, the acceptance of Reader’s Digest potentially reveals the upbringing Bert may have had, where the magazine was deemed as an acceptable source of information.

However, Stephen (G1) challenged Bert, saying that Reader’s Digest would not necessarily be accessible for all members of the Deaf community – ‘don’t forget that all of us sitting here, not of all of us have good English’. There were quite a few statements from participants that reflected concerns about the accessibility of written information for Deaf people, with a ‘them and us’ attitude, with Stephen explaining that some members of the same community are unable to read; they are ‘not that well-educated, not that smart.’ Amongst Deaf people, an overall average reading age in English of around nine years of age (Conrad, 1979) hides significant disparities within the community; these participants were aware of this by highlighting that some Deaf community members are good readers, some are not. However, being able to read English was also identified as not necessarily sufficient to gain full understanding, as Fran (G3) suggested that she ‘would like to find somebody who has been through that experience (of dementia) so they could have empathy and tell me what to expect.’ First-hand knowledge from someone who is ‘like me, as a culturally Deaf person’ was identified as an important source of information too.

Fred (G1) suggested that ‘Deaf people’s education should include lessons about dementia’ and the author has taken the assumption through the sign used that the participant meant within school education. These comments reflect the educational disparity there is within the small Deaf community and the strong knowledge/awareness that members have of these lack of opportunities.

One immediate solution offered was to provide a face-to-face environment that could be facilitated by specific services by using interpreters working with a hearing professional. However, the participants perceived this as potentially ineffective as they felt that the hearing person would not have the same level of empathy or ‘sameness’ as a Deaf person providing the information. Susie (G2) explained that their own Deaf family members would rely on them to be the key provider of information, simply because they would understand how to tune in and use the right register in explaining and clarifying information, regardless of the topic being discussed. Again, access to information was not necessarily enough to promote understanding, even if that information, on the face of it, was in BSL.

One concurrent theme pinpointed that information shared by a Deaf person is perceived as more valid as their life experiences are shared (due to being part of the same community). Bert ascribed the Deaf community as to being responsible for providing high-quality information to each other or to those less fortunate (defined as those who are not able to access the internet or who cannot read English at all). In stating this, he was pointing to a crucial cultural value of shared responsibility for promoting understanding between Deaf people. It is a value that has its roots in a strong collective awareness of how Deaf people miss out on information but also how individual learning needs are not always well met. It is worth remembering that the majority of Deaf people are educated in spoken language environments without
access to sign language interpreters and those who were educated in residential signing environments in the past were not necessarily educated by fluent signers who were Deaf. Scaffolding other’s understanding in such circumstances becomes second nature.

A prime example of checking a Deaf person’s understanding is recognising the ‘nodding head syndrome’ phenomenon which many Deaf and hearing people who work with Deaf people are familiar with; where a Deaf person will walk away having ‘nodded’ their assent to understanding new segments of information. However, if they are questioned maybe five minutes after the event, the refrain ‘oh, I don’t know what was said just then, but I didn’t feel confident to ask or clarify’ is commonly heard (personal experience). Potentially, Deaf people do not have inherent skills in how to ask for more detail or for clarification because they may not have been given those opportunities earlier in life or may not understand the social rules that exist around clarifying information. Hence, information on dementia provided to Deaf people by Deaf people was regarded as paramount because the ‘giver’ would be sensitive to these issues, which might otherwise interfere with a Deaf person’s understanding, as well as the advantage that Deaf information-givers have an awareness of preferred ways to convey information.

However, participants debated whether it was appropriate for ‘hearing’ organisations with specialist dementia knowledge to be the responsible provider of information; rather than asking their local Deaf organisation to collect dementia-related information to share with Deaf community members, or to set up support groups. It was agreed that the specialist organisation could learn how to work with the Deaf community and with local Deaf organisations to meet the community’s particular requirements.

There was some debate about the different communication needs of the Deaf community; whether information should be exclusively signed or exclusively subtitled. Tim added that information about BSL presented programmes should be incorporated in weekly television magazines. This demonstrated the expectation that the profile of BSL presented information would increase via the media.

5.6.3 Information and professionals

It was a general assumption within the focus groups that the GP is the ‘font of all knowledge’ if there were any concerns about medical issues. Even though the information provided is inaccessible, either because an interpreter has not been booked or because it has been written down by the GP, the information is ‘correct’ because the GP is ‘right’ (as described in Chapter 3, where hearing people are always seen as ‘right’, especially with the addition of a medical qualification). There was expressed frustration at how time-limited the GP’s appointments were; Kim (G2) explained how her GP had instructed her to ‘go home and look at this information on the internet’ because they did not have time to elaborate on the issues. There was an assumption made by the GP that Kim could access the information online in English and interpret it meaningfully to her own health issues; that the GP would skilfully signpost their patients to the ‘right’ place for further information. However, as the research reviewed in Chapter 3 has demonstrated, Deaf people are generally very poorly served by primary care and this faith in GPs may well be misplaced.
In terms of professionals directly involved with the Deaf community, there has been a strong history of social workers with Deaf people being key sources of information: they were previously called missioners in the early 20th Century. Most specialist social workers were BSL users and many were Deaf themselves, for example, one record of long-term provision of social work to Deaf people has been available since 1948 (Birmingham Institute for the Deaf, 2016). However, participants were keenly aware that jobs as social workers with Deaf people are diminishing across the UK due to government cuts and changes in the way in which social services and social care has been organised in the past 10 years in particular (NDCS, 2013; Ismail, Thorlby and Holder, 2014). Participants stated their concerns around re-assigned roles within generic social services creating barriers to accessible information as those social workers are assumed not to be fluent in BSL or cognisant in using BSL interpreters.

5.6.4 Information about dementia via the Alzheimer’s Society website

The participants were asked to look at the Alzheimer’s Society website as an exercise at the end of the focus group discussions. It was intriguing to see just how much information was gleaned within the half hour spent on the computer (PC). Initial feedback was feelings of frustration because there were videos on the homepage, but no accessibility function with subtitles or with BSL interpretation available. Paula (G3) explained that she’d had difficulty in spelling the word ‘Alzheimer’s’ within ‘www.alzheimers.org.uk’ and said that she’d ended up on a completely different website because she had not included the letter ‘z’ in her typing. This is a really interesting point as it demonstrates an example of the literacy of Deaf people and also the capacity in understanding and retaining real-time written information (as the website address was actually written on the flipchart in the room for people to see before they accessed the PC).

There was an overwhelming sense of anticipation that there would be information available in BSL, potentially because the group had been asked to have a look for it by a Deaf researcher and the study they were taking part in was funded by the Alzheimer’s Society. When participants did not find it, the participants expressed their disappointment in not being able to fully access the site. Tim (G1) declared, ‘the Alzheimer’s Society was deaf to Deaf people’s needs and that they’d ignored Deaf people by the lack of (information relating to – author addition) deafness on the website’. Four participants commented that the website was laid out in a clear format with the font size being an appropriate easy to read size. However, two of those participants felt frustrated that the online videos were not even subtitled, as ‘it would make it so much easier’. This was rather an understatement because they could not hear the videos either. In her frustration, Paula (G3) exited the website and took the initiative to search on Google to see if she could find any accessible material on YouTube and found a video presented in American Sign Language (which is a completely different language to BSL). It is important to demonstrate the strong desire provoked by this exploratory work to go and find information that the Deaf person felt ‘connected’ with despite the language barrier. The potential for autonomous exploration for knowledge acquisition is clearly there, but the resources do not exist for this to be fulfilled.
Bert (G1) suggested the possibility of having a website providing information that was completely delivered in BSL, similar to the Red Cross website which has been designed in this way (Red Cross, 2016). He felt very strongly that this was easy to engage with and appropriately visual. Iain (G3), who also felt that diagrams and photos of ‘conditions’ would be really helpful, reiterated this point.

Tim (G1) commented on the standard of English used on the website, saying that it was a bit too ‘advanced’ and that the Alzheimer’s Society should ‘think about translating the website into BSL’. When further pressed, Tim explained that this translation should be face-to-face, particularly for those in the Deaf community who do not have access to computers. Rose (G1) argued that she would be satisfied with just subtitled videos, even though she is aware that some Deaf people just pick up ‘key words and facial expressions when they’re watching the subtitles’. Separately, Jackie (G2) explained that she was worried that:

‘English can be so complicated as a language…I don’t understand it and I’m just trying to pick out little bits. If the English is in such depth, it’s confusing for me so I need something that’s in simple written English’.

The Deaf community is geographically diverse in that there are Deaf people resident all across the UK. It is, therefore, culturally acceptable to identify where people come from even before introductions are made. Two participants expressed surprise at how there seemed to be a higher prevalence of diagnosed cases of dementia in the North of England and Northern Ireland compared to London and the South as demonstrated on the website, where there were diagrams of diagnosis rates on a UK map. This cluster of information was valued and immediately recognised because of innate cultural values and knowledge of the diversity of the Deaf community. Rose (G1) remarked, ‘People in London have such a busy life. In Northern Ireland, people might be a bit idle’. Rose was assuming that because people were busier in London, they would have less time to go to the doctors to talk about any concerns they had about their memory.

The group demonstrated that their understanding of dementia had expanded through accessing the Alzheimer’s Society website by outlining that dementia has ‘symptoms’. They understood ‘symptoms’ to mean changes in a person’s memory, body, body language and so on. They were concerned those symptomatic changes would differ from person to person and that this would have an impact on their diagnosis. Mark (G1) said (as he viewed on the website):

‘It said there are “symptoms”, so it’s like looking at your body language or how you might spot (differences), well, you know symptoms for one person might be different from another person’.

His observation was of course correct, but the website had not given any indication to him that symptoms one might observe may have a cultural dimension too, as mentioned earlier (in section 5.5.2) in respect of how a Deaf person may present as living with dementia.
Richard (G3) elicited from the website that dementia could be passed on in genes; this information is correct and present on the website, but it is actually presented as a rarity and it is explained in depth how genetics works in the diagnosis of dementia. It is not clear how much Richard understood of this script and whether he just picked up key words and therefore determined that dementia is genetic. Fran (G3) recognised that there were nine types of dementia listed on the Alzheimer’s Society website but did not understand what each category meant. Accessing information in a second language without full fluency, as many of the participants were doing, could result in a key word strategy being used to make sense of it but this could also result in nuances being missed. Information may be partially correct from their understanding and interpretation of it - and therefore only partially understood if access to it is not complete.

Tim (G1) was adamant that face-to-face discussions about dementia were imperative as this would mean that they could ask the person giving the information ‘direct questions’. Tim likened this type of service to live chat that is now available on some websites. He wanted live chat to be available in BSL as he felt he would be able to get more ‘specific information’ rather than ‘trawling through reams and reams of general information’. Wayne (G3) explored the possibility of using a video telephone service in place of a telephone helpline. He wanted to be clear that he was not talking about the use of textphones, as he was worried about communication breakdowns (when using English as a second language) if using this particular method.

5.7 Support

This section will demonstrate participants’ views on what they felt would be appropriate sources of support should they have any concerns about themselves, their families or friends.

5.7.1 The identification of support

Participants clearly identified their GP as a primary source of support. However, there were some descriptions of GPs having brushed aside peoples’ concerns about their symptoms. These comments were not in relation to potential symptoms of dementia, but other health related concerns. Kim (G2) explained how on one occasion she had been given printed information by her GP and told to go away and read it. She felt this was not a supportive approach from her GP, especially as she felt the GP should be the expert in explaining what was on this piece of paper. Kim went on to describe how the family had recently moved house in order to find a more Deaf-aware GP. This action shows the exasperation felt with their former GP and their absolute desire to have improved and accessible services.

There was a strong emphasis on friends, neighbours and family being clear sources of support. Participants felt that technology had moved forward; for example, they could text their family members to ask for assistance. Alfie (G3) explained how he had had to ask their family for support with his mum (who has dementia) to ensure his mum was well treated and able to understand, in her confusion, who her carer was. An important consideration at this point is that Alfie was a Deaf carer of a hearing parent with dementia. The
hearing family members had to intervene to explain who Alfie was and validate his presence in his mother’s home. Alfie went on to explain that he had accessed the Healthy Deaf Minds group as a source of support in his carer role, in particular as they had organised a session around carers for people with mental health problems. It is important to clarify at this point that this carer support network was not directly linked to those living with dementia, as Healthy Deaf Minds is an accessible monthly voluntary forum (based in London) where Deaf people can understand and share information in BSL. Alfie’s story will be explored more in depth in Chapter 6.

Clare (G2) explained that she would prefer to ask a member of the Deaf community who was a family member of someone living with dementia to recount directly their first-hand experiences as it would be a more empathetic, reassuring experience and they would be able to tell her what to expect. Clare added that that getting information about dementia from the Internet would be too ‘disconnected’. The sign that Clare used here was ‘disconnect’, which was signed as if she were losing touch with, or was disengaged from the information (Appendices (ii), V6). This was quite an emotive way to talk about receiving information about dementia, however this not only reinforces the previous statement that members of the same community should share information, but also that its immediacy is important in reinforcing its relevance.

5.7.2 Where to go for support if you are worried about memory issues

There were multiple layers of frustration expressed about the lack of support available to Deaf BSL users. The participants were aware of the geographical diversity of the Deaf community through their own personal experiences and therefore understood that not all services could be tailored to individual needs for support in a many different locations, e.g. there may be only one Deaf person with dementia in any given area.

However, there was a real concern that that nobody would notice when someone begins to exhibit the early signs of dementia. Diminishing social networks, particularly with other Deaf people, as a result of ageing meant that there might be less potential for this recognition and forthcoming support to happen. Annie (G1) raised the question of whether she would be able to continue to live at home alone if she were diagnosed with dementia. She was also concerned her family might not know she had developed symptoms of dementia as she lives alone. Annie anticipated that her family and friends would recognise potential symptoms of dementia but did not acknowledge that she might recognise any changes herself. She questioned:

‘…It may come as a shock to find out I have dementia and nobody told me.’

Through our discussion, Annie soon came to the realisation that ‘I can’t stay in my own home forever then? I’d have to be moved out? That sounds horrible.’

There was an optimistic expectation from Annie that neighbours would help out in a crisis, especially if you had a good relationship with them. However, it was argued by Fred (G1) that some people might not even
know their next-door neighbours and still be very alone. This shows how there may be an historical expectation that ‘hearing people will always help’, which may not always be upheld in today’s changing society as social networks have evolved over time, becoming more digital and disconnected as opposed to having face-to-face contact.

Deaf people are likely to have fewer opportunities for others to recognise their symptoms because only a small number of people sign. So, living alone is, in essence, the same issue that hearing people would face, but living alone in conjunction with fewer opportunities for any meaningful communication and social contact creates a double barrier. An example of this is illustrated with the fact that there is a Deaf person who lives alone, with a full care package for their physical care but has absolutely no communication with anyone for days at a time, despite hearing non-signing people coming into their home up to 6 times daily (personal correspondence, 2016). Also, for Deaf people, cultural neighbours are those in the Deaf community; the geographical neighbour may be of far less significance or use, without the ability to communicate well or share a common cultural understanding. This experience of neighbourhood connectedness can vary from individual to individual in the Deaf community.

In terms of seeking support for worries about memory issues, Vineet (G3) came up with the immediate solution that if there were any worries, one should visit a hospital to meet and talk to the dementia expert there, as this would be a viable way to support someone, such as a parent or a friend as soon as possible. However this would be dependent on an interpreter being available; it is not something that could be done on the spur of the moment, would require planning and hoping the hospital would fulfil its duty to have booked an interpreter in the first place.

Participants expressed their frustration with barriers that they faced in their daily attempts to identify support. There is an automatic assumption that ‘hearing services for hearing people’ are easy to access and that information and support is acquired quickly. Wayne (G3) explained how he understood support groups to work; he assumed that hearing people would quickly and easily access these groups; they would be able to telephone other members of this group and make good use of helplines to help ease their concerns. This is an interesting viewpoint from Wayne, as it demonstrates how, generally, Deaf people may compare their barriers and difficulties against the perceived ease that hearing people have, instead of considering what positive measures and resources their own community may be able to offer. It also shows little appreciation that hearing people may also experience some difficulties in accessing support too.

Paul (G2) queried how helplines or support groups would work effectively for Deaf people because of the issues of communication. He pointed out that it is the same old story that Deaf people have to travel further than most to get the appropriate support they need. Owen (G3) further described accessing support as a difficult process for Deaf people because they have to wait for appointments – there is a long delay and they have to ‘put up with the person they see’ (indicating that he felt there was no choice in being able to say they want to see someone else). Owen also described this barrier as not being given a direct opportunity for one to one support because of the usual requirement that the professional would require an interpreter.
Participants further explained their understanding of there being a prolonged wait for interpreters, which delays their access to effective support systems. In demonstration of real-life experiences, Iain (G3) explained his personal experiences in trying to set up access to a physical health support group for a Deaf client:

‘It wasn’t a problem finding the actual group, but once I mentioned the person was Deaf, there were a lot of sharp intakes of breath: “oh, we’re not sure how we are going to be able to support that”’.

A further concern presented by George (G1) was that some Deaf people do not have access to the internet or to DVDs and have negative experiences of the education system – they were therefore asking how those particular groups of Deaf people can access and understand information about dementia. George (G1) later explained that he had sat on many committees and recognised that there were many Deaf people from different educational backgrounds. He felt this could create difficulties in presenting a unified argument to meet Deaf people’s needs, also, more practically, it could mean that if a group were set up for Deaf people, other Deaf people ‘might go off track or not be quite as sensible as us’. This attitude of potential unintended segregation within the community is representative of the malignant psychology that can happen when a hearing person is diagnosed with dementia and excluded from their own communities (Sabat, Napolitano and Fath, 2004) and the attitudes of Prescribed Disengagement™ as shared in Chapter 3 (Swaffer, 2015).

Vineet (G3) was confident in his statement that it was the Deaf community’s responsibility to adapt information for other Deaf people. He suggested that:

‘You’d need to get to know them (the individual and their requirements – author addition)…adapt our language, adapt information, make it much more basic and use a lot of pictorial/visual stuff to make it accessible’.

Vineet recommended that Deaf people take on the remit of adapting information to ensure its accessibility. This also shows his (and potentially general) assumption that hearing people who do or do not sign are naturally involved at the onset of the creation of information, therefore this information will not immediately be accessible for particular groups of people within the Deaf community. Therefore, Vineet’s idea that Deaf people may create their own accessible information in their own way from their own priorities was a positive step forward for new ways of developing this specific requirement.

There was a healthy debate around the responsibility of service providers to provide information and support for Deaf people who were worried about dementia. George (G1) debated that the responsibility for setting up new services rested with the local Deaf organisations, as they are easy places to refer to; however Bert (G1) argued that this was not an appropriate expectation to have. The concept of a mainstream service provider offering support groups was not popular with Annie (G1) who described this potential solution as something that was not appropriate for her cultural Deaf needs, ‘(…) I can’t bear the thought of having a hearing person in the group’ (Appendices (ii) V7). The sign Annie uses, which is the hairs on her arm standing up or getting
goosebumps, is representative of how some Deaf people may react to the concept of mixing with hearing people in particular situations. Annie’s facial expression was one of disgust, while she was signing her absolute revulsion at this possibility. In a nutshell, this demonstrates an element of Deaf culture where it is felt hearing people would not fully grasp, or empathise, with Deaf issues. However, some participants counter-debated that it was more appropriate for hearing organisations with specialist knowledge to be the responsible provider of information; rather than asking their local Deaf organisation to collect information from dementia organisations or set up support groups. It was agreed that the specialist organisation could learn how to work with the Deaf community and with local Deaf organisations to meet the community’s particular requirements.

Participants appeared conscious that they did not know what their future options were in terms of care and support; for example, they did not know how many care homes there were that would be appropriate for their specific needs or whether domiciliary care services could meet their communication needs. They were also very aware that they did not know how many Deaf people were currently residing in care homes and whether these were fully accessible for Deaf BSL users.

5.7.3 Service expectations

Participants clearly advocated the establishment of a 'one-stop shop' where it would be run by a Deaf service that could deal with people living with dementia, those with asthma, diabetes and so on. It was felt that the Deaf service could signpost people to specialist organisations and offer support while accessing those places. However, this was interjected with concerns around funding, for example for transport, Direct Payments for carers and employability of Deaf professionals into this type of service. It was expected that face-to-face support should be offered to Deaf BSL users, that is to say, without the cultural mediation of an interpreter or other third party.

There were concerns that professionals from dementia-related services would not be trained in fluent BSL and that they would not be able to effectively communicate with the Deaf person needing support. Ursula (G1) described her personal experience of being frustrated with social services not providing the person she wanted to see (a social worker with Deaf people) for her housing needs, as the person she met eventually could only sign to level one (which is equivalent to the level of English used by a pre-schooler).

The role of mainstream organisations that were experts in dementia information was debated and compared and contrasted with the role of Deaf clubs who would provide information in BSL. Bert (G1) anticipated that RAD (a Deaf organisation based in the South-East of the UK) could initially set up support groups for Deaf people as it would be ‘easier’ that way; however, it was argued by Fred (G1) that it should be the Alzheimer’s Society’s responsibility to set up such groups as ‘the RNID and RAD don’t know about dementia’. There was an expectation that the Alzheimer’s Society would have training in Deaf awareness and BSL. It was also felt that it was important for Deaf organisations to have action points with which to move forward. George (G1) explained his priorities; before he accessed a service, it would be paramount that an interpreter would be
provided and the service would need to confirm this. However, Tim (G1) explained that while he was aware that he could find information on the Internet, if he went to a Deaf organisation for more support, he would find that people at the Deaf organisation were accessing the same internet sites for the same information, as they are ‘jacks of all trades, masters of none’.

5.7.4 Service design and limitations

It was generally expected that social workers would provide support for those who needed it. However, there was an awareness of changes in the provision of social workers with Deaf people. In the past it could be relied on that there would be specialist Deaf teams and social workers that were fluent in BSL. However, changes in how social services have been structured and services delivered in the past 5 or 6 years has resulted in the dismantling of Deaf or sensory teams in all but a very few locations (Young et al., 2010). There was an element of frustration around people without social work qualifications attending appointments instead of ‘proper social workers’ as well as hearing social workers attending appointments without BSL interpreters.

It was expected that the Alzheimer’s Society (as a result of the findings from this research project) would set up a Deaf group nationally using major cities as a starting point. However, it was argued that it would be more appropriate for the local NHS services to set up local groups working in partnership with local Deaf organisations. There was concern that the Alzheimer’s Society would not be accessible to Deaf people; indeed there was a common perception that it was not accessible currently. Tim (G1) argued that he felt it was the Deaf community’s responsibility to set up support groups and that members of the community should be proactive in doing this.

Additionally, there was a clear awareness that local Deaf organisations were not dementia experts. Ursula (G1) suggested SignHealth as another potential source of support for signposting dementia services. Age UK17 was also named as a potential source of support, specifically their coffee mornings, but there were worries about how accessible these groups were for Deaf BSL users. However, Norah (G1) positively recognised that there is a growing trend for social network sites to be identified as a source of support, as people can now set up groups on certain sites. Information can be easily accessed, discussion forums could be established and all this can be accessed remotely if you can use a computer. Tim (G1) disagreed with this suggestion as he felt strongly that computers might not be so easily navigable for the much older Deaf population, particularly if they were experiencing the onset of dementia. Nobody questioned whether information on social network fora would be reliable or correct.

There was a consensus that there should be more care homes specifically for Deaf BSL users, particularly for those living with dementia, within each county to make it easier for family members to visit. There was

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17 Age UK is a mainstream organisation that offers advice, support and befriending to older people living in the UK. [http://www.ageuk.org.uk/](http://www.ageuk.org.uk/)
mention of a care home nearby, in the same county where the discussion group was held, that provides support for older Deaf people, but Owen (G3) responded, ‘I wouldn’t send my grandmother there’ as he felt that the level of specialist care provided by this home was not satisfactory. The focus on the need for a specialist Deaf home arose because there is a scarcity of care homes that support older Deaf people in the UK (Hunt, Oram and Young, 2011) and the participants were anxious to know that suitable plans would be made for the future. They anticipated that this dialogue within the focus groups would enable progress to be made on the development of care homes that were more appropriately dispersed across the UK, which would meet their specific cultural and linguistic needs.

Jackie (G2) was adamant that the person living with dementia should always stay with their family, but Susie (G2) argued that her family had had to make the choice to send their grandmother to a care home as it has been too stressful with her absconding from their family home. Susie, a Deaf BSL user who had a background of working in mental health services, used the term absconding, therefore the use of this terminology has transferred into her dialogue here instead of the usual word, which might be dementia-related wandering (Algase et al., 2007). This is evidence of her lack of knowledge of this behaviour and the usual labels used within the dementia field. Susie has used her work-related knowledge and labelled this behaviour within a specific parameter that she is used to at work.

This discussion intensified with the shared assumptions that if a hearing person went to live in a care home, they would be content and would have effective communication strategies, as they would have access to the conversations going on around them. If a Deaf person was admitted to a hearing care home, both Owen (G3) and Wayne (G3) thought they might ‘become more depressed, give up on life, die sooner or their mental health might deteriorate’ due to the lack of appropriate communication support in the home and the potential communication deprivation that could occur while being isolated in a home where BSL is not a first or preferred language (Hunt, Oram and Young, 2011). This comment validates the concerns that are present within the Deaf community about the limited options there are with regard to care homes and appropriate levels of support.

Annie (G1) put forward her view of being grateful that the actual focus group itself had provided an opportunity to discuss these issues for the first time and to consider options for the future. It is interesting to see how Annie responded to the focus group as a source of support, even though that was not the intended aim of the session. Annie declared:

‘Well, it’s just really amazing to share (this) with everyone and have a really good discussion. And I feel I want more of this on any topic at all.’

5.8 Summary

As revealed through the focus groups, there was lots of evidence from the participants that; (i) they were very conscious of the many differences within their own community; (ii) Deaf community bonds meant there
was an expectation of Deaf people taking responsibility for other Deaf people; (iii) hearing communities tended to treat Deaf people as ‘them’ and do things ‘for them’ which is at odds with Deaf people’s own heightened sense of responsibility to each other and doing things for the whole community through each other.

There was also peer-to-peer evidence provided of the paucity of information available for Deaf BSL users about dementia, within the community, within wider networks (via mainstream organisations) and via online resources. However, there was resilience present whereby members of the focus groups supported each other in clarifying and correcting their shared knowledge about dementia. They were all aware that there was very little information available in their language, BSL, but felt strongly they could pass on knowledge to one another in a supportive way. Moreover, there was hope, that by creating this new dialogue, there would be specific provisions made, such as the Alzheimer’s Society providing information in BSL, or care homes in each region, for future generations of older Deaf BSL users.

The next chapter is an addendum, which will explore Alfie’s story of being a carer for a hearing parent in more depth. Chapter 7 will then cover the stories of Deaf people living with dementia and their families.
6. Addendum: Alfie’s Story

This thesis focuses on two streams of enquiry: the knowledge and understanding of dementia from the Deaf community’s perspective and the everyday lives of Deaf people living with dementia and of their families. You will have previously read about what the general Deaf community has understood and known about dementia in Chapter 5, and in Chapter 7, you will be introduced to Beryl, Ernest, Harold and Maggie, who are Deaf BSL users living with dementia, and their families and be invited to read their stories.

However, while generating data from the focus groups with the general Deaf community, as reported in Chapter 5, an individual story was shared that was an anomaly that did not fit into the general experience of Deaf people nor with the personal experiences of Deaf people living with dementia. This story was recounted by a Deaf gentleman who was a BSL user, and also the main carer at home for his mum who was living with dementia; the difference was that he was a Deaf carer and his mum was a hearing person who was not a sign language user. He shared with the group his personal experiences, as a Deaf carer, of dealing with hearing professionals who did not use BSL themselves, their attitudes towards him being a Deaf carer and the support he received from his family in supporting his mum. This focus group and its topic of dementia fundamentally gave Alfie a much-needed outlet to express his worries and anxieties about supporting his mum, particularly as everyone present conversed in BSL and he felt that he was in his second home amongst people who would understand where he was coming from (as previously discussed in Chapter 3).

While this material would lend itself to a future research project that focuses on the support needs of Deaf carers who are caring for their hearing family members, it was felt appropriate to record the impact of this experience here to illustrate what it is like to be a Deaf carer. This is not that unusual an experience because over 95% of deaf children will have hearing parents and sign language is rarely a shared family language (Mitchell and Karchmer, 2004). With the increasing proportion of older people in society and them living longer than in previous generations (see Chapter 2) this experience of Deaf carers of hearing parents with dementia is likely to become more common.

Firstly, you will read that Alfie talks about being a Deaf-blind person as he has Usher. There are several kinds of Usher syndrome where a person can have both deafness and retinitis pigmentosa, which causes a range of difficulties with vision and blindness. There are approximately 9,750 people who live with Usher Syndrome in the UK (Sense, 2012). Alfie was fully aware that his personal issues might cause difficulties in being able to fully support his mum.

Alfie introduced the story by discussing how he and his family had conversed with one another to explore what they thought were potential changes in the presentation of his mum. It is useful to remember at this point, Alfie is the only Deaf member of this family; all the others are hearing and do not sign:
‘I asked my family, my aunt and people like that, to clarify the information. I’ve got a sister and a brother and we were asking people what they knew about this. We asked, “is this behaviour strange, what do you think?” And other members of the family came along and said, “Ah she’s alright, she’s just a bit forgetful, don’t be worrying about it” and we asked lots of people their opinions and said “have you ever seen anything like this in your family?” Lots of people sort of tried to pretend it wasn’t happening, they said she was ok but we were sure there was something was wrong until eventually it was recognised that yes, she was experiencing something like dementia.’

Alfie then shared the realisation that his mum would need an assessment with the psychiatrist and his anxieties started to emerge. These were linked to having the ‘right’ people around her if she was diagnosed with dementia, and specifically he felt worried that he would not be up to the task:

‘When my mum met up with the psychiatrist I was like shit, you know, what’s going to happen in the future when she got that diagnosis? I had to ask for help from my family because I didn’t know what to expect in the future and I needed that help and support to make sure my mum was well-treated and looked after because I couldn’t do it myself; my brother and sister weren’t able to help me. I’m Deaf, I’ve got Usher, you know, what was I supposed to do?’

Alfie, who is in his mid-forties, believes that he has limitations in himself in terms of being a potential carer. However, his deafness and Usher are necessarily the core issue here; it is more his acknowledgement that he does not fully understand dementia and its symptoms and he is aware that he does not know how to support someone living with dementia. Additionally, the family has conflicting thoughts about what is happening to their mum – up to this point; they see their mum as just being forgetful and not something to be worried about. Alfie elaborates further:

‘And of course mum had been diagnosed by then or at least we’d recognised that there was an issue but we were lost. Whilst we knew about issues to do with deaf-blind services and Usher services, we certainly didn’t know what to do with my mum so we agreed perhaps we should go to a psychiatrist and it was really upsetting and the process started like that really. People did eventually get in touch with us with help but it was a long, slow process and eventually it became clear. It was from there really that things slowly started to happen. So last year professionals / services started to get involved and they started to formally assess mum, provide equipment and so on, and it was at that point that more of the family started to accept and agree that actually stuff was happening for her, she did have this condition. It wasn’t absolutely the most terrible thing because yes there was some support around, but she has her good days and bad days, you know, times when things are better or worse for her.’

Later on, Alfie shared the insight that his mum’s dementia had deteriorated to the point that even though his mum lived in their family home, she did not recognise her surroundings anymore. Alfie appreciated how
stressful this was for her and described an incident when his mum was confused about who he was when he tried to speak to her while she was trying to leave the house one night:

‘Her life had changed, she was at home and at night I’d come down after getting ready for bed and mum would be opening the door and I’d say “oh no you need to close the door.” I would say “I’m Alfie” and she would say, “Who are you?” I was having to say to my mum “I live here, I’m Alfie, don’t you recognise me?” and she wasn’t recognising me, it was shit, it was awful, really bad. She nearly said, “Get out of the house” and I was waiting for this negative response and I was really crapping myself hoping she wouldn’t say that. She said, “oh your hair is long, your hair is long, I don’t recognise you” and I was like “phew, so you kind of recognise me”.‘

Alfie ends this dialogue by explaining that he’d had to make contact with his (hearing) auntie to speak directly with his mum so she could validate who he was and why he was in the house:

‘I had to get my aunt to come and say, “Look, can you tell mum that this is who I am.” So I needed support.’

Alfie responds to the situation on the basis of communication difficulties – his mum does not sign and he does not speak well. It is much harder for him to disentangle that from whether her lack of recognition is actually associated with her dementia, rather than with a communication breakdown, which is some ways is easier to process.

While members of the focus group were being asked about access to services, Alfie was fully aware of the local services in his area available for his own support, but not specifically for people living with dementia, like his mum:

‘Basically what happened was after we recognised that mum had this issue we were stuck; we didn’t really know what to do, what was the next step? So yes, it was easy enough to get on the Internet, we had time to have a look at that but it was what actually do we do? Were there services that we could get? I mean in my area, there were Social Services; we had a deaf-blind services team and a person from their team came along. We knew someone from that team, and we met them, discussed the issues that we thought we were going to have in our family; we wanted to know who to contact and what to do next.’

Alfie determined there was a shift in how he would usually obtain and understand information – he knew of local services that could meet his own needs, however, he struggled with knowing where to go and who to speak to about his mum. He tried his familiar support services first because he knew they could communicate with him but they would not necessarily know about dementia. It was also troubling that he could not converse directly with his mum about what to do as he felt her decision–making capabilities were not the same as they used to be. We have to remember at this point, Alfie has Usher Syndrome and his
mum would have been the key communication guide throughout his life as he lived with this dual sensory loss. To have experienced the many changes in his mum’s role with the onset of dementia and also the change in his role from being a child/adult with additional support needs, to becoming a primary carer with his own specific needs for his mum would have been a twofold setback for Alfie:

‘I knew that there were things out there but then how did I apply for them? What was I then supposed to do? What did it mean to me? Who was I supposed to contact? How many people am I supposed to contact and how many different organisations do I need to reach out to? I was very confused with the information and it took a lot of time and I felt quite burdened with it as well; I didn’t really know which avenue to take. I’m at home with my mum now; I’m trying to sort things out. I need to give the organisations the proof of how my mum’s coping at home and sometimes I forget things because I have to deal with life. I can’t ask my mum for the information because she’s got dementia herself and she won’t remember everything so I’m kind of like in a silly situation.’

As Alfie already had this level of contact with Adult Social Care Services in his area, he felt empowered in being able to ask them directly for support, knowing that he did not need to start from scratch in explaining his own needs first:

‘I contacted Social Services and had a chat with them and explained the situation, that I was a registered deaf-blind gentleman and that my mum’s got dementia, that we’re both at home and I really needed the support. We were looking at what support they could then offer. I was really worried about being there at home on my own, the risks that I was facing. We had to go through a sort of checklist and it was agreed that we’d have to look at a care home and that was the last thing I wanted for my mum.’

Alfie was very aware that he was the main carer for his mum and that he shouldered a huge responsibility in caring for her:

‘I myself felt a bit lost, you know, as her son. I’m still my mum’s child. I’ve obviously got aunts and uncles around, but it’s just myself making that decision, sending my mum to a care home and everyone blaming me saying, “that was a bad decision, you couldn’t be bothered to look after your mum”. So I had to ask my family to give me the help that I required and also to give me their perspective on it, but I was then on my own. I had to make that decision. Social Services agreed, you know, that maybe the next option is a care home and I was relieved about that but I needed to reconcile myself to the idea.’

Finally, Alfie shared with the group that there were solutions being offered and correspondence was taking place with a local branch of the Alzheimer’s Society. Alfie was aware that his mum’s safety at home was paramount but struggled with agencies’ lack of cohesion in appreciating that he was his mum’s main carer when his identity was more readily understood as someone who was being cared ‘for’ as a Deaf-blind adult:
'There are all sorts of considerations about her pension and her financial situation and so on, when you make the applications. There is a whole raft of things that have to be covered before you can get help. We've had to get safety alarms put in; we have to think about her safety in terms of electrical things in the house. My uncle is quite a good help as well in contacting people like the DWP\textsuperscript{18}, making phone calls and so on, but my mum, it's really difficult to explain things, I'm asking the DWP things but they won't discuss information with me even though I'm saying "I'm her son and she's got dementia so she can't come on and discuss it with you" – it's really difficult, really problematic getting the right support. For now, we're just getting on with it. We're in touch with the Alzheimer's Society but the problem now is talking about services; she's got very complex needs so we're trying to get the right funding to try to get my mum to a day centre. That's actually worked quite well but we have to have the assessment first, then you have to apply for stuff, then you have to pay for it and then get the funding back.'

In summary, Alfie has very kindly shared his experiences of caring for a hearing parent living with dementia and the everyday uncertainties that this can bring, being a Deaf BSL user and on top of that living with Usher. He shows resilience in understanding how Adult Social Care Services operate because of his own needs; therefore he has the prior knowledge of how things should be carried out. Alfie is very respectful of his mum in that he appreciates how life is now different for her and is anxious to make sure she is as comfortable as possible. However, the barriers he faces in being a good carer and doing right by his mother as he wishes are highly complex and multi layered as represented in Figure 3:

\textsuperscript{18} DWP is the Department of Work and Pensions. Their work can be found here: https://www.gov.uk/government/organisations/department-for-work-pensions
There is a complete role reversal in that Alfie has now become the main carer for his mum, who used to be his main carer (or communication guide).

Alfie now relies on his family to support him and communicate to his mum for him (when it used to be the other way around).

Have the family considered and resolved their new role(s) in supporting both Alfie and his mum?

As a Deaf person, Alfie has limited access to understanding and knowing about dementia.

Social Services are aware of Alfie's needs, but do the same professionals understand and appreciate the needs of his mother who has dementia?

Are there any dual service provisions available, that allow Alfie to fulfil his new role?

Alfie is unable to communicate well with his mum because BSL is not their shared language.

When they have a communication breakdown, is this because of his mum's dementia or because they don't share the same language?

Are his mum's usual lexical choices that she used to make for Alfie altered because of her dementia?

Language and communication

Role assumptions

Resources and support

Family

Alfie is now seen as vulnerable and cared for, not as a potential carer (by Social Services, not his family).

Alfie now has the loss of everyday support and clear communication from his lifelong carer.

Alfie himself assumes that he cannot be an effective carer because of his Usher, not because of the onset of his mother's dementia.

Figure 3: Representation of the intersectionality between Alfie's needs and his mother's needs.
In summary, Figure 3 shows the different complex layers that need to be considered in Alfie and his mother’s current lived situation. From the dialogue shared in the earlier sections of this addendum, Alfie’s awareness of differences in language and communication between him and his mum are exemplified by the fact that his mum is no longer his guide because of the onset of her dementia. Whenever they misunderstand one another, is this now due to his mum’s potential changes in her usual communication strategies or simply because Alfie is a Deaf BSL user and may not always understand his mum’s words as he attempts to lip-read her? It may be that Alfie’s mum’s language could have changed in that she has started to talk to Alfie to her more usual way of speaking, as she may have forgotten to clearly enunciate her words as she usually would for Alfie while he is lip-reading her.

Additionally, Alfie recognises himself that he does not have a lot of access to appropriate information about dementia in his own language, BSL. Alfie’s care/caring needs are now split into two. He is used to being the one that is cared for, by his mum and other family members, but now recognises the move into the position of being the main carer without the appropriate information available in BSL about how to support someone with dementia. How does Alfie ensure that his needs are met, that his mum’s needs are met and which need would be first priority? These questions would also be posed and offered resolution by any social service provision in his area, as they would need to explore how they would clearly prioritise Alfie and his mum while ensuring they are both safe in their own home while maintaining a positive quality of life.

In Chapter 7, you will read Beryl, Ernest, Harold and Maggie’s stories, which will give an insider perspective on what living with dementia is like as a Deaf BSL user, with parallel contributions from each of their carers.
7. Findings - Interviews

7.1 Introduction

This chapter draws on the interview data (Study 2) and will explore the experiences of Deaf people living with dementia and their families. Themes concerning everyday experiences, diagnosis, family and community support and service provision will be expanded. There are two tiers to the presentation of these findings. Tier one analyses these data on Deaf participants’ terms, paying attention to what they decided was important both in terms of content and how they chose to tell their stories. Tier two examines the context and inter-personal dynamics of the relationships that framed the interviews and what can be learned from the researcher’s observations of these. The findings will be presented using three approaches; thematic analysis, storied stories and situational analysis. A discussion will then follow these findings in the next chapter relating them to the broader theoretical literature and considering the implications of this new knowledge.

7.2 Introducing the families

In line with the research protocol, all names have been changed and all locations have been deliberately de-identified. No regional information has been shared, as this would make identification of participants easier in the study in such a small community. Genograms have been used here to introduce the structure of each family unit. The first diagram shown has a description of what each shape means and this remains the same for all diagrams of the family structure. In addition, there are drawings of each room as it was when we met for our interviews, which demonstrate where each person sat down and where they were in relation to one another, including the researcher.

7.2.1 Beryl and Sheila

Beryl, 79, is a Deaf BSL user, a retired seamstress in a factory, and lives with her daughter, Sheila, who is hard of hearing, and her son-in-law, Mark, who is hearing, in their family home. She has two grandsons – one is away at university and much missed. Beryl has been living in her daughter’s family home since her diagnosis, having previously lived alone in a flat near the seafront. Her husband, Malcolm (Deaf) passed away 12 years ago. The main method of communication between Beryl and Sheila is Signed Supported English – which is not a language, but a method of using spoken English and using signs in English word order - and some BSL. Beryl is aware of her diagnosis and its impact on her everyday activities but remains resilient in wishing to maintain her independence within the family unit.

The structure of the family unit is shared in Figure 4:
Figure 4. Beryl’s family

- The abbreviation m. means married.
- Squares refer to men and circles refer to women. If there is a cross through the square, this means the person is deceased.
- If the name is in bold, this means the person participated in the interviews.

As Figure 4 demonstrates, Beryl is now the only member of the family who is a BSL user and culturally Deaf since the loss of her life partner 12 years ago. In her current living arrangements, her first language is not used. This is a very big difference in her life from some 40 years of marriage to her Deaf life partner that has preceded this point.

In both interviews, the seating arrangements remained the same as illustrated in Figure 5. As discussed in Chapter 3, physical location of individuals in conversation is important for clear communication in a visual language. More will be discussed later about how this structure was a factor in communicating with one another throughout both interviews and what it might contribute to understanding Beryl’s everyday experiences of living as a Deaf person with dementia and those of her family.
In the diagrams of seating arrangements, the legend is:

- D = Deaf
- DPwD = Deaf person with dementia
- Int = interviewer
- VC = video camera

7.2.2 Maggie and Teresa

Maggie, 86, is a retired cleaner within the public sector. She lives alone in a mainstream sheltered housing complex with 24-hour care support. Maggie has three children but only maintains a strong relationship with one daughter, Teresa. Maggie has grandchildren but does not see them due to the estranged relations with her children. Teresa is hearing and lives about 30 minutes away from Maggie. She visits her mother at least once a day, sometimes more frequently, depending on her work commitments. The main method of communication is BSL between Maggie and Teresa. The carers in the housing complex do not sign at all. Maggie does not believe she has dementia and struggles with what she regards as the enforced lack of independence that living in this complex creates for her.

The structure of the family unit is shared in Figure 6:
Figure 6: Maggie’s family

These living circumstances mean that Maggie was living in a linguistically impoverished environment, where nobody shared her language; this is a marked contrast to her previous living circumstances where BSL was used everyday around the house with a partner and friends and when she attended Deaf events very regularly with a wide circle of Deaf friends. Prior to her diagnosis of dementia she was living alone following the death of her partner but in her own home. Now she is living alone, not in her home and she is living with minimal exposure to communication in her own language despite her own retained abilities to communicate well in BSL. The progress of her dementia has not yet significantly reduced her linguistic resources for social conversation.

In the first interview, the seating arrangements were as Figure 7.
The researcher could not sit by the table, as this would have meant they were out of shot for the video camera, which was set up in that corner. This then prompted the seating arrangements in the diagram.

However, for the second interview, the seating arrangements were different, as Maggie wanted the researcher to sit next to her, as illustrated in Figure 8.
More will be discussed about how Maggie interacted with the researcher on this occasion, as we were able to use some technology together, which added a new dimension to our dialogue. Maggie sadly passed away in March 2015.

7.2.3 Ernest and Libby

Ernest, 84, a retired BSL tutor and assessor, and his wife, Libby live together in a retirement flat. They have been married for over 50 years and are both Deaf. They have recently relocated to this complex from another major town in the UK where they had lived for over 30 years, as they wanted to be nearer their two hearing children after Ernest’s diagnosis. They also had one child who died in his late teenage years. Ernest and Libby have grandchildren who visit often. The main method of communication is BSL. Their hearing children also use BSL with their parents. Ernest has a very strong interactional relationship with Libby where he is aware of his dementia but will rely on Libby to ‘fill the gaps’. In this sense dementia is shared between them as most aspects of their married life have been for such a long time.

The structure of the family unit is shared in Figure 9:
Ernest was still living in his own home with his life partner in a BSL rich environment where both shared a common language. Although the diagnosis had prompted some changes, such as moving house to be physically nearer family, it had not fundamentally changed the linguistic environment in which he lived nor the status of being part of a couple. Both interviews were held in Ernest’s favourite part of the house, the conservatory, which was just off the kitchen. He and Libby sat in the same chairs throughout. Ernest sadly passed away in October 2015.
7.2.4 Harold, Pearl and Rebecca

Harold, 87, a retired carpenter and joiner, and his wife Pearl live in the family home where they have lived for over 50 years. They are both Deaf. They have two children, one is hearing and one is Deaf. Owen (hearing) lives nearby and Rebecca (Deaf) lives about an hour away. Owen visits often – more so since his Dad’s diagnosis. Rebecca visits once or twice a week, but is more involved from the sidelines in communicating with the family GP, organizing interpreters and appointments with the memory clinic. Harold and Pearl have one grandchild but they are not in contact with them. The main method of communication for the whole family is BSL. Harold is aware that he has dementia and is clear in how his diagnosis has impacted on his family, communication and service provision.

The family structure is shared in Figure 11:
Harold was living in a BSL dominant environment where everyone shared a common language and was living in his own home with his life partner. This arrangement is exactly how it had been for the 60 years prior to his diagnosis and the opportunities for social interaction and conversation in his preferred language have not changed since his diagnosis.
Figure 12: Seating arrangement for Harold, Pearl and Rebecca

Notes: Harold’s chair was moved by Pearl so he could see better; the couple had two TVs in the same room as they had different preferences; Rebecca was off-camera for the 1st interview, and then joined us for the 2nd interview.

During the interviews, the room was specifically arranged so that Harold, Pearl and Rebecca could all participate. Harold remained in his favourite chair, which was not moved, while Pearl and Rebecca’s armchairs were moved forward so that the face-to-face dialogue was held in a circular shape with maximised options for visibility. Harold sadly passed away in October 2013.
7.2.5 Linguistic Environments

A summary of language continuities and changes since the diagnosis of dementia is laid out in Table 4:

<table>
<thead>
<tr>
<th>Person</th>
<th>Their language environment remained similar?</th>
<th>Their living arrangements remained similar?</th>
<th>They understand they have dementia?</th>
<th>Is their everyday communication in BSL?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beryl</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>Maggie</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Ernest</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Harold</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>

Legend: N=No, Y = Yes.

Table 4: Language continuities and changes since their diagnosis of dementia

It is clear from Table 4 that for Beryl, Ernest and Harold, while in their native environment (a signing environment they had lived within for many years), their understanding and subsequent dialogue about living with dementia was empowered and within a ‘safe’ context. Maggie was the only one who did not understand that she was living with dementia, but she was also the only one who was living in a supported living accommodation with no BSL support in place.

7.3 Storied Stories

As previously discussed in Chapter 4, storied stories are a way in which the experiences of a person that have constituted ‘data’ can be re-represented in narrative form (McCormack, 2002). In this section, the second component of this analysis will utilise the perspective of storied stories to demonstrate Beryl, Ernest, Harold and Maggie’s experiences of living with dementia. Each have a different take on what it means to them which come through in how they present and what is observed through the researcher re-telling an extract of their story.

7.3.1 Inside my own bubble: Beryl’s story

When I met Beryl, she was 79 years old and a strong, active member of two Deaf clubs. She was aware that she had been diagnosed with dementia but did not express any strong feelings about her diagnosis or describe its impact on herself or her family members around her.

Instead, Beryl described her current situation to me as a comfortable existence; she is happy living with her daughter and their family but she did not recognise or empathise with the possible impact of her diagnosis on Sheila and the other family members. Beryl came across as an independent person firmly
anchored within the family unit and proud of her varying roles. This is how she wanted to be seen. To be the grandmother of Sheila’s two sons, as well as Sheila’s mother was an important part of her identity; so was being a member of the Deaf community. Like many Deaf people of her generation, Beryl has two families – her home family and the Deaf community – both are a source of pride and make her who she is. None of that was lost for Beryl despite her dementia. Still a humorous woman, she was also at pains to point out she had other identities too, ‘sometimes I am just the plain old tea-maker for visitors!’ she quipped.

Beryl was determined to stay as active as possible. She regularly went out with her friends and family and was still maintaining her regular trips to two Deaf clubs in the area and going on annual holidays (which are organised by the Deaf clubs). Beryl spoke of her Deaf friends as her equals but also with recognition of their roles in supporting her to get on with things in her everyday life. In our dialogue together, Beryl came across as being nonchalant about living with dementia; it was as if she fitted it in around the other parts of her life that were important to her. It did not define her. The trouble was that other people did not see it that way.

Other people in the local Deaf club kept checking on her to see if she was all right. She explained they seemed to think she had changed, but that is not how she felt. It was so exasperating! Beryl described these kinds of interactions with quite clear frustration. When she explained a typical encounter to me with her ‘old friends’ (signed ironically) she adopted a form of signing that was like a role-play being acted out. She might be one of the characters but she was also standing outside of the play and saying ‘look at what they do to me’:

‘Me, just sitting there at the table, with my cup of tea, just minding my own business (unspoken – just pottering along) then they ask me every week, how are you? Every week the same. I say oh, I’m fine, fine, fine (using the same handshape for the word (in a rolling way) THUMB-UP-OK. They then reply, “OH-BUT-YOU-LOOK-SAME —SIGN-SAME”. How do they expect me to look? Why are they looking for signs that I am different? It’s me! I am the same! Treat me the same.’

It was clear to Beryl that she had not changed as a person with the onset of dementia. However, she felt that she was under unnecessary scrutiny from her local community when she was quite happy just getting on with her routines and enjoying her environment where she felt no different to anyone else. Whether in reality she had changed and her friends were noticing this was irrelevant. For Beryl living with dementia involved a strong conviction that she was just the same as she always had been and it was other people’s problem if they could not see that.

7.3.2 Once a BSL tutor, always a BSL tutor – Ernest’s story

When I met Ernest he was 84 years old. He quickly explained that he had worked for the same company all his life until he retired in his mid-50s. He was the only Deaf employee in all that time. Upon
Ernest was ready for a new challenge and became a BSL tutor in his region. He was amongst the first generation of Deaf people who had a route to becoming qualified to teach their own language to others as part of a new national accreditation scheme for BSL tutors and learners. These were real pioneers in a time when BSL was only just being seen as a ‘real’ language. It would be another 20 years until the Government recognised that officially (as discussed in Chapter 3).

Ernest was very well known and earned respect and recognition as a good tutor amongst his other Deaf BSL tutor colleagues. Throughout both interviews, Ernest shared how proud he was of his role as a BSL tutor and his extensive knowledge of BSL. His reputation was important to him and at the time I met him he was able to see the difference between how he had been as a BSL tutor and how he was now living with dementia and what it was doing to his language. This meant that he was very keen to ensure that confidentiality would be maintained – in his words, ‘they won’t know about me, will they?’ – ‘they’ being his Deaf counterparts. He wanted people to remember him, as he was, not as how he is now. It was a crucial part of the consent process and subsequent interviews that Ernest felt supported with his anxieties in how he would be represented to the outside world as someone living with dementia.

Although Ernest has experienced many changes since the onset of his dementia, he remains firmly a BSL tutor and an arbiter of his own language. In our initial dialogue, he corrects a sign that I use when posing a question to him. It doesn’t matter to him that I too am a Deaf BSL user – he is still the master of his language, BSL. He does this with a gentle but firm manner and has no qualms in ensuring that I have used the right sign. I can imagine what it must have been like to be taught by him. Later on while we are talking about Ernest’s career history, he feels comfortable within his own language to make an insider joke, with someone who shares the same language as him, about the context in which he uses an erroneous sign. Ernest uses the “wrong” BSL sign to describe his job, smiles wryly and self-corrects. He was explaining about how he used to work at the sack factory, but at first he used the sign that refers to sacking someone from their employment, rather than the sign for the noun ‘sack’. He continues with a smile on his face, ‘The Deaf always get this sign wrong, don’t they. It’s ‘sack’ (as in canvas/wool) isn’t it?’ I nod and smile too. We share the knowledge of a common mistake together.

The fact that Ernest is able to use this sign and then correct it indicates that he maintains a tenacious grasp of both BSL and English and is able to switch between both, with an injection of wry humour too. He has retained the ability to ‘monitor’ himself in his first language and share this outwardly with comfort and resilience. He knows he has dementia and he knows it is changing his language and communication. Nonetheless he hangs on to the strength of his identity through his language and the employment it brought him as a fundamental part of who he is. It is so essential to him that the thought that anyone might see him without the full command of BSL he used to have is a source of great anxiety because it would rob him of part of who he knows he is.

Harold and Maggie’s stories have been previously published (Young, Ferguson-Coleman and Keady, 2014b) and these have been reprinted with confirmation from Elsevier (see Appendix O).
7.3.3 Knowing from the inside: Harold’s story

‘When I met Harold he was in his 80s. A proud member of the Deaf community all his life he had been brought up in the community and passed on its language and culture to his own Deaf and hearing children. I met him at home with Pearl, his wife and Rebecca, his daughter, whose approach to his care and support was to keep him at the heart of the family, still being dad, still contributing to the vibrant life of the family and the wider Deaf community. He was not so much cared ‘for’, as cared ‘with’. He was very keen to support the research study contributing all he could about how he felt now, living with dementia. From his point of view, his involvement was ‘for us’, the wider community of Deaf people and those Deaf people who would come after him and face dementia, and he knew it was not ‘for me’.

Like many people in the hearing world, Harold had times when he self-consciously knew he had dementia and could for a short time stand outside his own condition, consider what it had done to him and reflect on the person he was now and the person he had been. One such moment came during our second visit to the family. I have chosen to record it here both to illustrate the vivid dimensions of how his moment of reflection is communicated through the unique resources of a visual–spatial language (BSL), and to caution how easily such a profound expression of identity could be missed if not seen with Deaf eyes. First it is important to understand a specific feature of sign language grammar before explaining how Harold used it.

BSL like all signed languages throughout the world, make use of multi-channel signs. These are complex utterances which combine at one and the same time a characteristic mouth pattern and facial expression, a specific gesture located in space and/or on the body and a precise movement. When produced together they augment and extend the semantic content of what someone is saying by layering it with resonances, which are inferred from the multi-channel sign. Notoriously impossible to translate, they are a fleeting complex expression in BSL that might require three or four sentences in English to render its meaning precisely. There are common characteristic sets of multi-channel signs which reoccur to indicate, for example, “something that was once present and was expected to be seen but is now missing”. Other multi-channel signs are coined in the moment spontaneously and for specific purpose to express a multi-layered meaning in one fleeting and deft movement. As quick as one might click ones fingers, the multi-channel sign is there then gone, but it is powerful and precise. It was also what Harold used to open a window and allow us in to his awareness of how dementia was affecting him and more importantly his identity.

Sat in his favourite chair, he was telling me about the lessening of his sign language, his hands making the shape and movement to indicate someone signing. But then he broke eye contact with us, looked at his hands and looked back at me — holding my gaze. His shift in eye contact had told me he was observing his own expression and this “thing called signing” had become objectified as he asked me to look too. His hands were both the expression and the object of that expression – seeing sign language as of himself (produced through his body) and about himself (he could comment on his own language).
He signed “disappeared”. Then he made one of his hands flat and horizontal and slowly let it fall over the front of his upper body in the middle of his chest, whilst on his face his eyes were downcast and his mouth made an oval ‘o’ shape whilst gently exhaling air. That was the multi-channel sign, produced in a second and easily missed but layered with a profound insight.

The middle of the upper body in BSL when combined with a handshape which moves vertically is the site of the most common expressions concerning “role”, “personality”, “self’, ‘confidence’ and ‘being’. A downward movement, in some instances, indicates loss or decrease but any potential ambiguity was more clearly communicated as an intended meaning of lessening and/or loss because of the simultaneous mouth pattern. The oval ‘o’ shape is commonly used to indicate something small or becoming smaller particularly when combined with breath exhaling, as if a balloon were deflating. In contrast, breath inhaling commonly indicates acquisition and growth.

In one brief expression Harold had told me that he was referring to his language, his sign language, that was a fundamental part of his being, and that he knew this was slipping away from him and that this was a cause of deep sadness and despondency. Dementia has ‘got him’ he was losing his battle to retain his language.

From a cultural point of view, sign language use is a primary marker of cultural affiliation. Being deaf is not visible to others without an external referent and for the Deaf community this is sign language. In Harold's lifetime, he has seen the wider world make a transition from assuming BSL is a form of pantomime or visual English to an appreciation of its independent and complex linguistic status. He has seen the Deaf community cease to hide their language, or be concerned about the stigma it might attract, and become instead proud and highly visible people within wider society. Signing is absolutely core to his identity and being. Its loss and his conscious awareness of it slowly being carried away as if on a breeze over which he has no control, was deeply moving to observe.

However it was witnessed within the signing environment of this interview where the researcher, Pearl and Rebecca all shared a common language and cultural background. In another context, the complexity of Harold's expression might have been identified as non-linguistic and it was very quick. Yet Harold was making his views known, expressing his personhood and firmly asking for it to be recognized as a contribution to our understanding of Deaf people's experiences of dementia. He shared his story with resilience. The signed interview was his opportunity to do so.’ (Young, Ferguson-Coleman and Keady, 2014b).

7.3.4 Living with the red cord: Maggie's story

‘When I met Maggie she was in her late 80's and had been a BSL user all her life. The Deaf community was the place she felt she belonged. Now she has dementia and lives alone in sheltered
accommodation. She is the only Deaf person in the complex of flats. Carers visit her twice a day to make sure she has her medication and in the corner of the room hangs the red cord.

But to Maggie they are not just carers; she is quite particular in pointing out they are ‘hearing carers’. I ask her about them and in one breath she tells me they are ‘nice’ and in the next with very demonstrative signing, DOOR-FLASH-ME-WALK-OPEN-DOOR-SEE-SHUT DOOR HARD. She clearly does not appreciate having to answer the door to hearing parties who cannot sign. The flashing doorbell that has been a part of her life always, still takes her to the door, but when she opens it there are now people who cannot sign, who cannot communicate with her and yet she still must open the door. Where has her native language gone? Why does the flashing doorbell no longer bring signing friends?

We sit down and I ask her about the red cord. It hangs in the corner of the room as it does for every resident of the sheltered housing complex. RED-CORD-THERE-WHAT-FOR? I ask, pointing to the exact location over and beyond her right shoulder. But she does not look. She does not follow my finger with her gaze as Deaf people usually do when asked a question like that. Instead she looks away from me and from the red cord and looks downwards. Without a shared eye gaze, our interaction ceases. She is telling me with her glance that this subject is closed. She is not going to discuss the red cord with me. To her it was not a source of security, something that could be pulled to attract the help she needed. No, it was just another way in which hearing people with whom she has nothing in common, with whom she cannot communicate, turn up on her doorstep. No reassurance there, only more frustration. In this non-verbal, fully linguistic response, Maggie is saying to me, ‘RED-CORD-THERE-WHAT-FOR?’ (Young, Ferguson-Coleman and Keady, 2014b).

Both Harold and Maggie’s stories are available (and re-enacted by a well-known Deaf actor and actress) in BSL on the web site www.deafwithdementiahub.com where they have been used to support the Deaf community’s awareness raising and knowledge about dementia.

7.3.5. Summary

These four storied stories have brought to life the ‘voices’ (in their hands) of Deaf people living with dementia in a way in which the previous analysis of the content of their interviews cannot. I see four very different approaches to dementia in their lives, which reflect also four different facets of personhood:

- I am still who I am and will work around the dementia. It is other people’s problem if they think I am different (Beryl) [Personhood as the maintenance of identity]
- I will not let dementia take away from me who I was. People must remember me as I was because that is who I am. (Ernest) [Personhood as recognition of continuation of previous identity regardless of current differences]
• I know dementia is eroding my identity because it is eroding my language. It robs me of myself. (Harold) [Personhood as acknowledgement of the person disappearing]

• The problem with dementia is the hearing people! They are not helping me. I will stand firm against this as I always have done. (Maggie) [Personhood enacted as attitude and resistance]

These kinds of reaction and response are not unusual amongst the broad range of people who will live with dementia. However in the case of Deaf people, they are largely hidden experiences and hidden responses because they have not been documented before. By using a storied story approach, hearing readers unused to Deaf culture, community and language are being shown some added information to understand the significance of what Beryl, Ernest, Harold and Maggie are telling us.

7.4 Themes

The following themes are addressed within the ‘normal’ context of being a Deaf person within a hearing majority world. Participants would often refer to dialogue/communication with a hearing person who cannot sign as ‘normal’ and not something that is ‘different’ (as discussed in Chapter 3). The researcher and the Deaf interviewees share this epistemological position, which assumes that certain perspectives and assumptions are implicitly ‘known’ (as this did not need to be explained to the Deaf researcher) and the narrative is framed within this shared experience. Therefore, in the presentation that follows, explicit references and connections will be made for the reader who does not share this Deaf experience with additional explanations offered of what may not be explicitly stated but is implicitly shared in order to illuminate the implications of the participants’ stories.

7.4.1 The process of diagnosis – language and interpreting

None of the participants had an assessment connected with the process of diagnosis of dementia that was provided directly in their first language, BSL. All but one participant had their assessments carried out without a qualified BSL interpreter present. Instead, a family member, in all three cases, their hearing or hard-of-hearing daughters, relayed the information from the healthcare professional to the participant. This in effect meant that an unqualified person had to translate spontaneously, and without prior knowledge of, a standard instrument, such as the Mini-mental State Examination (Folstein, Folstein and McHugh, 1975). This meant that the family member was put in the position of translating without necessarily appreciating what might be important in that instrument and, therefore, why one translation might be preferable in comparison with another. It also meant that a carer was required both to fulfil that support role and to take an active part in a process that was leading up to a diagnosis of dementia in respect of their parent. The use of a relative and/or unqualified interpreter is also contrary to NHS guidelines in draft (NHS England, 2015). Two participants had a BSL interpreter present at their second assessment (after intervention from their children who raised an objection to the lack of the presence of a BSL interpreter for their family member). While this is not acceptable as the family members were not qualified BSL interpreters, and even if they were, it still would be a conflict of interest, it unfortunately is a
common occurrence (SignHealth, 2014) not to have an interpreter present during the assessment process as reflected in these interviews.

Each family had their own way in how to deal with this scenario. The hearing professional’s admission that this was the first time they had ever met a Deaf person in their clinic contributed to Sheila’s decision to relay the assessment questions, as she felt it was important to offer some cultural mediation between the hearing professional and the questions asked. However, due to the lack of awareness of the hearing professional around Deaf culture and the structure of BSL, the person felt that Sheila was interfering with the questions asked and giving the answers on behalf of her Deaf mum:

’The professional was asking Mum what season it was. I knew Mum wouldn’t understand the word ‘season’ so I thought, well I’d ask her ‘it’s summer now, isn’t it Mum?’ to which Mum replied, ‘no, it’s winter now’, which was the right answer. The professional wrote on the notes ‘answered with help from the daughter’. I totally disagreed with that.’

In addition, Sheila struggled with directly informing her mother of her diagnosis. The hearing professional was unable to communicate directly with Beryl, so it fell to Sheila to decide how this information was imparted. Sheila was very upset at the actual appointment and therefore decided to wait until she and Beryl had returned home:

’The doctor told me to tell Mum, “Sorry, you have got Alzheimer’s”. I told him I couldn’t tell her that, I was too upset and I also knew Mum would ask what it was (that she wouldn’t know what Alzheimer’s was). I told her I’d explain to her when we got home.’

Harold explained that he went to the first assessment with his paid carer, Glenda. Glenda was a Deaf woman who was providing community care support to Harold once there were concerns about his memory issues. She was paid via Direct Payments and sourced through the local social services department. Harold felt it was more appropriate for Glenda to come to this assessment, as he did not wish to rely on Pearl, his wife. Although she respected his wishes and did not initially attend these appointments, Pearl felt quite aggrieved by this decision, as she felt she had a lot to contribute to explaining the changes in Harold’s behaviour.

Harold was disappointed that there was not an interpreter present at the first assessment, which meant that the professional at the appointment was very difficult to communicate with. However, during the second interview, Pearl was pleased to elaborate that Harold had agreed for Pearl’s support at the

19 The Care Act (2014) stipulates that Direct Payments are a government benefit where the person receives the benefit into their bank account and they manage this themselves in making choices and paying their carer or support service directly. 
hospital as they had been informed that Glenda was too ‘controlling’ and she had been asked to no longer support the family.

Rebecca shared with the researcher that she had been able to identify an interpreter (with personal experience of supporting a parent with dementia) for the second appointment for her father, Harold. However, this particular interpreter was very concerned about Glenda who had been present at Harold’s prior hospital appointment and decided to make direct contact with Rebecca. This is not usual practice for an interpreter as they are bound by a code of ethics, which instigates absolute confidentiality unless the interpreter is concerned that the person may come to harm (NRCPD Code of Conduct, 2015, p. 220). The interpreter made it clear that they had asked Harold’s permission to make contact. The interpreter felt that the independent carer was too controlling and that they were overtaking the assessment process without allowing Harold to express himself at his own pace. This independent paid carer had also been booking interpreters of her own preference, without informing the family of who these interpreters were. Rebecca explains:

’I was suspicious of the carers’ intentions but she denied it all. I had to sort it all out and explain to her that my mum (Pearl) was perfectly capable of booking interpreters herself.’

Rebecca and Pearl evidently felt that this was a drain on their time, dealing with the consequences of ensuring that Harold had the appropriate support at his appointments.

The other participants did not discuss any direct issues with the interpreters booked for their appointments, if and when this occurred.

However, there were circumstances where there was an unwritten expectation that the primary carer would be the interpreter. Maggie’s daughter Teresa described that she had to be the interpreter at every appointment for her mum and felt that this role was part and parcel of being her Deaf mum’s daughter. She felt powerless in asking the professionals to book an independent interpreter as they ignored her requests time and again. Teresa felt particularly frustrated in this situation as she was a qualified social worker (working in the local borough with hearing people) and she felt she had inside knowledge of how the system worked but was constantly meeting barriers in how to support Maggie. Maggie did not directly contribute to this dialogue, as she appeared to take this ‘as the norm’ and did not question this frustration as part of her usual everyday life.

Libby stated that there were no interpreters at the first assessment with the memory clinic with Ernest. They did not make a direct complaint on the spot, but informed their hearing daughter about this when

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20 National Register for Communication Professionals with Deaf People (NRCPD) have published a Code of Conduct available here: [http://www.nrcpd.org.uk/code-of-conduct](http://www.nrcpd.org.uk/code-of-conduct)
they returned home. Their daughter then had to intervene by making a telephone call to the clinic and explaining that an interpreter needed to be provided for the next meeting.

In summary, Deaf participants’ and their families’ experiences of assessment and diagnosis were overshadowed by concerns about language, communication and intercultural understanding. This made an already emotionally difficult set of experiences even more distressing. The hearing professionals concerned were ill equipped to do their job well when faced with a Deaf person with a potential diagnosis of dementia. These circumstances made it much more difficult for the Deaf person to understand, in whatever way they could, that they had dementia.

7.4.2 Support from the Deaf community

Beryl, Ernest, Harold and Maggie were all life-long members of their local Deaf communities. As discussed in Chapter 3, such contact is a vital part of Deaf people of this generation’s cultural identity; it is more than social contact, it is an expression and maintenance of that identity. Contact with other Deaf people was always consistent and occurred at least once a week, which was within the context of attending the local Deaf club, or receiving visitors at their homes.

Maggie was the exception in that she attended just the one Deaf club, whereas Beryl, Ernest and Harold would attend more than one in their region, often making two separate visits in one week.

Ernest would attend his local Deaf club to offer an afternoon’s respite for Libby by his own admission (although he declared that he did not really talk to anyone while he was there). Ernest did not elaborate on whether he felt any differently treated because of his dementia, although confidentiality about his dementia was clearly very important to him:

‘I don’t want outside (people) to know about me, “ohhhh, Ernest now has demential!” with shocked facial expressions…’

However, Ernest and Libby both attended a different Deaf club together as they both felt they benefitted going as a couple rather than separately. This reflects how important their relationship was to them, in that they allowed one another to be autonomous in going out at different times without each other and enjoying each other’s company when they chose to. Libby added that she felt an element of responsibility in explaining to some members of this particular club that Ernest has dementia as she felt it was important for them to know why he was repeating himself. It was evident she struggled with this decision as she felt she should afford Ernest as much respect as she could without disempowering him in informing community members about his dementia. Furthermore, Libby was emphatic in her reassurance of Ernest and his self-image (linked to his feelings about having dementia):
‘You said I’d told everyone about your dementia, but really, you’re not stupid, all these famous people have had dementia, like Reagan for example, Margaret Thatcher too. She went to Oxford University and was a prime minister but she still got dementia, so you’re not stupid at all. It all used to be behind closed doors in the old days, but not now, no more.’

Harold and Pearl shared their frustrations in their changing relationship(s) with the Deaf community. Harold felt that since he had received his diagnosis, that members of the local Deaf club were inflexible in meeting his changing needs:

‘I used to sit and play dominoes with this group. I’ve done this for many years. But since my dementia…. I have slowed… I get asked to leave, leave the table as too slow. I then stopped going, I backed away.’

Pearl added that she directly challenged these negative attitudes but did not feel heard or understood. She bitterly remarked that she had retaliated to these individuals:

‘Just you wait until this happens to one of you; you’ll understand how it feels then!’

Pearl also felt rejected by her friends in her local Deaf club for attending the Deaf club without Harold next to her. Harold and Pearl elucidated:

Pearl: ‘Harold said it was OK for me to go out, I did ask him first.’
Harold: ‘Yes, yes, I actively encouraged her to go out.’
Pearl: ‘But when I got there, I was trying to sit there with a cup of tea and all I got was, “what are you doing here, you should be at home looking after your husband, and you’re neglecting him”. I was absolutely shocked as I wouldn’t do that to him.’

Harold and Pearl shook their heads in unison showing how saddened they were after sharing this story with the researcher. This rejection is more than just a judgemental approach from people who are lacking awareness about dementia care, but also it is a two-pronged rejection because this is from their community, the people they have shared a life-long affinity with because of their shared language and culture.

Maggie attended a local Deaf club once a week where she felt that she was quite happy to be amongst her peers. She felt frustrated that she needed support to get to the Deaf club and back to her flat again, as she was adamant that she would be fine to go to the club independently. However, she appreciated how she received visits from one Deaf person to her flat occasionally as she felt this was a welcome change from the hearing care workers visiting regularly:
'I just don’t get on with hearing people because….it’s difficult….they just say I’m Deaf and dumb and walk away (with a facial expression that reflects her feelings about this). I lip-read them, I see what they say (about me), I don’t bother with them, they don’t worry me.'

Beryl attended two different Deaf clubs each week in her region. She valued the differences in these clubs; one was more proactive in supporting her after her diagnosis, while the other one was less supportive:

'Well, they know I have dementia. I have told them and I have asked other people to tell each other about me. It’s fine. They are a bit overzealous with bringing me cups of tea though; I keep needing to go to the loo!'

Sheila added later on in this conversation (directly to the researcher out of Beryl’s line of vision):

'They’re bringing her cups of tea all the time, not because she has dementia, but because she finds it hard to walk across the club in between the tables. She’s 80 after all!'

When asked about her participation in the Deaf club, Beryl clarified that she was actually a committee member for one of the clubs. She was their money collector, where she would be the person who counted the money for external trips. When Beryl told the committee members that she had been diagnosed with dementia, she was asked to stop counting the money and to leave the committee. Beryl felt extremely devalued by this:

'Before, I used to be the person who counted the money for the trips out and about. (Since my diagnosis), they’ve asked me to stop doing it. Now, I just tidy up the chairs. I don’t like it.'

It is clear that Beryl feels both devalued and disempowered by the external decision to stop her from being a valuable part of her local Deaf club. Furthermore, the same group were unsupportive in making assumptions about potential changes in Beryl’s ability to communicate after her diagnosis:

'I went back to the Deaf club again the following week and the committee members looked at me and asked if I was OK. I replied, “yes, I’m fine”, to which they responded, “well, you look the same, you still sign the same”.'

In summary, involvement in the Deaf community and in particular attendance at regular Deaf club events remained a vitally important part of participants’ lives. It was not just the continuity of experience that was important but rather the re-affirmation of belonging that was sought and contact with others who were ‘like’ not ‘different’ which reaffirmed cultural identity. Consequently, when experiences in the Deaf club, however subtle, sought to exclude, or to criticise, or to marginalise, the impact was very great, both on the Deaf person with dementia and also their care partner. Participants expressed in different ways
the lack of knowledge and understanding they saw amongst their lifelong friends that was largely a result of ignorance about dementia and its consequences that they understood because they had been the same before it happened to them.

7.4.3 Accessing mainstream or specialist services after diagnosis

Participants described their anxieties at accessing mainstream services for several reasons. The overarching anxiety was that there would not be clear communication between themselves and the service provider. For example, they were worried that they would not be understood, that they would not be able to understand the information given to them nor make use of what might be available within the mainstream. They cast the problem in terms of their memberships of a linguistic cultural minority rather than in terms of services failure to take them into consideration and meet those linguistic requirements.

After his diagnosis, Harold was prescribed Aricept®. He, Pearl and Rebecca did not feel entirely clear about what potential side-effects there might be after starting this medication. Rebecca explains further:

‘(This process has) been trial and error, really, I do wish we’d been better prepared, given better information about how these tablets would have an impact on Dad. If we were hearing, we would have been able to get straight on the phone and get the responses and reassurances we needed. Because we are both Deaf, we’ve been absolutely stuck. It has been a drain on our time.’

However, Pearl had nothing but praise for the nurse that visited their family home to see Harold and to check up on his medication:

‘She is lovely, she writes lovely, her communication is marvellous, no problem at all, it’s a big relief’ (with Harold nodding in the background in agreement).

When Pearl talks about the nurse ‘writing lovely’, she means that the English that the nurse uses when she is writing things down is at the right level for her and easy to understand. She doesn’t use jargon that would overwhelm Pearl. The time that the nurse takes to write things down is appreciated so much that Pearl thinks it is marvellous. An outsider seeing this expression might assume that this means Pearl has made herself understood to the nurse, when it is actually a one-way process in that Pearl feels a sense of relief that she has control of what the nurse is saying to her in a graspmable method, not that she can engage in return with the nurse. Pearl goes on to explain the difference between this nurse and others who visit:
’Well, the first and second nurses were lovely, friendly, full of gestures, communicating directly with him (Harold). The third one, well, she was all *perservperservperserv* all the time she was here. I asked her to write things down but she just brushed the pen and paper away.’

As Pearl mimics the nurse’s lip pattern (Appendices (ii) V8), Harold is chuckling next to her. He laughs because he recognises this common complaint that is often discussed in their family home, but also in the wider Deaf community as a communication breakdown between hearing and Deaf people. When Pearl is asked about challenging the nurse in her refusal to use pen and paper to communicate, she replies:

’I was too frightened. I can’t do that; I have to respect hearing people. I was told that she might come again and (I thought)22, oh, I hope not.’

As a strong Deaf woman comfortable in her Deaf identity, Pearl did not feel able to directly challenge this individual nurse as *hearing people always know best* (as previously discussed in Chapter 3, this form of internalised oppression is quite common amongst Deaf people of the older generation).

Maggie attended a day centre in her local area, which primarily provided services for older people and not specialist dementia care/support providers. Teresa explained that they were not Deaf aware but did visual and tactile activities with her mother which appeared to be satisfactory to Maggie. However, Teresa was worried as the day centre had recently been in touch to highlight difficulties in communicating with Maggie, particularly when she was confused and that they could not ‘manage’ her.

In summary, communication was identified as a key barrier to accessing and using post diagnostic support services, but it was not just communication per se, it was also anxiety about effective communication. Deaf participants expressed low expectations of what kind of interaction with professionals might be possible and were surprised by any kind of access to information and support they received. Challenges to unsatisfactory levels of communication could be difficult, especially for those who had been brought up to believe that hearing people knew best and should be respected.

7.4.4 Unrecognised difficulties in making use of specialist dementia support services

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21 Pearl mouths ‘perservperservperserv’ to describe what a person’s lips look like when a Deaf person is trying to lip-read someone who has not clearly enunciated their words or altered their communication accordingly.

22 For the brackets (I thought), Pearl actually signs the word ‘inside’, which means this was her thought process plus her feelings about what was happening. I have translated this to ‘I thought’ from BSL into English.
Ernest and Libby were the only Deaf people within these interviews to access any type of specialist dementia support services. They both attended a monthly memory café \(^{23}\) run by the Alzheimer’s Society in their region. They were very grateful to have a volunteer (who already worked at the café) who could use sign language (but not fluently, as they had just passed their level 2, which is equivalent to Key Stage 2 English\(^{24}\)). This volunteer was not always present each month.

During our first meeting, Libby asked the researcher if she would go through some handwritten notes on A4 paper before the actual interview took place. Libby, who had been trying to follow a presentation given by a psychiatrist at the café, had written these notes by hand but had no idea what the content meant. About 30 minutes was spent with Libby explaining with her in her first and preferred language, BSL, what the content was and explaining what the psychiatrist had been talking about. However, from the Alzheimer’s Society’s perspective, they will have seen Libby using a coping strategy and made the assumption that because she was writing down the information, she would have understood it; while it is clear she evidently did not.

Libby also shared that at Christmas time, singing songs were a popular activity at the café. She could see that this was a really positive activity for other members of the group but she and Ernest would just sit there, doing their best to join in. The other members of the group would smile with them, mouthing and gesturing the words at Libby and Ernest but they both felt quite excluded, as they did not know what the songs were. This reflects how culturally appropriate service provision needs to be designed for specific linguistic minority groups.

Rebecca explained that she had been trying to source dementia information online provided with BSL after her dad’s diagnosis as she wanted to know what dementia was. She was confident in her English reading abilities but felt frustrated that there was nothing in BSL. She resorted to watching what she felt was a basic video available on the Alzheimer’s Society’s website in Scotland (Alzheimer’s Society, 2011) but she did not feel that this met her specific requirements.

Furthermore, Pearl and Rebecca discussed with one another the possibility of accessing a dementia information session and support group in their local area with an interpreter. Their local district nurse had previously raised this with the family – Pearl remarked:

\(^{23}\) The memory cafes are organised for people living with dementia and their carers as a source of support and sharing information in the community. For more information, see [www.memorycafes.org.uk](http://www.memorycafes.org.uk)

'I was trying to explain to the nurse what I would need (in terms of support) but she was talking so fast at me, I couldn’t understand and Rebecca had to relay-interpret for me. The nurse soon learned that she needed to slow down while talking to me.’

Pearl added:

'I couldn’t go to a support group. I’d just sit there and it would all go over my head. I am so stupid, so thick…'

Harold, Rebecca and I all interjected at this point to challenge what Pearl had said about herself and how it was not her that would be the ‘stupid’ one; nonetheless this is how she felt when faced with an inaccessible support group, she saw the lack of appropriate communication as something that was her fault, rather than thinking about how the group had not made itself accessible to her.

Rebecca’s empowering response to her mother was:

'Imagine you sitting there in the support group and no one there has any Deaf awareness. They’d be the stupid ones, not you!'

In summary, some of the participants had tried to use some other support mechanisms following diagnosis but faced barriers not just of linguistic access but also cross-cultural understanding. For some, the experiences were negatively reinforcing rather than positively supportive. However in the face of no support that was specifically targeted at Deaf people, something was regarded as better than nothing.

7.4.5 Where to go next? Going on to live in a predominantly hearing environment

Considerations of residential care were a very sensitive subject for Beryl and Sheila, which had evidently been discussed previously. Beryl became very uncomfortable during this dialogue and her signing space changed from the usual location being in front of one’s torso, to becoming compactly signed from her lap, rather than within the usual signing space (Appendices (ii) V9). Such a change in signing frame was indicative of her anxiety and her attempts literally to minimise the dialogue (in terms of its size) and to hide from it. Signed languages can express a great deal about the BSL user’s attitude towards a subject as a result of how something is signed, in this case, the size and location of the signing (Sutton-Spence and Woll, 1999). Sheila struggled to recognise her mum’s discomfort and adamantly pushed the issue in that these choices needed to be made before Beryl may become unable to make these decisions herself. However, Beryl was clear in her knowledge that wherever she would be living, she would not be understood as a Deaf person:

'If I go to a care home, if people talk, I won’t know them.'
Beryl's main anxiety was elaborated in the phrase, 'I won't know them'. She was not simply saying that she was aware that she would be amongst strangers; it was a more pressing concern that she would not understand or be able to communicate with the hearing people present in the room and so would not get to know them. This also hinted at the knowledge hearing people would be from a different cultural background, they did not share Deaf culture, history and social lives, and so Beryl would, in another sense, feel alien. Such concerns have been recorded previously in the small numbers of studies of older Deaf people and residential care (Hunt, Oram and Young, 2011). This alien feeling was further exacerbated by the carer representative's visit (from Social Services). This person had visited to find out what support Sheila needed for caring for Beryl at home. Sheila was aghast at Beryl's panic when this person came without an interpreter and started talking to her:

'Mum panicked when the carer representative came to see us. She just started talking at (my mum). Mum thought it was going to be that person looking after her and she just couldn't understand them.'

The use of the word 'at' is deliberate here as Sheila could see exactly how the hearing person's approach and communication with Beryl was totally inappropriate for her mum as a Deaf BSL user. Beryl's response was a natural reaction of horror and panic because this person was not communicating in her native language and she thought that this was the new arrangement that she would have to cope with in the near future.

Sheila was also frustrated with the response from Social Services at this point in future planning for her mum's care. She felt the majority of the responsibility in choosing an appropriate care home had fallen to her:

'They told me that I would personally have to go and visit each care home in the area to see if they are suitable for Mum. They have no idea what is available for Mum here.'

Sheila explained that she had been appointed a new social worker recently, who appeared to have a better understanding of Beryl's dementia and communication requirements. However, she remained sceptical of the system:

'It'll be an interesting process as to how her workplace will restrict her with what she's doing for us. I've had to argue that Mum can't just have any carer, she has additional needs because she's Deaf, she has communication needs.'

Maggie already is living in the type of environment that Beryl is so determined to avoid. Maggie and Teresa are clear in their frustrations about the accommodation and the services it provides:
Teresa: ‘It is difficult though, she is the only Deaf person here, and no-one can sign. All the ladies who help her get dressed in the mornings are from the welfare. She tells them to go away. They get upset then and ring me up and I have to come round. They don’t all have the same ideas in how to engage with my mum.’

Maggie: ‘I don’t need help getting dressed in the mornings; I’m not a fool. If I pull that red cord (in the corner of the room), it would mean lots of people would come in here, what for? The warden is OK, but I just want a peaceful life. The lady comes to the door in the morning, I open it, I don’t want her to come in, I like my own space.’

7.4.6 Summary

This section has explored the service provision that Beryl, Ernest, Harold and Maggie have all had different experiences of, but they share common experiences in the everyday barriers that they face alongside their carers. Each family unit shows resilience in their everyday interactions with hearing professionals who do not use BSL, through supportive language and shared exasperation at the lack of Deaf awareness. They were all conscious that mainstream service provision was not tailor-made for their specific needs but showed tolerance of this, due to their life-long experiences of being Deaf people.
7.5 Situational Analysis

7.5.1 What is situational analysis in this context?

As previously discussed in Chapter 3, there is awareness that in the hearing community, there can be changes in communication patterns when a person develops dementia. These may vary on an individual basis but indicative changes of cognitive functioning seen in a hearing person with dementia may include, for example, hesitating in producing the right words, forgetting words, exhibiting repetition and/or difficulties in following conversations. Non-verbal communication is also important when communicating with the hearing person with dementia; for example, observing their facial expressions for signs of distress. Advice offered to hearing people is available with different strategies to facilitate communication (Alzheimer’s Society, 2016). However, there is a paucity of information available that directly explores communication changes for a Deaf BSL user as outlined in Chapter 3, section 3.19. There are very few guides to effective communication strategies with Deaf people who are sign language users and have dementia (SCIE, 2014; Young and Ferguson-Coleman, 2015).

Study 2 afforded the rare opportunity to observe the communication of Deaf BSL users who are at different stages of living with dementia and their interaction with others in their home environments. The following section focuses on describing a range of altered features within their communication that are the equivalent to indicative or typical communication changes observed in hearing people. It is important to be clear that this is not intended as a complete and full linguistic analysis. The focus is on communication and interaction and the ways in which the visual, non-verbal, spatial features of a signed language may demonstrate altered states of communication and therefore the creation of alternative communication strategies for Deaf people with dementia designed to support their continued inclusion and contribution.

The naturalistic setting for the interviews provided the opportunity to observe and participate in the spatial arrangements that were in place in the home with the Deaf person with dementia. Whilst there was some degree of rearrangement to accommodate the video recording (as illustrated earlier in Chapter 7), the interviews did not disrupt the preferred location, chair or orientation of the Deaf person with dementia in the room. Despite the fact that the carers present might also have rearranged their positioning to participate in the interactions of the interview, this situation still presented a real life example of how space would require accommodation for any instance of multiple interactions between several people in the same room as the Deaf person with dementia. In what follows, short vignettes drawn from the data illustrate different arrangements followed by a discussion of their implications.

7.5.2 What could be considered as potential changes in language and communication for a Deaf person living with dementia?

7.5.2.1 Language changes
Before a conversation starts, eye contact with a Deaf person or with Deaf people in a group must be established. This is imperative for the comprehension of BSL, as Deaf BSL users will not just look at the hands; they will also take in the person’s face, including their eyes, lips and facial expressions. It is also how someone discerns who may want to contribute next through a physical movement or with the flicker of an eye – clear and uninterrupted vision is therefore required for turn taking. The visual is also the means whereby comprehension is indicated – the sustained concentration in another’s visual field or facial expression of encouragement or disagreement is the equivalent of a hearing person’s ‘ummm’.

7.5.2.2 Eye contact control

It was anticipated that a Deaf person with dementia might potentially lose this eye contact, as a possible symptom of their condition. This, in turn, could create potential difficulties in following and participating in conversation with others. However, the opposite was found to be the case. Throughout all the interviews with Beryl, Ernest, Harold and Maggie, eye contact was consistently maintained, be it for shorter periods of time throughout the dialogue than would usually be expected. Eye contact was used to engage with me, with their carer and also as a cue to shut down communication when the person did not wish to continue talking e.g. deliberately looking away or looking down.

An example of this would be when Beryl, Sheila and I were talking about professionals visiting the family home to assess Beryl’s needs. Beryl expressed her discomfort about this subject by breaking eye contact away from the established varied dialogue that had been occurring throughout the prior sixty minutes together. It was clear from the disengagement that Beryl engineered that she did not wish to discuss this with Sheila and I. However, breaking eye contact like this should not necessarily be viewed negatively. Reviewing the videotapes of this interaction, it was clear that Beryl was using it as a deliberate means of expressing intent and asserting her wishes. A hearing reader seeing this explanation might well think that everyone does that anyway – if you are not interested or disagree with something, looking away is one of a range of strategies that everyone might use to convey this sort of message. However, as explained previously, eye contact has much more of an essential and therefore powerful meaning amongst Deaf people because it is a fundamental pre-requisite for all communication. To look away is to end the possibility of all communicating (whether comprehended or expressed) because Deaf people are not able to pick up dialogue if it is continuing around them if they are not looking. Eye contact control and its uses amongst Deaf people with dementia in this study came up many times as means of expressing agency, control and personal opinion.

In another example of non-verbal communication being powerful in its semantic intent, Sheila initiated a dialogue with me about the limited choices available for future care home residences for Beryl. I attempted to include Beryl in this part of the conversation, but by her refusal to make eye contact with Sheila or myself spoke volumes in her denial to discuss this matter further with the both of us. Beryl instead made direct eye contact with me and started talking about her Deaf friends who would take her out for tea. Beryl had not misunderstood the intent or the content of Sheila’s sentence, but instead she
asserted her refusal to engage with this discussion or entertain making plans for the future as she firmly wished to stay in the family home.

Harold also used eye contact control very assertively as a means of ensuring he could have his say. He was very good at maintaining eye contact with Pearl, Rebecca and I and he used the common practice of looking at each of our faces depending on who was signing to signal that he was following the conversation. Viewing the tapes, it is not necessarily clear that he is following the conversation in terms of understanding its content, but he is most certainly following it in terms of knowing who is contributing and his eye contact behaviour is communicating that he considers himself part of the conversation. However, he also used eye contact control to indicate when he wanted to say something. He would do this by looking round the group while pointing and shaking his forefinger in a clawed hand shape until all eyes were resting on him for him to say his piece. This authoritative turn-taking behaviour remained instilled in Harold’s communication schema, regardless of the progression of his dementia. He used this communication strategy to gain attention and to control others eye contact with him. This is not a commonly used one in groups of Deaf people where, more usually, a more subtle approach would be preferred such as using the flicker of the eye, a flicker of an eyebrow or momentary pauses. Nonetheless it was an approach that was within culturally accepted norms and was effective. He had not broken with convention, he had just used a blunter version of this convention, which was warmly received and accepted by all the people in the room with him. If a hearing person who was not used to culturally Deaf norms had been present in the room, they may not have picked up or understood the subtleties in how the group were unconsciously respecting and scaffolding Harold’s management of the usual conventions of communication.

7.5.2.3 Facial expression

As previously mentioned in Chapter 2 section 2.2, BSL is a language of many components, with facial expression being one of the most important elements. When someone is signing with another person, they will create signs using their hands and some parts of the body in conjunction with facial expressions to convey the meaning of what is being signed. It was noticeable in some interviews that the Deaf person with dementia’s facial expressions reflected how they were feeling about the dialogue; even though they may not have been able to explain in BSL what their thoughts were, their facial expression clearly showed this and appropriately reflected their feelings. When the use of language was diminished, even when the person could not use as much grammatical facial expression, appropriate emotions were still visible on the face and non-standardised gestures used to convey their thoughts about a difficult situation.

For example, Pearl explained that Glenda, Harold’s paid carer, had been a difficult component of the diagnostic process as she had been very controlling in his appointments by speaking over him and across Harold when he was trying to respond to the GP’s questions. Instead of Harold adding his views in BSL grammar and structure, what he did instead, most powerfully, was:
For Deaf people, facial expressions are associated with grammatical components of language throughout their whole lives. Therefore how someone, who no longer is able to use BSL but nonetheless uses facial expressions as a means of communication, should be regarded as imparting meaning in a more deliberate way than a hearing person might. This is not non-verbal communication as conventionally hearing people might understand frowning or shaking the head. It is non-verbal expressions that have some precise semantic resonance. For example, pulling eyebrows together is usually used grammatically to indicate dissatisfaction with someone or something, while pursed lips is a common component in BSL grammar to indicate disagreement. Harold wagged his finger to indicate that he was expressing these views and looking around the room to position himself within the context of disapproval of what Glenda’s behaviour meant to him. With this non-verbal interaction, Harold made his feelings very clear about Glenda and this was actually followed up in between our interviews, as it was established in the second interview she was no longer the paid carer for the family and Pearl subsequently attended the GP appointments with Harold.

When a Deaf person has what appears to be restricted facial expression along with a flattened affect, this has grammatical implications where it is difficult to read what someone was intending to sign because a significant part of the signing that creates meaning is missing. For example, Ernest was a very curious gentleman who asked me a lot of questions about my background and where I was from. What was notable about him posing these questions was that he would ask them with a flat affect; the content was there within the question but it was not accompanied with the usual facial expressions that would usually be present such as ‘eyebrow-squeeze’ or ‘eyebrow-raise’ facial expressions that would usually occur in parallel with the signed question. This is a very obvious feature of changed communication that Deaf people will observe quickly. It is the equivalent of spoken language dialogue in a monotone and without any prosody. It is also potentially confusing because without some of the grammatical markers on the face the intended meaning might not be clear. There are however other instances when flattened affect might be indicative of other conditions such as depression. In personal correspondence, one woman was explaining to me that a mutual friend had recently been diagnosed with dementia. I asked her how his diagnosis had come about and she replied, ‘well, he’d lost his smile’. She did not mean literally that he had lost his smile, but this gentleman was known for having a very expressive face, particularly while telling jokes, and it had become very noticeable to her (and others) that his countenance had become recently flattened and limited in visual cues.

7.5.2.4 Limited signing space

When someone is signing to another person, their inherent ‘frame’ for communication is approximately in a box shape, which is within arm’s length in a 3D space across the torso area (Sutton-Spence and Woll,
1999) with movement forwards and backwards across the width of this space to reflect time and placement. This is a natural positioning for when someone using BSL wishes to communicate with others. There is evidence of altered signing space and the usage of signs when there are neurological issues (Marshall et al., 2003).

For the Deaf person with dementia, our observations from the interviews and from watching the videotapes afterwards, show that signing shape, size and positioning can alter dramatically and also from person to person.

For example, Maggie would sign following conventional rules, but with her hand hovering over her lap with minimal use of one hand. This was not her usual way to sign prior to the onset of her dementia.

Beryl would, at times, sign in a much-reduced space, with her signs being formed only from the direction of her lap, or else she did not use signs at all, choosing to ‘mouth’ her words with no voice – this may either have been reflective of her relationship with Sheila – [as Sheila is hard-of-hearing and likely to use their own family signs as opposed to fluent BSL] - or this may have been a reflection of how she felt about the dialogue that was taking place at different points in the interview, such as showing disapproval about the hearing non-signing professionals that are visiting their home.

Harold would sign limited words within a frame that was around his stomach area and limited his space to approximately a 6-inch square. When he was talking to me about losing the ability to sign his signature on bank cheques, he did not express this change in a clear grammatical way but instead within his limited frame:

‘ME – CHEQUE - SIGN – TAPER OFF’  
(With a minimal shake of his head and his tongue movement exemplifying the loss while using the sign for taper-off)

In describing these changes in signing space, the intention is not to show errors or to demonstrate deterioration in language. Rather, it is to demonstrate that regardless of the changes occurring, these Deaf people were still confident to use their language in a different way. They were in that sense resilient in the presentation of their communication. Certainly, Harold was very aware that his style of signing had changed and he recognised and mourned this (see Harold’s story in Chapter 7). These recognisable changes are however also important in what they potentially communicate to other Deaf people and fluent signers about how dementia is affecting the individual. It is unlikely a hearing person with no background in BSL would notice anything as unusual as they may have no background knowledge of fluency in BSL and its implications when signing space changes.

As discussed in Chapter 4, being a Deaf researcher supported these interactions with Deaf people living with dementia because it was possible for me to understand the limited communication presented within
its context. I could see it for what it was but also respected it and recognised the positive and continued intent to express their personal views, wants and needs. This communication process was not an easy one, and would be even more difficult for a hearing person who is not fluent in BSL. It is important to note this difference at this point, as a hearing professional who meets the person with dementia with no experience of BSL may automatically assume that they have always signed this way.

7.5.2.5 Use of old signs

BSL, like other languages, changes over time. In different generations some words are more common than others and some gradually fade from use. For example in some hearing communities in the UK it is rare these days to hear the word ‘wireless’ used for a ‘radio’ because a wireless was very much the common way to describe it when it first came out, as it was its most surprising feature. It is a word of the older generation, not the younger generation. Those who grew up in the pre-decimalisation era are familiar with words like farthing, shilling and sixpence even if they are not commonly used today. For younger generations, they are unknown vocabulary items. In signed languages too there are old signs and new signs for similar reasons, but often these are connected with the visual appearance of an object. As an illustration, how one might sign telephone today is not how it was signed previously when it was a different shape. An example of this is shared from one interaction that was had with Maggie later on in this section. Sign languages have changed just as modern languages have too; words such as ‘internet’ and ‘Wi-Fi’ were not around 25 years ago, but they are now embedded in our everyday language, and signs have evolved to reflect these new words. The sign for Wi-Fi (wireless) is different from what would have been the sign for the old wireless (radio) as it is within a different context in a different generation.

It is also well recognised in the Deaf community that historical influences on Deaf education have had longs lasting effects on how someone communicates. There was an era around the late 1800’s and early 1900’s (Dimmock, 2002) when it was very common for Deaf children to be taught to communicate through fingerspelling of English words at a rapid pace. This is not true of signed languages today; the use of fingerspelled sentences is specific to this particular era. Some residential Deaf schools also had a long-lasting influence on, for example, vocabulary items. Signs for the alphabet (for example, the letter E) might be particular to that school or region (Appendices (ii) V10) so whenever those signs are used, Deaf people betray their early childhood environments.

Harold and Ernest were both from the educational era where extensive fingerspelling might have been common. Whether as adults this had been a usual characteristic of their communication, or whether as a result of the effects of their dementia, the reason as to why they were using communication approaches of a different era was unknown. However, both gentlemen used fingerspelling for more words than expected; for example, when signing yes, which can be indicated just with a nod of the head or a clenched right hand shape used in a downward movement, they would deliberately spell the word...
out Y-E-S. Sometimes this approach is used for emphasis, but they used it all the time, not for special emphasis.

Harold used two older signs for while he was talking about the nurses that visited him at home and also in response to when I was asking what his favourite biscuits were.

Firstly, Harold signed ‘nurse’ with the use of his right hand across the crown of his skull. This is not a sign I recognised so I had to ask him to repeat it and Rebecca intervened to tell me what it was, using a more modern sign for the noun. While Rebecca was able to provide scaffolding in explaining this new sign to me, Harold was gently laughing in his chair at my confusion but recognising that there was a knowledge exchange of the transitions and changes in signs taking place between Rebecca and I. However, this type of exchange was allowed in the fact that I had fluently signed throughout our interviews and I was able to recognise my lack of understanding and acknowledge it. If this had taken place with a hearing person who could not sign fluently, this could have been a point of stress for the family as they would feel that they were constantly teaching someone how to sign a word correctly.

I asked Harold what his favourite biscuits were as I wanted to bring those with me as a token of thanks to the next interview. He used the old sign for fox, which are two fingers in a hook shape on the cheek. Again, I was flummoxed at this sign – Harold recognised my puzzlement and then kindly fingerspelt this out for me. He understood that I hadn’t got the sign and immediately repaired this for me by changing his mode of communication to fingerspelling. [The more modern sign for fox is right handclasp shape away from nose]. Harold was drawing on a vocabulary of a younger era, not of contemporary language in the same way in which hearing people with dementia might use words common in pastimes rather than those of the present. For reference, Harold’s favourite biscuits were Fox’s (http://www.foxsbiscuits.co.uk) and his request was met at our next interview.

This effect was seen also with Maggie. She used the sign for television which was right hand-claw shape-twist movement-repeated, as though turning the dial – which is an old, established sign which reflects how television sets were operated before remote controls were invented. Maggie was responding to a question about what programmes she liked to watch, and while posing the question, I had used a more modern sign for television. This demonstrated the fact that Maggie had understood the question and then identified the same object with a different sign. This demonstrates the strength of Maggie’s functional memory in terms of how she understood a newer sign and used an older one for it; her sign was not a mistake, but it was correct only in a historical context that she had previously occupied.

7.5.2.6 Repetition

Repetition is a symptom of dementia that is recognised in both the hearing mainstream (SCIE, 2016), and within the Deaf community as the focus groups shared in Chapter 5, section 5.5.2. A definition of
repetition is when the person repeats what they have said, whether this is a statement or a query. This can occur whether factual or mistaken information is being shared and tends to exclude any other form of interaction.

For example, Ernest asks Libby, ‘How long have we lived here?’

Libby replies, ‘2 years’.

I ask, ‘Why did you move here?’

Libby replies, hesitantly and carefully,’...because we needed to be near our daughter … (but is struggling with what she thinks is the obvious reason for moving) because (then turning to Ernest) … you …you have Alzheimer’s…that’s why we live here’.

Ernest interrupts Libby and emphatically says, ‘No… no… no...It’s not just because I, I, I, have dementia, I know, I know that I have it, but.... we’re here to be closer to our family too.’

This interruption demonstrates Ernest’s confidence in presenting his own point of view about their house move. In addition, it was observed that Ernest used the sign ‘move’ (in terms of relocating) upside down, with his clasped fingers pointing upwards, instead of the usual orientation of one’s clasped fingers facing downwards (Appendices (ii) V11). It does not matter at this point to Libby or I that this sign has been orientated erroneously as his interruption and meaning of the interruption is just as valid.

7.5.2.7 Unexpected contributions

The examples thus far of eye contact control, scaffolding and turn-taking are all connected with either the Deaf person with dementia demonstrating their presence within conversations, regardless of whether they are following the content of those, or finding ways actively to contribute to dialogue. However, there were other examples in the data of when a Deaf person with dementia was not demonstrating involvement or others were not cueing them in to conversations but, nonetheless, they were on some level following what was happening, and chose their own moments and means of taking part. Maggie, for example, maintained turn-taking behaviours in a minimal way and she needed to be prompted more than the other three people with dementia to take part in the conversation around the interview. She was more engrossed in objects; such as photographs (with both paper and digital versions via her daughter’s iPad) and exploring these in a manual- touch responsive way, rather than discussing topics following conversational rules. However, there were some occasions where Maggie would surprise Teresa and I, as she would appear not to be actively watching the conversation but would intuitively respond with her view where it was appropriate to do so.
For example, Teresa described how she felt about being Maggie’s carer, that it was a thankless task, and that it was a difficult journey, particularly with hearing professionals who could not sign with Maggie:

‘It’s hard at times with Mum, you know, hearing can’t sign with her. So they ring me and I come round after work to help. It’s so hard.’

Maggie does not immediately respond, while I nod and shake my head in agreement with Teresa. Maggie looks down at her lap and then replies (after a short period of time) sitting forward directly looking at me (not at Teresa) and signs:

‘She’s a good girl; she’s very good to me.’

This statement, for two reasons, visibly takes Teresa aback. One, Teresa thinks that Maggie had not understood what she was signing to me about the hearing professionals and two, Teresa feels unappreciated as her mum’s main communicator and to receive this praise from her mum is a rarity. Teresa looks at me with tears in her eyes and replies to Maggie:

‘That’s not what you usually say to me!’

Maggie does not respond in turn to this comment; she sees Teresa’s response and then looks down at the photograph that she had in her lap prior to this exchange of dialogue. It is unclear how Maggie feels about Teresa’s comment but she does not show what she feels about this. In hindsight, while considering this remarkable exchange between Maggie and Teresa, there is a possibility that the actual process of the research interview engineered the opportunity for a warm and positive dialogue reaffirming their relationship that might not have happened amongst the monotony of their everyday lives.

7.5.4.8 Employing the use of scaffolding strategies

Scaffolding is used to refer to the ways in which other people present in the person with dementia’s environment might enable and support the communication of the person with dementia so that they can follow and/or contribute effectively to conversations and interactions. The interactions generated by the interviews filmed in people’s homes provided the ideal circumstances in which to observe how scaffolding took place within a visual language for a Deaf person with dementia and the different strategies that might be used. Not all of the participants’ carers and family members did this in the same way. Not all strategies were as effective as others.

For Harold’s two main carers, Pearl and Rebecca, an important part of scaffolding was how to provide him with a means of entering the conversation. They knew he did not always understand a question or a topic of discussion or that a response might be required from him. Their approach was to turn a
question directed at Harold, into a conversation between themselves which gave Harold an opportunity to get a general sense of the topic under discussion first then they would point to him as if to say, ‘this is YOUR story to tell now’, stopping themselves from answering for him, looking at Harold and asking him if he wanted to tell the story himself.

Finger pointing is not a usual way in which turn taking is indicated between Deaf people. Usually turn taking and other conversation regulators are indicated more subtly with just eye contact, turning of the head or eyebrow movements (Coates and Sutton-Spence, 2001, p. 512). It is however within the potential repertoire of turn-taking mechanisms and it is interesting that Pearl and Rebecca used it, presumably because it was more visually obvious a way of signalling turn taking because they assumed the more subtle markers of this may be missed by Harold. It was also clear that this strategy was not necessarily a conscious one they had decided to use; it was more like a culturally unconscious adaptation that made the commutative environment more accessible for Harold. It supported his ability to contribute to a conversation.

Libby and Ernest, as a couple, had their own scaffolding mechanisms in place as husband and wife that superseded the management of communicating well while living with dementia. Ernest was very clear in his position as the person living with dementia in having continuous support from Libby. When I asked him and Libby if there were any specific memory aids around the home, his immediate response was:

‘Oh, ask her (Libby), she knows everything. She’s responsible for it all.’

Libby’s initial response was one of recognition that this role was becoming a bit too much for her; she added that their two daughters felt that Libby was doing too much for Ernest. Under her breath, she remarked:

‘...But I need a break, I’m so tired’.

Ernest did not see this comment, as it was signed very subtly, so he did not reply to Libby’s emotional response. However, at another juncture in our dialogue, Ernest does demonstrate his awareness of Libby’s needs for a break:

‘I go to the Deaf club, I do. I just sit there at the table. I don’t really know anyone, I don’t talk much, but I go, as she needs a break.’

Additionally, Ernest is very keen for people at the Deaf club not to be aware of his dementia (his reluctance about disclosure and his reputation in the Deaf community has already been discussed in Chapter 7) and Libby attempts to scaffold and also challenge Ernest’s thinking by responding:
'But, I’ve told you, you’re not stupid! You moan at me, moan at me (you pull this face) for telling people, but look, I think it’s important for people to know, the Deaf lady who runs the club, her mother’s got dementia too, you see.'

Libby is trying hard to respect Ernest's wishes, but also wants to ensure he is able to manage well in his social role in the Deaf club and wants to justify his unusual responses to other Deaf people present at the club, in support of him, rather than deliberately allow him to run into difficulties (Robertson, 2014). It is clear from this interaction on the video that this is an on-going dialogue between this pair as Libby uses a facial expression towards Ernest, which can be described as a prompt or as an acknowledgement that he knows she is simply being supportive.

7.6 Individual strategies employed to maintain autonomy and independence

This section addresses other features, beyond those associated with language and communication, which are nonetheless context-rooted and employed to maintain autonomy and independence. Many of these are also relationship based and so they are presented by person, rather than by theme to demonstrate the individuality of them.

7.6.1 Beryl

Beryl and her daughter Sheila sat closely next to one another on the sofa with their shoulders almost touching. Sheila was positioned within Beryl's line of vision and Beryl, at times, would intently watch her while they were signing to me. Beryl occasionally would look over towards me; responding in a limited way whenever she was asked questions but there was not a great deal of interaction. It was mainly her carer who contributed most.

However, despite the apparent lack of response, Beryl was able to position herself in such a way that she presented herself as being part of the conversation. She composed herself in such a way that she was able to indicate she was present as in with us (physically) but perhaps not following the dialogue in its entirety, as in with us (in her understanding). For example, Sheila was explaining that she and the family had bought a new microwave for the kitchen firmly believing that it was user-friendly for Beryl. Sheila explained that Beryl was, unfortunately, really struggling to use this piece of equipment, particularly with the use of digital numbers for cooking different items. Throughout this explanation, Beryl's facial expression did not change or indicate that she either understood or whether she agreed or disagreed with Sheila's perceptions of Beryl's apparently diminished abilities.

Whether Beryl's following by presence - if not by contribution - was a new adaptation as a result of dementia is questionable. Many Deaf people have life-long experiences of presenting themselves in such a way as to seem to understand conversations (usually spoken ones) when with hearing people, through where they stand or sit, or how they look. Perhaps Beryl was simply deploying a pre-existing
resource and skill when faced with a different circumstance where she did not understand the context, but wished to communicate that she mattered within an interaction through physically reminding others of her presence. This would be a positive and resilient reading of her behaviour. However, perhaps the intent was less deliberate and it was just another example of the ways in which Deaf people are able to maintain their presence through 'passing' (Goffman, 1963) as if they are involved in interactions to deflect stigma and exclusion. A third interpretation is that over time Beryl had decided that she wanted her carer to take the reins of the conversation to prevent her being excluded by others in everyday interactions.

Beryl might have seemed passive and there was no evidence of turn taking between Beryl and her carer in terms of conversational exchanges but there was subtle communicative interaction, nonetheless. For example, Beryl used eye contact towards her carer to confirm she agreed with what the carer was talking about. She also used eye gaze to check in with her carer for affirmation / confirmation of the accuracy of the content of her responses to the posed questions. For example, when asked about her preferences about different Deaf clubs, Beryl responded warmly and enthusiastically, flicking her eyes to the carer and back again as she signed. Equally, there were examples when she withheld eye contact with the carer and did not use this checking eye behaviour. This happened when Beryl clearly felt strongly about an issue and believed in the validity of what she was sharing with me. It exploited the possibility of sitting next to someone and looking away at a third party meaning that little contact actually had to be made. One example of this separate, but next-to-each-other communicative behaviour, was when Beryl was explicitly stating that she did not want to consider what her options were in terms of living in a care home. This was evidently a difficult subject for both parties; if Beryl had made eye contact with Sheila then she would be in effect cueing her in to elaborate further and so by not making eye contact, she exerted some control to stop the conversation from being elaborated further upon. This was a rare moment where I could read or gauge Beryl’s change in affect through her facial expressions, which conveyed her underlying emotions in this difficult process.

Beryl’s story and communicative behaviours have demonstrated varying coping strategies one could potentially use to express oneself. Firstly, what would appear to be an apparently awkward seating arrangement – two signers sitting directly next to each other (not facing one another) and so potentially making it more difficult to maintain eye contact – seemed to work well during this interview. This strategy appeared to be a successful one for Beryl, as the physical proximity of Sheila was of greater symbolic value and a better scaffold for her, than the physical distance usually required for easier interaction as a Deaf BSL user. The touch and proximity were reassuring. Secondly, being out of the usual line of sight may have been exploited meaningfully by Beryl as a method of closing down an unsavoury topic and excluding Sheila from further comment.

Whilst motivation and intent may remain unknown, this is a good example of how space, touch and proximity (as well as eye contact) are vital components of how a Deaf person with dementia might
choose to shape their environment to support the continued assertion of their meaningfulness within the context and social interaction.

7.6.2 Maggie

When I joined Teresa and Maggie again for the second interview, Teresa was in a very difficult position as she had just recently had a telephone call from the local day centre and she expressed her frustrations. Until recently, Maggie had been accessing her local hearing day centre for activities with a dementia-friendly support group. Previously I had asked her what she thought of this place and she replied:

‘Oh, that, it’s alright, it’s alright, I like drawing…’

Maggie had not placed any clear emphasis on what her peers were like at the day centre or what the support staff were like in terms of communication; it appeared the activities themselves were of more intrinsic value to her. However, the social services team had just informed Teresa that Maggie was not welcome at this group anymore because the day centre had reported that they could not ‘manage’ Maggie. Upon questioning the support workers further, Teresa was able to establish that Maggie was an active participant and enjoyed doing the arts and crafts activities. However, the support staff identified that Maggie found it very difficult to follow instructions from the support staff and therefore there was a management problem.

When Maggie was asked more about this, she remarked:

‘I don’t like it when they talk, best for them to leave me alone.’

Teresa, in her frustration, strongly believed that this comment was linked to difficulties in communication between both parties. Maggie could not understand the instructions and the staff at the day centre did not have any appropriate communication strategies in place (i.e. a BSL interpreter, or BSL fluent staff). This was an exasperating scenario for both Maggie and Teresa, particularly as it was therefore determined by the day centre staff that Maggie was the ‘difficult’ service user, with no reflection on the responsibilities of the day centre or their limitations in not being able to communicate with Maggie effectively. However, from Teresa’s point of view the issue was one of her mother’s rights to access and receive services that supported her linguistic and cultural identity. For Teresa, the problem was firmly that the lack of Deaf awareness and inability to communicate implied a lack of support for Maggie. This process was upsetting for Teresa, as she felt frustrated with the lack of motivation on the day centre’s part to communicate more effectively with Maggie and think how that could be achieved. In this scenario, the day centre staff opted instead for Maggie to be the ‘issue’; she was the one easily labelled disruptive or difficult, rather than staff exploring avenues around funding for a support worker fluent in BSL. Teresa was additionally frustrated because Maggie could not attend her local Deaf centre to do
the same type of activities, as the Deaf centre staff were not trained in how to support a person with
dementia (and did have any plans in place for the provision of such activities for older Deaf people who
lived in the vicinity). This is an example of the double barriers that Deaf people living with dementia face
in achieving full citizenship if by that we mean accessible, supportive services that enable participation in
terms that make sense to the person with dementia. As a person with dementia, Maggie could not
integrate back into the Deaf centre and as a Deaf person she could not integrate into day care services.
Integration is a two way process and in both instances one of the parties would not or could not move.

7.6.3 Ernest

Upon arrival at Ernest’s home, Libby, his wife, was the primary guide in positioning us for our interview.
Ernest remained in the same chair in the conservatory with his daily paper; reading intently while Libby
was in the kitchen making our coffee. I sat in the chair that was directly opposite and used facial
expression and hands to ‘query what he was reading’ (eyebrow-squeeze-forefinger-WHAT-IS?). Ernest
then went into detail about a political coup that was happening in the Far East, using the appropriate
signs and words, but with minimal affect or gestures, to demonstrate the seriousness of the political
dialogue. The impact of this style of signing is like looking at a colour photograph, but visually only
receiving sepia tones. This initial conversation was a useful way to ‘position’ us in our communication: to
initially engage with one another and to start building rapport along with understanding each other’s
signs.

Libby came in and sat in the chair that was next to Ernest, moving it slightly so that he could see her
face and hands and she, his. This action demonstrated how Libby felt it was her responsibility to ensure
that Ernest could see her comfortably, rather than the expectation that Ernest would consider and
perform this action autonomously. It is more usual in interactions and communications for Deaf BSL
users to simultaneously move their seats until a collective accommodation is reached in which everyone
can see each other. It is rare for just one person to move within a group scenario so in this case, Libby
was the sole initiator for this movement while respecting Ernest’s communication preferences. However,
interestingly, once Libby had completed this positioning, Ernest then started shuffling his seat about in a
mirror image of what Libby had done seconds before but this seemed to be disconnected with the need
to position himself appropriately in space and more like a repetition of something observed – this could
be observed as an element of echolalia (Ghosh, Dutt, Bhargava and Snowden, 2013).

Within the dialogue that followed, there were questions asked about which schools (primary and
secondary) I had attended (as part of the getting to know one another stages of the interview as
discussed in Chapter 4). Ernest appeared to retain the information about the first school, but not the
second, so he repeated the same question throughout our introduction; ‘but what school did you go to
after that one?’ It was important to Ernest that this information was shared with him and that he was
able to clarify with me if we had any shared Deaf history – as explained previously in Chapter 3, this
dialogue is often a cornerstone of creating a shared identity when Deaf strangers meet each other.
While I was completing the consent form with him, Ernest initiated a question (which could also be interpreted as a response to the current situation he found himself in):

‘…But will they know me? Will they know it’s me doing this? Will they know about this?’

in that he wanted to double-check that his identity would not be revealed to the Deaf community after the interviews. This question was repeatedly brought up whenever there was a pause in the questions being signed in BSL by me, and he was reassured with the same answer each time, that this data was confidential. At a later point, this repetition was evidently frustrating for his carer, who leaned back slightly in her chair, outside of Ernest’s line of sight, and used just facial expressions to convey her shared experience of dealing with these repetitions on a daily basis. She mouthed ‘See’ at me and pursed her lips alongside a small hand gesture (two hands up in the air pointing towards Ernest). She also signed to him ‘just sign the form, will you’; Ernest maintained his autonomy by shaking his head at her, and stating that he wished to make sure he understood it all. This is an example of how moving outside of space as the carer did to communicate is used to break an interaction and talk over/around the person with dementia. It is something you can do with a visual language that you cannot do in the same way with a spoken language. If a hearing person were to talk about someone who was present to a third party they would hear the words uttered, unless they were whispered, but even then in such close proximity, they would still be aware the person was talking. As a Deaf person, you can sign outside of a line of sight and the person will not be aware. However, given how good Deaf people are sensing movement usually and turning to where it is happening, does this also show that Libby had become aware that Ernest’s inherent abilities to spot this type of movement had waned and she altered her communication technique to reflect this knowledge?

Ernest clearly illustrates his scaffolding strategy in communicating with people outside of his family unit. When he is asked about the symptoms of the onset of dementia, Ernest immediately refers to his carer and says ‘she knows more about this than me, she’ll tell you’. Libby then adopts the role of storytelling, while Ernest remains focussed on her and nods and signs ‘right, that’s right’ intermittently throughout. He appears not to feel disempowered by his wife sharing this information and goes on to clarify with the researcher, ‘Will you be telling other Deaf people about me going FOREFINGER-SIDE-FOREHEAD-TAP-TAP-TAP’. This is not the usual sign used for dementia; it is in fact a gesture that is used to describe someone who perhaps has mental health issues. It also potentially demonstrates how Ernest feels about his dementia and how it has impacted on him and his self-view.

There was a very warm level of interaction throughout the interview between this pair. It was evident that Ernest enjoyed watching his carer signing, as he would jerk his head back with a smile or laugh at appropriate points (particularly when the carer was sharing a happy memory or talking about a funny event). In turn, she would she would glance over at him out of the corner of her eye whilst looking at me, and tap his arm or thigh to keep him within the conversation. This action was not about making sure
Ernest ‘understood’ what was happening; but more about making sure he was included in the conversation. Ernest reciprocated this tactic by using the ‘yes’ sign to validate his understanding of what his carer was discussing with me. Hearing people may generally use touch to show empathy, to indicate emotion to indicate a shared understanding (which can be often accompanied by touch between family or friends), this is not necessarily a common tool used to bring someone back into a conversation unless they have wandered off, literally, or to indicate to them that they are part of what we are saying. Libby’s actions, therefore, go over and above the usual communication tactics employed to engage and maintain Ernest’s involvement in our dialogue.

When Libby clarifies their grandchildren’s ages, Ernest responds with, ‘What will become of me…I don’t remember, I’ve forgotten?’ Ernest mouths the word ‘forget’ and signs ‘BOTH HANDS-TRIANGLE-THUMBS-SQUASH-HAND-SHAPE-HANDS MOVE AWAY’ (Appendices (ii),V12). The sign for ‘forget’ is not signed in the usual way for someone talking about how they’ve forgotten something. Ernest is offering an emotive representation of how he feels about his dementia, as the use of this one sign represents (i) his missed recollection of his grandchildren’s ages; but also (ii) that he feels that part of him is lost too. This one sign encompasses all of this without the need for further elaboration.

In this context, Ernest is also responding to Libby, who has corrected information that he believed to be right about his family, so this sign is reflecting his own feelings about not recalling information but also is a subtle response to his wife in that he’s forgotten. He is taking control of this situation by stating he ‘knows’ that he has lost the information, is subtly telling Libby ‘I’ve forgotten this, but you’re my bolster, you’ll know the right answer’ and subliminally expressing his feelings about not being able to remember.

7.6.4 Harold

Harold’s home life illustrated how scaffolding of conversation, involvement and participation can be provided in the non-verbal and in absolute silence. This far, when scaffolding examples have been illustrated, concepts such as verbalised/signed scaffolding or tactile scaffolding have been explored. However, Harold and his family offered another perspective on how the Deaf person with dementia can be scaffolded to achieve participation through being enabled to be present in the moment, not necessarily within active conversation.

When Harold had something to say, he would sign it with conviction as shared earlier in Chapter 7, section 7.3.3. However, there were quite a few moments in our dialogue in both of our interviews together, where he appeared to be content to sit back and observe what was happening without feeling the need to contribute. It is important to clarify here that Harold was not deliberately excluded at any point, nor did he struggle to keep up with the conversation, in fact it was the opposite.

Pearl and Rebecca quietly scaffolded Harold’s position in that they consistently maintained eye contact and used their eyebrows to maintain his presence in the room. For example, whenever Pearl or
Rebecca contributed to the dialogue, they would look at me, look at one another and also look at Harold, thus signalling that the conversation involved all of us. The power of this must be appreciated in terms of the special place that eye contact holds for Deaf people in enabling communication to be understood in the first place (you have to look at someone to sign and be looked at to be understood). The behaviour in itself held semantic significance in indicating turn taking, subject/object and inclusion to Harold, even if he was only ‘watching’. Pearl and Rebecca would also jerk their heads and/or raise their eyebrows in a subtle manner as if to say, ‘are you with me here? yes, you know what I mean, don’t you’, but without expecting him to offer a response. For hearing people, eyebrow behaviour may seem like a non-verbal facial expression but for Deaf people who have signed all their lives, eyebrow behaviour is something more. It can be used for example to indicate emotions, such as being unhappy or happy, to ask a non-verbally asked question, to exaggerate a feeling, to respond with derision, and so on. Knowing there is language in eyebrows is important for the BSL user, whether they are Deaf or hearing, and that more importantly, that Harold has retained and maintained use of this lexical facial communication.

Neither the expectation nor the pressure to reply immediately was present within this family unit, which was quite a different type of interaction compared to the other three Deaf people with dementia in their interviews. In those, the carers were much more physically active in ensuring the person responded to any posed questions.

This relaxed repose and comfortable position could be because this was a multi-generational Deaf family in which non-verbal interactions that carry semantic significance (that to a large extent is conventionalised because of how the grammar of the language works) are a crucial part of their everyday lives. These were not diminished by the onset of Harold’s dementia. He retained an understanding of them.

In this example of non-verbal and non-pressured scaffolding, a typical response from Harold would be a subtle rising of his eyebrows in return, and/or the use of a small pout on his lips while nodding in agreement. These are features of BSL that are commonly found in multi-channel signs. They work together in sync to indicate that the person is agreeing with something that has been signed, or demonstrate the person’s view that they disagree with something if this is done in conjunction with a head-shake. These messages can be fleeting, which is why it is important to incorporate the whole of the body, hands and face at the same time when communicating with a Deaf person.

He looked like he might have been considering the discussion and subjects that were being brought up, and quite often, he did not feel the need to contribute, quite possibly because he was content with Pearl and Rebecca’s answers – he was comfortable with how well they both knew him and his story from their unique but inclusive perspectives. He also knew that fundamentally he was being included. He knew Rebecca in particular was ensuring that he was involved in the dialogue as she would check in with her dad by locking eye contact with him subtly over the top of her glasses and using her thumb towards him...
as to ask, ‘You OK there, Dad?’ or ‘Am I right?’ when she’d shared something with me about his
diagnosis or his medication.

However, most importantly, if there were any points that Harold did wish to make or add, he was able to
lift his hand up, wag his forefinger while maintaining eye contact and rising his eyebrows once, looking
around the room while he was waiting his turn. This is a more blunt form of how Deaf people usually
would signal that they want to join in a conversation or that it is their turn. The subtle and
conventionalised forms of conversation joining such as nodding one’s head, making eye contact,
eyebrow raising and raising one’s hand subtly were no longer open to him; perhaps this was an effect of
his dementia. Nonetheless he was able to signal his intention to contribute precisely because he knew
that he was being ‘seen’ through the non-verbal routines of engagement that had been maintained. He
would laugh at appropriate interjections with a twinkle in his eye, particularly when communication
breakdowns with people external to their world were described. There was no need to reinforce any
dialogue with him, or to ensure that he had understood everything that had been signed, as he was able
to maintain his presence in the conversation and just be.

As a Deaf interviewer and analyser of these data, these routines of engagement, the semantic
significance of the non-verbal and the clever scaffolding by Rebecca and Pearl without anything actually
being ‘said’ were obvious. What would a hearing person see if they had not experience of how BSL
works, or how Deaf people socially communicate with each other? Would they see Harold’s silence or
would they see the silent scaffolding?

7.7 Summary

In this chapter, an in depth representation of the individual everyday lives of Beryl, Ernest, Harold and
Maggie has been discussed to demonstrate their coping strategies, attitudes and behaviours while living
with dementia. For some, they are happy to participate in dialogue and for some, they are happy to just
‘be present’ in the here and now while their family members share information. The analysis has shown
how each person has maintained resilience and agency in their familial positioning and sharing their
views about the external decision-making processes that occur as part of their everyday routines.
8 Discussion

8.1 Introduction

Overall, this thesis has sought to understand dementia from the perspective of Deaf people who use BSL and who are members of the Deaf community, sharing a common cultural experience and heritage.

The combined studies were designed to meet the overall objectives of:

1. Enhancing understanding of the Deaf community's knowledge of dementia;

2. Understanding the everyday lives of Deaf people living with dementia and their carers; and

3. To consider future dementia-related service provision for this cultural and linguistic minority group.

It sought to gauge the body and depth of Deaf people’s understanding and knowledge about dementia through discussing this topic in focus groups (Study 1); and furthermore, to interview directly, for the first time, Deaf people who were living with dementia (Study 2); and to consider the cultural influences on care relationships, whether that was care provided by other Deaf family and friends, or hearing carers in the home or within ‘hearing’ environments. The data have been collected and presented through the lens of a Deaf researcher and her ontological experience of ‘being’ Deaf but not (yet) of being a person with dementia. This chapter will consider how to interpret the knowledge and insights gained through both of the studies undertaken. It will draw on various theoretical frameworks and will be arranged according to six main discussion areas. The first of these is communication, embodiment and agency.

8.2 Communication, embodiment and agency for Deaf people and dementia

8.2.1 Why is communication important in this context?

Communication is important for everyone, as without it, humans would not be able to express the most basic functions through to the most elaborate thought processes (Oxford Dictionary, 2015). With effective communication, people are able to be agents of their own lives; they can put forward their thoughts or make their own decisions. These contributions, as full citizens, support the person with dementia to be their own agent. If effective communication strategies are not in place, then this may have an impact on how the hearing or Deaf person living with dementia is able to demonstrate, or indeed assert, their agency (Ratner, 2000).
8.2.2 Why is communication important for Deaf people?

Deaf people cannot hear, therefore within mainstream society, clear methods of communication need to be in place. For example, Action on Hearing Loss and the British Deaf Association offer ideas of how to communicate clearly with these groups of people (Action on Hearing Loss, 2016; BDA, 2016d). Hearing people who have not met Deaf people previously may not always consider what these methods might be and which ones may be most effective. Communication is different for each individual and any communication strategy must be engineered to match this.

The focus groups in Study 1 identified communication as an everyday stress for the Deaf community based on the knowledge that there are barriers to good communication amongst all walks of life and contexts and that these are a life-long experience. It was strongly felt that clear communication was key to how information should be shared about dementia. It was said that the person conveying the information needed to be trustworthy and to build that trust, the person needs to be a good communicator from the Deaf community’s perspective, not in the opinion of hearing people or hearing organisations.

Moreover, the focus groups declared that professionals who work with Deaf people should know how Deaf people communicate in order to be the right source of support for a Deaf person with dementia. For example, the focus groups stated that hearing people need to know that key aspects of communication for Deaf people include maintained eye contact, being tactile, being visual and being clear and if the hearing professional did not know about these components, they could miss vital and crucial messages in their diagnosis of a Deaf person’s dementia. Good communication cannot be taken for granted and is the bedrock of knowledge-building about dementia for Deaf people.

8.2.3 Communication and its importance for people living with dementia

Being able to communicate at an interpersonal level is central for the person with dementia to be able to make their own decisions, offer their opinions, and express preferences. The literature in dementia studies has explored how the person with dementia should be naturally enabled to contribute to dialogue, if they are taking part in a conversation or making decisions about their future. Aspects of good communication strategies include turn taking, relevance and comprehension (Sabat and Harré, 1992; van Langenhove and Harré, 1994; Jaworska, 1999; Goldfein, 2007; O’Connor and Purves, 2009). Participation in meaningful communication to express preference and choice has been linked to an understanding of positive, rather than malignant, positioning of people with dementia in everyday life (Sabat, 2003) and an extension of active social and political citizenship (Bartlett, 2014; 2016).

Parallel arguments can be drawn with the Deaf community. Deaf individuals who are members of this cultural linguistic minority group commonly experience malignant positioning (Sabat, 2003) by hearing people in their mainstream everyday lives on a daily basis whereby communication barriers can deny dialogue and choice. For example, if a Deaf person uses BSL with a non-signing hearing person, there
is a barrier as the two parties cannot understand each other. However, this situation is not neutral with both parties experiencing communication difficulties. The rule of phonocentrism (Derrida, 1976, Corker, 2001) prevails as spoken language is given a greater status and as such the signing Deaf person is disempowered. For example, the hearing non-signing person might ask the Deaf person to speak, or they might write things down (when English is a second language for many Deaf people) or they will turn to another hearing person to ask them what the Deaf person signed. It is the Deaf person who is expected to modify their communication to match the dominant language not the dominant speaker who usually adapts to the strengths of the Deaf person. These are life-long experiences for Deaf people; not new experiences that may happen as a result of dementia.

8.2.4 Impact of communication on the promotion of agency for the Deaf person living with dementia

So far, I have argued that the experiences of changed, poor and often disempowering communication experienced by hearing people with dementia are nothing new for Deaf people. For different reasons, these are experiences that Deaf people are used to, regardless of whether or not they are living with dementia. The experience of disempowering communication on the ability to express agency that is experienced by hearing people with dementia is also not something new for Deaf people; it is part of their everyday life. Moreover, the pre-existing context in which to understand the impact on agency for Deaf people with dementia is very different from the usual context for hearing people. It is, therefore, an important finding from this study that Deaf people with dementia and their care partners – even with the above issues – are nonetheless able to express considerable agency and maintain agency in ways that may be too easily overlooked.

There are two different contexts in which agency can be explored. Firstly, the relational agency in which can occur between the person living with dementia and their primary carer, which may be their spouse, child or close friend (Sabat and Harré, 1992; Hellström, Nolan and Lundh, 2005). The emphasis is on the couple (or care partners if not spouses) to create a nurturing context in which the person with dementia and their spouse/care partners are able to maintain their status in doing things together, including communicating as they always have done. Ernest and Libby demonstrate this naturally throughout their interviews in how they respond verbally and non-verbally with each other. They are a very tactile couple and use a method of tapping one another’s chair or gently placing their hand on one another’s knee to support turn taking or to reassure the other that they agree with what has been shared. Maggie also pats Teresa with a full hand on her thigh while pursing her lips (which, in BSL, is a non-verbal representation of agreement), as if to say ‘you’re good to me, you are, and yes, I agree with you’ when Teresa shares in the interview what it is like for Maggie being resident in the sheltered accommodation as the only Deaf person there.

Secondly, there are dementia care triads, where the agency shifts, as this occurs between i) the person living with dementia, ii) their primary carer and iii) one (or more) health professional that is offering care and support. Adams and Gardiner (2005) offer the theory of ‘disabling dementia communication’ in that
the person with dementia is unable to contribute to dialogue, or that they are perceived to be unable to make decisions. For example, this occurred for Maggie when she could not access the activities at the day centre because the hearing support staff could not communicate with her and also for Ernest and Libby when they could not access the singing group at their local dementia café.

Furthermore, Beryl’s reticence at discussing future care options with Sheila could have been further exacerbated by how Sheila discussed these issues with the social services practitioner. It may have appeared to Beryl that i) Sheila was siding with the practitioner because they were going to meet her carer-specific needs (as in receiving some respite, or going away for a family holiday) or ii) it may have been that Sheila did offer her mother support while she was unhappy at the thought of being amongst hearing people in an unfamiliar environment. It is difficult to know fully what has happened during this process, particularly as Sheila was the ‘interpreter’ in this scenario. However, Beryl asserted her agency by refusing to talk about this during the interview; but, also, it could be acknowledged that this decision-making process between Sheila and the external support services may have disabled Beryl’s agency and personhood as her wishes were not met.

Throughout both interviews, Harold and Pearl described their interactions with their hearing dementia care nurse as being all ‘perservperserv’; that is a common mouthing pattern used by Deaf people to express what it is like trying (and mostly failing) to lip-read unfamiliar dialogue with a person who cannot sign (see Chapter 7, section 7.4.3). This life-long experience of being disabled by hearing professionals who cannot sign is handled well by this couple, as they are able to reflect and smile upon the fact that, again, the people they are dealing with cannot use their first language, BSL. They do not demean the nurse in her attempts to communicate, as they do appreciate her presence and support, but they are aware that there is a barrier between them. Adams and Gardiner (2005) suggest that healthcare professionals should have appropriate supervision to facilitate better awareness of the impact of communication, and the dynamics within their dementia care triads. In this example, perhaps the hearing professional had no idea how much work the Deaf couple were doing to make things easier for her, and in reassuring her that they understood or that it did not matter when they did not understand.

In summary, these findings from the everyday lives of Deaf people living with dementia have shown the vital importance of communication in maintaining and expressing agency. It is, therefore, crucial that individual communication strategies are identified - and met - when supporting a Deaf person with dementia. The findings have also shown, however, that this simple point is not necessarily fully appreciated or acted upon by hearing professionals and carers. Without strategies to support full communication, including an understanding and recognition of communication between Deaf people with dementia and their carers, appropriate care and support will be denied. The Deaf person with dementia and their families are in the best position to advise healthcare professionals on what their requirements are in terms of communication, rather than the support services making the assumption that hearing or hard of hearing family members will interpret (i.e. Teresa for Maggie, Sheila for Beryl) or that the Deaf family members will book the interpreter themselves (Libby and Ernest; Rebecca for Harold and Pearl).
There is no possibility of agency without communication and without the recognition of effective communication where it is already occurring, e.g. between couples united by a life-long experience of being Deaf.

8.2.5 The importance of non-verbal communication for people with dementia

There has been a surge in research literature, since the turn of this Century, linked to the exploration of the concept of embodiment in dementia; where it is discussed that it is the responsibility of families and paid carers to recognise and value the non-verbal representation of how a person is feeling or thinking, if they are not able to actually verbalise their sentiments. The common foundation in all these activities to recognise intent is the assertion that the person is no longer able to verbally communicate (see Hughes, 2001; Kontos, 2004, 2005; Hydén and Örulv, 2009; Kontos and Martin, 2013; Ward, Campbell and Keady, 2014). It is argued that people living with dementia are able to represent their personhood (and citizenship) through non-verbal communication i.e. their facial expressions, body language, preference of dress, how their hair is styled, and how women relate to their handbags (Buse and Twigg, 2014) and, in some cases, culturally conventionalised gestures (Kontos, 2005; 2012).

However, within this research study, embodiment of the self, linked to language and communication, is not a revolutionary concept; it is a life-long experience for Deaf people. Deaf people's language is an embodied experience, as Harold demonstrated so well in his view of the effects of dementia on him, inseparable from his view of its effects on his language (as described on page 160). Being visual beings is an innate way of life for sign language users; for example, Deaf people are constantly visually orientating themselves to the world around them, using sign language as a kinaesthetic modality in how to perceive the world, and how to present oneself to others (Bauman and Murray, 2009). The difference between the non-verbal and language does not exist in the same way as it does for hearing speaking people. Language is non-verbal. However there have been consistent everyday barriers in which clear communication between Deaf people and their hearing counterparts has been impeded because there has been a lack of awareness and empathy in understanding and valuing what it means to live as a visual being, and that language is embodied. Sign language cannot be separated from the body; it is the body (Sutton-Spence and Woll, 1999). Furthermore, the body's gestures, facial expressions, movements, and handshapes in space and time are linguistic in their form and meaningful (Perniss et al., 2013, p. 1133). This experience is very different from the idea that the non-verbal might be meaningful for hearing people with dementia.

It is therefore necessary to challenge the concept of embodiment and what this means for Deaf sign language users living with dementia. In the interviews shared in this thesis, there were clear examples of non-verbal communication when the person was not signing (as they were not using grammatically correct expressions), but they were still embodying their intent from the basis of a life-long experience that use of space, shape and movement have specific significances (a history that hearing people do not have to draw upon). For example, if we explore a scenario with Dennis, is a hearing person with
dementia who is sitting in his favourite armchair at home. Dennis is with Flora, his wife. Dennis just simply lifts his forefinger to point at something but does not add any verbalisation to show his intent. Flora might then verbally ask Dennis questions such as, ‘what were you pointing at, Dennis? What have you seen? What is it that you want?’ There is no linguistic underpinning to this movement for Dennis; this action might be his attempt to communicate one of his thought processes; for example, he might have seen a bird outside in the garden, or he might be pointing at the next door neighbour who has walked past the house but is not able to verbalise this. Flora and other hearing people who support Dennis have a specific verbal and listening framework in engaging with Dennis, using their natural method of verbal communication to establish exactly what he meant when he pointed his finger. There might be a positive outcome, or there might be no information established.

To explore the concept of pointing further and what it might mean for a Deaf sign language user, the scenario now will be changed to include a Deaf life-long BSL user, such as Ernest, who is sitting in his favourite armchair. Libby and his family know that Ernest has used the mechanism of pointing in his language all his life and have the cultural context in which to understand it. Pointing has in fact been studied by sign linguists in many signed languages as an important feature of grammar (Cormier, Schembri and Woll, 2013). They are aware that the context in which he uses this handshape can linguistically offer a wide range of meanings but pointing is conventionalised in signed languages, it is not a random action. The purpose of using his forefinger can only be understood in Ernest's unique linguistic context; in how he has used this finger to perhaps indicate his intention to speak, in how he has used this movement to talk about time (as the forefinger can be used across the body to describe the movement of time as in the week, the month or the year); or in how Ernest is perhaps using the sign for ‘I told…’ (which is usually a single finger directed from the face), or finally, Ernest could be explaining how he watched someone walk past his living-room window (again, a single finger moved across his chest from his shoulder). These are just a few examples of what the possible intentions could be rooted to how sign languages operate. This same sign can be used in different linguistic contexts; therefore this one action of Ernest pointing his finger has a much more meaningful semantic significance, compared to Dennis’. As Young, Ferguson-Coleman and Keady (2014b) elaborate further, ‘if language in its entirety is gestural, in the sense of using space, time, vision and movement, then culture resides in the entirety of expression in that medium, not in a single item that might use that medium’ (p. 67).

To summarise, in terms of non-verbal communication and Deaf people with dementia, these findings demonstrate that the life-long experience of visual language and visual orientation within the world potentially offer a source of strength and retained ability to communicate that may be different from the adjustments hearing people with dementia might need to make to accessing the non-verbal channel open to humans. Embodiment of the Deaf person’s self has a positive life-long presence and is not altered through the development of dementia. As a Deaf researcher, I was able easily to see meaning in how Deaf people with dementia were continuing to try to communicate and remain involved in interactions as the subsequent discussions in this chapter will illustrate. However, these findings also
highlight that there is a danger that the meaningfulness of the non-verbal communication by Deaf people with dementia might not being recognised in their own right.

8.3 Resilience, Deaf people and dementia

Deaf people with dementia (and their carers) are resilient in their everyday lives. Resilience has been described as the ability to respond well to adversity (Wagnild and Young, 1993) or as being the building up of strength and skills from cumulative lifetime adverse events, that allows the person to process and deal with new adverse events (Seery, 2011). Resilience has also been defined as the combination of four attributes; which are 1) being able to rebound, 2) having a sense of self, 3) maintaining determination and 4) having a pro-social attitude (Dyer and McGuinness, 1996).

In the context of dementia, the mainstream literature on hearing people with dementia usually discusses resilience in terms of responding to a new adverse life-event within the context of their social location. Hulko (2009) argues that if the person has experienced discrimination or adversity previously, that it will position them in being able to be resilient while living with dementia. There is a paucity of literature focusing directly on measuring or valuing the resilience of the person living with dementia, while some dementia-related literature offers a focus on resilience from the perspective of the carer(s) for the person living with dementia and how they maintain their coping strategies in this new or assumed role (e.g. Russell, 2001; Svanberg, Stott and Spector, 2010; Donnellan, Bennett and Soulsby, 2015).

8.3.1 So what does resilience look like for a Deaf person?

For Deaf people who are not living with dementia, resilience is an essential component of everyday life because, as discussed in Chapter 3, Deaf people face considerable everyday challenges, setbacks, and the lower expectations of others around them, resulting from the lack of awareness and understanding of the Deaf community. Young et al. (2011) define this as, ‘it is pertinent to reframe resilience in terms of the successful navigation of the experience of being deaf in a world that creates risks that might impede self-fulfilment, safety, and wellbeing’ (p. 12).

Leigh (2009) suggests that the key to resilience for Deaf people is their ability to maintain their identity as a Deaf person and their positive self-affirmation of this in a majority hearing society. A fundamental component for Deaf people in building and retaining personal resilience is the cultural bonds with the Deaf community. As Bourdieu (1986) argues, membership of a community enhances one’s social capital simply through the beneficial exchange of culture, values and meaningful interaction, within a community where someone feels they belong. He uses the term ‘social capital’ to refer to the exchanges in communication, knowledge and shared experiences that an individual has; that enables them to belong to a community or to a group with shared understanding and values.
Deaf people’s life experience is one of challenges, hassles, setbacks and discriminations against which Deaf people succeed, therefore they are resilient. If a Deaf person has resilience, then they are able to normalise what is happening around them in their life context (Wadham et al., 2016). Within each study, different aspects of Deaf people’s resilience in the context of dementia emerged, but all with the same end result; the maintenance of citizenship and agency whether as a Deaf person and/or a Deaf person living with dementia.

8.3.2 We’re all in this together

In Study 1, for example, there was a focus on knowledge, information and understanding about dementia in the Deaf community, and the findings revealed how little Deaf community members were aware of, or understood about, dementia and how it can affect people. Nonetheless, it could be seen that the Deaf community demonstrated a staunch resilience in their approach to becoming more aware about dementia and a clear desire towards learning more about this condition. Their avowed lack of knowledge did not disempower them; rather, in the face of ignorance and lack of experience, they maintained a conviction that they would soon ‘know’. Deaf people’s life-long experience is often of accessing knowledge about a topic or gaining understanding of it later than the general population because of challenge of access and fewer opportunities for discussion (see Chapter 3, lit review and Chapter 5, data presentation). Consequently, not knowing yet about dementia was not an unusual position to be in, and their previous experiences of coming late to accessing information held them in good stead for the acquisition of new knowledge. Resilience is and was demonstrated in the Deaf community’s approach to new understanding – there was no regret that they did not know previously, but their resilience gave them passion and thirst to acquire this new knowledge.

Throughout the dialogue shared within the three focus groups, it became apparent that the Deaf community members would at times assume the role of interpreters with a communal lifelong habit of being cultural language brokers in sharing and translating information between one another (Stone, Walker and Parsons, 2011; Adam et al., 2014). This role of community interpretation was also an expectation imposed onto members of the Deaf community, as it was believed that their shared social ties would render them as responsible for ensuring information was distributed appropriately in their first language, BSL. This is a key strength and privilege of a small cultural community with strong obligations of mutual understanding. In terms of resilience, such behaviours support the building of other Deaf people’s knowledge, but also ensure that the collective increases their understanding, rather than just an individual learning process. Without this shared knowledge, then it is less possible to be resilient in the fact of changing life circumstances such as dementia. For example, if one does not know what dementia is as a condition, how can one deal with this adversity or ‘bounce back’ from the devastating news that someone one cares for has dementia? However, the life-long bank of resilience, built via being a Deaf person in a majority hearing world, potentially enabled these Deaf community members to identify sources of support in terms of accessible information in BSL (see Chapter 5, section 5.4.3.2).
of resilience demonstrated in each of these focus groups did not, however, determine what sort of emotional support was needed in terms of bouncebackability (Young et al., 2011).

8.3.3 How are Deaf people with dementia resilient?

There have been no previous in depth and personal portrayals of the experience of dementia through the eyes of Deaf people with dementia themselves. Study 2 has provided these data for the first time. Part of the problem in these accounts not previously existing is simply that nobody has previously considered asking Deaf people directly, or if they have, they have not shared a language and culture, which enables them to understand what is being shared through the words/signs of the Deaf person. One of the aspects of that experience that Study 2 has demonstrated is Deaf people with dementia’s underlying resilience in maintaining their personhood; the continuance of positioning themselves as natural citizens within their own community.

The resilience demonstrated by Beryl, Ernest, Harold and Maggie in Chapter 7 in different ways summarised their awareness that their local Deaf communities were ignorant of their specific needs, but they remained unwavering in their pride of being culturally Deaf citizens, still able to share their everyday experiences regardless of the new contexts they found themselves within. They demonstrated their sense of self, rebounding from adverse events, determination to maintain their everyday lives and maintained a prosocial approach with their family and friends (Dyer and McGuinness, 1996). For example, Harold carried on playing dominoes and card games on his iPad and with his family and friends, and Beryl continued to attend her day trips and planned holidays with her Deaf friends.

Resilience is built up through adverse experiences throughout one’s lifetime, such as being a Deaf person in a hearing world (see earlier in Chapter 3, section 3.16). However, when one is a lifetime member of a community that has built this life-long stock of cultural resilience, what then happens when others construe the Deaf person with dementia as no longer a member of their Deaf community? In different ways to varying extents this happened to Beryl, Ernest, Harold and Maggie. However, from their point of view, their membership of their community was not diminished, and any deliberate actions of exclusion did not strip them of their innate Deaf culture nor their values being Deaf citizens. They did not accept the actions of exclusion, but responded with their own coping strategies in dealing with this rejection. Harold, for example, invited two of his friends to come to his home (rather than him attending the local Deaf club) and playing cards with them there. Beryl just rolled her eyes and shrugged her shoulders (her way of rebounding) in her belief that the members of the local Deaf club were being overprotective of her in bringing her cups of tea. She allowed them to carry on with this behaviour because it was easier to let them do it, than to challenge them (this was reflective of her personality, more than being submissive because she was living with dementia).

The Deaf person with dementia (and their Deaf carers) also showed resilience in their learned skills and coping strategies in dealing with the majority community, the hearing professionals who were in their
lives in different roles, such as the diagnostic clinician who did not know how to assess a Deaf person in BSL, the carers that could not sign, the support staff at the memory café who could not communicate or the family members that offered background support but were not necessarily effective. Dealing with hearing people in their everyday lives whom could not sign and made no clear attempt to learn their language was hardly a new experience; in fact, this innate life-long resilience offered them a range of coping strategies in being able to express their exasperation or their unwillingness in having to deal with these non-signing people. Ernest and Libby, for example, laughed with hilarity at how their local memory café were offering ‘singing for the brain’ sessions; they knew they did not fit in this social frame, but they did not feel deliberately excluded, they knew it mattered for the other members of the group – like an unspoken ‘hearing thing’. Their life-long experiences of being in the minority group (Deaf) enabled them to take a step back and determine what was happening around them with the knowledge that they did not fit in, and offered them a resilient response in their bouncebackability (Young et al., 2011). For Ernest and Libby, social location (Hulko, 2009) was important and influenced how they were able to manage living well with dementia while being a Deaf person with their two worlds (the majority hearing society and their Deaf community). They knew they would be able to go to their second home (the Deaf community) to recharge their batteries, to equip them with dealing with everyday life events in the hearing world.

Beryl, Ernest, Harold and Maggie knew their communication skills were different from what they were like previously to the onset of dementia, but they did not feel they needed to alter their communication style for the hearing people around them; they were resilient in their life-long developed communication strategies and comfortable in the preservation of their identity (Beard, 2004). Life-long experiences of varying levels of successful/unsuccessful interactions with hearing people enabled them to bounce back and respond accordingly within their new situations. Maggie, for example, showed resilience in how she felt about having to communicate with non-signing hearing carers, ‘I just shut the door on them’. The hearing carer might not interpret this action as being resilient - however, they, with their lack of appreciation for what it is like to exist as a Deaf person in a majority hearing world (i.e. wearing ontological blinkers), might not understand Maggie’s resilient response to their lack of signing skills as an on-going communication issue for her, but more that Maggie is not being co-operative with their care package requirements. Ricoeur (1991) states that we have an adaptable narrative self, that shifts in the face of challenges and manages adverse life events by shifting our self around what has happened. In terms of how this applies to Deaf people living with dementia, their life-long experience of facing adversity enabled them to maintain a consistent thread of ‘being Deaf’ and living with dementia did not detract from this core identity and personhood.

8.4 Personhood and Citizenship

Both the Deaf community in general and Deaf people living with dementia embraced their individual challenges of maintaining personhood and achieving the status of citizenship.
8.4.1 Citizenship from the mainstream dementia perspective

Personhood as a concept and as a practice for dementia nursing care has been examined in dementia literature only in the last 20 years, where it was seminally defined by Kitwood (1997); the focus should be on the person living with dementia, rather than focussing on their dementia as diminishing the person as their own agent and being.

Further to Kitwood’s (1997) dialogue, deeper exploration of this concept has been undertaken; with the emphasis of personhood being one’s agency, sense of self, identity and reflexivity (Higgs and Gilleard, 2016). The concept of personhood has taken on a political perspective in the dementia field; for example, Baldwin (2008), Brannelly (2011; 2016) and Bartlett (2014; 2016) and argue that citizenship for a person with dementia means that their personhood is heard and acted upon, they are active political citizens and are visible, both in the sense of being heard and being seen; they are living well with dementia. For example, campaign groups, such as EDUCATE based in Stockport, UK (see Chapter 3 section 3.19) and the campaigner, Kate Swaffer based in Australia (2014; 2015) are now often seen in the public eye as people living with dementia who have a political agenda and are asserting their rights to be full citizens (rather than allowing the mainstream to label them as being people who cannot live well with dementia).

Powell and Edwards (2002) claim that from an older person’s perspective, that citizenship is a two way process; in order for older people to be full citizens in society, society has to enable the older generation to be full citizens, particularly through social memberships and everyday activities. Citizenship cannot be claimed in isolation from its fulfilment and enablement within wider social structures. Furthermore, citizenship is not just an ascribed status that is conferred by rights offered by the state, such as the rights to vote, to free speech and free education. It is an identity too, with overtones of national origin, cultural identity and language. To be a US citizen evokes a different meaning than to be a French citizen. Additionally, each country has its own laws and rules in what rights mean for their citizens. For example, in the USA, each state has a different ruling of what their citizens are allowed to do and not do. For instance, with regard to Deaf citizens, the Americans with Disabilities Act (ADA, 1990) is an influential piece of legislation which gives their Deaf community far more rights and opportunities to be full citizens than their UK counterparts. As an illustration, in England, Wales and Northern Ireland there is no legislation conferring legal rights associated with BSL use (although in 2015, the BSL Scotland Act changed this situation for Deaf citizens in Scotland25). There are small changes afoot, however; the BSL Scotland Act (2015) signifies a positive change in the thinking of the mainstream community about sign language users and our rights to live as full citizens in mainstream society. It places specific duties on public services to respond to and plan for the rights of BSL users in the delivery of services, including education.

Citizenship has been a particularly important topic in dementia studies literature because enabling citizenship is about building visibility, challenging beliefs and knowledge, with common shared experiences (Baldwin, 2008; Bartlett and O'Connor, 2010; Bartlett, 2014). People living with dementia have not been afforded their personhood, nor a rightful status of citizenship, because of the stigma placed on the concept of dementia and how people express themselves; Bartlett and O'Connor (2010) argue that personhood and citizenship are intertwined as one cannot exist without the other.

8.4.2 What is the definition of personhood and citizenship from a Deaf perspective?

The term personhood is a relatively new concept in the Deaf community (Senghas, 2003; Young et al., 2011). Personhood (within the context of being Deaf) is defined as the Deaf person becoming an agent, with his or her own values and opinions, which they are given the opportunity express through their language, sign language. Ladd (2003) argues that Deaf people, in evolving their personhood, experience the process of achieving Deafhood (Young and Hunt, 2011). Deafhood is about being proud of one’s minority community, with its cultural and linguistic status, regardless of the adversity; oppression and lack of rights that have occurred throughout the generations (see Chapter 3, section 3.19 for further discussion).

Citizenship in the context of Deaf people has been a negative experiential state of affairs in which rights to full citizenship, including the right to vote, the right to manage one’s own affairs and finances, the right to education and right to have children have been denied at different points in history. All have been justified in terms of Deaf people not being full citizens, either because they do not speak or because they sign. For example, Alexander Graham Bell (1884) pledged that Deaf women should be sterilised and attempted to prevent Deaf people from getting married to one another to stop the reproduction of a new Deaf generation (Lewis, 2007). In more recent times, Porter and Smith (2013) write about how the Human Embryo and Fertilisation Act (HEFA) in 2008 initially had a statement of supporting evidence, which clarified that, any defective embryos, including those from genetically Deaf families, should not be implanted.

Emery (2007; 2009) discusses social citizenship of Deaf sign language users and how they can be full agents participating in society or, rather, the difficulties in being full citizens as the Deaf community’s linguistic and cultural rights are not fulfilled by the phonocentric world (Derrida, 1976) around us/Them. Emery (2007) shares his view on three achievable outcomes for Deaf children: (i) access to their natural language is a priority, (ii) sign language should be at the centre of education and (iii) the recognition of sign language should be a priority for the nation (that the Deaf person/community lives within). This will be expanded on later in this section when exploring personhood from a Deaf person with dementia’s perspective.
Currently, in the UK, BSL is rarely the language of instruction for deaf children, despite its recognition as an indigenous minority language of the UK (DWP, 2003). Moreover, Deaf people are still not allowed to attend jury service because the BSL interpreter is perceived to be a thirteenth person in the room while the jury discuss the court trial, even though they are simply facilitating communication for the Deaf and hearing jury members to share their ideas with each other (Swinbourne, 2012). How, then, does a Deaf person achieve full recognition of personhood, and full social or political citizenship?

The United Nations Convention on the Rights of Persons with Disabilities (2006)\(^{26}\) has published guidance that support the promotion and protection of people with disabilities, with articles (sections) which all specifically document signed languages and/or Deaf culture as a priority, namely: Article 9: Accessibility, Article 21: Freedom of expression and opinion, and access to information, Article 25: Health, and Article 30: Full participation in cultural life, recreation, leisure and sport. It is recognised at European level that Deaf sign language users have the right to all these aspects of life experiences, but how are these enforceable without the correct responses from mainstream society in place? Unlike the majority of hearing people in the UK, Deaf people do not have full citizenship rights in the first place, so how does this impact on arguments about citizenship for Deaf people with dementia? Within the mainstream dementia field, Mittler (2015) has argued the case for people living with dementia’s rights to be considered within a disability context to the UNCRPD.

8.4.3 Knowledge as citizenship for Deaf people living with dementia?

I would argue that by being present in the focus groups in Study 1, the Deaf community members were actively claiming their citizenship status in two different ways; the first was that they were laying claim to knowledge, both concrete knowledge and assumed knowledge. They felt that being part of the focus group was a right, as a member of the Deaf community, because they were thirsty for knowledge and knew that this group was an opportunity to access this in their first language, BSL. It did not matter to them if their personal knowledge was erroneous because they felt it was OK to check this information within this setup, which offered them a safety net where there was no criticism or judgement. Annie remarked that she would like this type of setup again and again, but in different subject areas. She did not feel that her citizenship was diminished because of her lack of knowledge; in fact, she was proud of her status as a member of the Deaf community and felt safe, as she knew she was not alone in discovering this new knowledge within a group of people who were the same as her.

The second way in which the focus groups operated to claim citizenship concerned visible demonstration of membership of the Deaf community. This was a Deaf-only group and it was about Deaf people and authored by Deaf people. The topic was dementia, a topic that was new to most members and the collective engagement in knowledge acquisition and discussion reinforced community

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bonds around a new topic. This too was active citizenship in attempting to access and grasp knowledge that previously was denied or inaccessible.

8.4.4 How does the concept of citizenship work for Deaf people with dementia?

From the findings in both studies and the discussion thus far it is possible to propose a schemata about Deaf people's citizenship in relation to dementia. Table 5 illustrates three different membership groups and how citizenship is bolstered differently for each group.
### 8.4.4.1 Citizenship schemata for Deaf people with dementia

<table>
<thead>
<tr>
<th>Who?</th>
<th>Citizenship status</th>
<th>Who?</th>
<th>Citizenship status</th>
<th>What is being done about this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing people</td>
<td>Full assumed citizenship from birth</td>
<td>Hearing person with dementia</td>
<td>Diminished citizenship: a new state</td>
<td>Dementia movement to empower and enable their voices (a new movement)</td>
</tr>
<tr>
<td>Deaf people (in mainstream society)</td>
<td><strong>Diminished citizenship</strong></td>
<td>Deaf person with dementia (in the mainstream hearing community)</td>
<td><strong>Diminished citizenship: continuation of the same state (recognition that life-long citizenship status remains unchanged)</strong></td>
<td>Deaf activist movement to fight for our citizenship (life-long experience) has already been established but NOT a Deaf activist movement associated with dementia (yet)</td>
</tr>
<tr>
<td>Deaf people in the Deaf community</td>
<td>Full membership, which affords full citizenship as Deaf person within the Deaf community and worldwide citizenship as a Deaf person in Deaf communities internationally</td>
<td>Deaf person with dementia (who is a member of the Deaf community)</td>
<td><strong>Double layer of diminished citizenship</strong></td>
<td>No Deaf with dementia movement that engages Deaf people living with dementia within the Deaf community – hence the double layer of diminishment</td>
</tr>
</tbody>
</table>

Table 5: Citizenship schemata.
The schemata demonstrates the additional layers that require consideration when looking at Bartlett and O’Connor’s (2010) reinforcement that citizenship should be a status afforded to the person living with dementia when this concept is applied to Deaf people. These are now further elaborated. Descartes (1637) said, ‘I think therefore I am’ and this theory has underpinned traditional stigmatising attitudes about the person in relation to their dementia; i.e. if their ability to think is diminished, then so is the identity and individual human status of the person. It was a concept challenged not just by the personhood movement but also by more structural thinkers, who suggested this removal of self (and the ability to think for oneself) is a status attributed by society (Sabat and Harré, 1992), not a consequence of dementia itself. At this point, it needs to be shared that this stigma of not being able to think has been imposed on Deaf people since they were born, because they cannot hear and because they cannot make themselves understood in the mainstream hearing communities and therefore they cannot think for themselves. For us, this is not new and not seen to be associated just with dementia.

With this hearing mainstream’s stigmatising ethos, the status of citizenship therefore is already diminished regardless of whether or not the Deaf person begins to experience the onset of dementia. The data in Chapter 7 tells us that as a Deaf person, living with dementia did not result in further reduction in their citizenship as human beings within the mainstream. The everyday barriers experienced throughout their lifetimes were still there and the onset of dementia did not appear to add further diminishment of their citizenship. Conversely, what was different in terms of being full citizens was Beryl, Harold and Maggie’s removed presence in their local Deaf community. Their membership of the Deaf community was a life-long experience which had contributed to their citizenship status as being valid members of a minority community. However, Beryl, Harold and Maggie all reported of being rejected or their self-removal from their local Deaf clubs; that activity in itself was a diminishment of their Deaf citizenship status. Their status itself then became problematic because the Deaf community could not understand their condition (dementia) and were not informed (by the Deaf club members’ own admission) on how to empower and enable their peers in continuing their membership.

8.4.4.2 How do we therefore enable citizenship for Deaf people living with dementia?

This process of this piece of research in itself has offered conditions for enabling citizenship for the first time, since being diagnosed with dementia, to Beryl, Ernest, Harold and Maggie. Their full participation in the two interviews was their first empowered opportunity to tell their stories and to be heard. Having a Deaf researcher who was fluent in their language, BSL, and who is a cultural insider, enabled the four Deaf people living with dementia to be able to share their stories on an equal platform. The same would also be argued for their carers, Libby, Pearl, Rebecca, Sheila, and Teresa as they were able, for the first time, to share their experiences of being carers for their Deaf family members, with their care partners present with a Deaf researcher. Furthermore their stories were then re-told to different audiences.

27 Descartes’ famous quote can be found here: http://newlearningonline.com/new-learning/chapter-7/descartes-i-think-therefore-i-am
through this research, its publications and its public outreach to other Deaf people too. This study stops short of any claims to co-production of evidence (Keady, Williams and Hughes-Roberts, 2007) although perhaps that is for the future. However, this thesis does faithfully represent the lived experience of those who participated in Study 2.

8.4.5 Deaf activism in fulfilling citizenship

In Chapter 3, section 3.19, the different stages in how Deaf activism has taken place were discussed. With regard to the contribution that the focus groups in Study 1 offered, their views and support of this research project overall could have been perceived as a subtle level of activism in that they wanted to ensure that the Deaf community was in a better position to understand and know more about dementia. However, the participants’ own declaration that they were present in the focus groups to find out more about dementia, eager to challenge their thought processes and make it clear what future service provision should look like meant that this was less of an activist perspective and more of an anticipated learning process. However, there were elements of subtle activism, for example, when the focus groups discussed service provision being delivered in our/their language, BSL, and how information about dementia should be provided online in BSL and within mainstream dementia organisations and support services. The obligations on the researcher to report these preferences and demands were a form of activism, i) in their trust in my involvement and ii) in their knowledge of my history of activism on a range of issues within the Deaf community.

For the Deaf people living with dementia and their carers, there was a strong resilience in sharing their stories and everyday experiences, regardless of the double layers of diminished citizenship (as outlined in Table 5). It could be therefore be argued that the Deaf people living with dementia and their carers were all representing themselves as activists in this research process, as they understood that they wanted to share their stories for future generations of Deaf people potentially living with dementia. They knew that by taking part in this research, they would be influencing and changing current service provision but that it was too late for them in the here and now. Beryl said it was important ‘to tell them, they need to know about this’, and Harold, in particular, shared his view that ‘it’s too late for us now, but not for them’. Deaf people have a strong obligation to other Deaf people in all aspects of life and this was one more example of that orientation.

8.4.6 Carers scaffolding contribution to citizenship

Throughout the eight interviews with Beryl, Ernest, Harold and Maggie, there was a strong theme of their Deaf identities being maintained throughout our dialogue with one another. In fact, Deaf people in general view the maintenance of Deaf identity as something of a deliberate struggle to achieve; it cannot be taken for granted, given the on-going negativism (or ontological blinkers) of mainstream society’s attitudes towards BSL and Deaf culture. The fact that there was very little evidence of their personhood being quashed, with each individual able to share their stories directly in BSL, this fact should not be
underestimated. From Deaf people’s perspective, their personhood is under attack from both living with dementia and living within the wider society therefore its maintenance is a considerable achievement. Their carer’s support strategies (see Chapter 7, Section 7.5.4.8) were vital in this achievement and reinforce that cultural and linguistic scaffolding as a priority for future service provision that is tailored for Deaf people living with dementia and their carers.

In the interviews where there were couples present, there was clear evidence of the spouses’ scaffolding (with conversational, practical and emotional aspects) being bolstered by and intertwined with their long-term married roles. Ernest saw Libby as his main source of support and as his wife, not as his carer as such, ‘she knows everything, she does’. Harold and Pearl had their own separate roles within a strong family unit where their children were part of their everyday activities. Both couples worked in partnership as life-long married partners to maintain personhood, which, in turn, promoted the Deaf person with dementia’s agency and decision-making processes (Hellström, Nolan and Lundh, 2005; Harris and Keady, 2009).

Yet, there were a few moments in our conversations where the individual shared or became aware of how the positioning of their identity was being challenged by people inside and outside of the care relationship; for example, Harold’s knowledge that he was no longer welcome in the local Deaf club because he was too slow to keep up with playing a game of cards; Beryl’s disappointment at no longer being on the Deaf club committee because she could not count money and was better off stacking the chairs; Libby telling other members of the new Deaf group (that the couple were attending) that Ernest had been diagnosed with dementia, against his wishes; and Maggie choosing not to go to the Deaf club because she felt she was better off at home by herself; she did not have any friends there anymore. These roles in the Deaf community (i.e. membership of a group playing card games, committee member, and Deaf club attendee) could be considered as transformative (Giddens, 1991) as the Deaf person living with dementia adopted a new role within their community, mostly with their care partners, and made their own adaptations. For example, Beryl continued to attend her Deaf clubs twice a week, even though she was not a committee member any more. Ernest maintained his presence in the new Deaf group, regardless of the disclosure of his status. Maggie was content to stay at home in her flat. Harold carried on playing card games at home with his family and his gentleman friends.

8.4.7 Social citizenship considerations from the perspective of a Deaf person living with dementia

If Emery’s (2007) discussion about the three core elements of social citizenship for Deaf people is explored and considered with respect to Deaf people with dementia, then the following conditions would hold true:

a) **Access to natural language is a priority.**
How can this access be facilitated for the Deaf person living with dementia in their own home with their carer? Beryl, Ernest and Harold told stories of being content at home with their Deaf carer, knowing that communication was not an issue – BSL was the main language in the home. If someone lives in sheltered accommodation where one is the only Deaf person resident there, how is access facilitated? Maggie told of her frustration with hearing carers at her door; appreciating Teresa’s support in being able to understand what they said, but by Teresa’s own admission, she was not there for 24 hours, 7 days a week. Maggie describes her experiences without Teresa present as difficult ones where she is exasperated with the hearing carers around her not being able to sign. This lack of communication therefore could indicate that the level of care she receives may be considerably substandard compared to her hearing peers in the same facility.

All four participants told of their experiences with the local Deaf community’s rejection of their new status as a Deaf person diagnosed with dementia and of the lack of empathy and support available to both them and to their carers. Pearl told of her experiences in being asked to go back home to look after Harold, as that was the best place for her; by being present at the Deaf club, it was perceived that she was wilfully neglecting him. The local Deaf community were blind to the fact that this environment is like a second home to many Deaf people and that, in her role as Harold’s main carer, Pearl needed that time out to be able to socialise and communicate with other Deaf people in her language and get support from her Deaf friends.

In accessing mainstream dementia support, Ernest and Libby talked about how they were thirsty for access to more information about dementia in their local (hearing) memory café. There was a volunteer present who could sign up to level 2 BSL (which is the equivalent to someone learning English at Key Stage 228), but they were not able to sign fluently particularly with complex concepts. Libby felt she just had to write relevant notes down and then take these notes home with her in case she would meet someone who could explain them to her in more depth.

In terms of future care support, including the potential next steps of moving into residential care, Beryl was fearful of moving into a local residential home (Sheila had informed her she would need to do so while the family went on holiday) because she knew she would be isolated as the only Deaf person in the home. Neither the local residential home nor the local social services team offered any reasonable adjustments or practical solutions to resolving these communication worries for Beryl and Sheila.

b) **Sign language should be at the centre of care provision.**

All four participants discussed how, in their everyday lives, they came across barriers to communicating with hearing professionals who were providing different levels of care and support. Not one example

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28 Key Stage 2 is taught with primary school age children in the UK.
was given of how those hearing professionals had considered that they were working with a person who came from a minority group, nor was there any evidence shared of those professionals learning BSL in order to communicate with their signing Deaf clients. In their interviews, Harold and Pearl discussed how the community nurse visiting their home tried her best to communicate clearly, but in their words, she was a really hard person to lip-read. Additionally, Maggie talked about the nice lady that came into her flat with all smiles but admitted that she did not understand a word she said. Beryl showed her fear at knowing that she would have to try and understand the social services assessor who was visiting their house to talk about future care provision; fundamentally, she was very conscious that they wouldn’t ‘know’ her in terms of her Deaf identity nor use her first language, BSL.

c) The recognition of sign language should be a priority for the nation (that the Deaf person/community lives within).

Mainstream organisations that offer specialist dementia information and support are making small steps towards developing accessible information in BSL for Deaf people living with dementia. For example, the British Deaf Association in Northern Ireland have worked in partnership with the Alzheimer’s Society to develop a DVD in BSL explaining what dementia is and offering personal stories of Deaf people caring for a family member with dementia (BDA, 2015c). However, providing this one-off format of information does not support the Deaf person living at home with dementia and their Deaf carer in their everyday lives and their access to support. When they meet front-facing staff who support the mainstream community with dementia, oftenmost, they are not able to sign at all. If they were to have prior preparation, these staff could attend a Deaf awareness course, which would facilitate opportunities for full communication.

During the interviews, it transpired that one family had asked their local branch of the Alzheimer’s Society to pay for interpreting support but the request was refused on the premise that it was too expensive for their local budget. This request was then taken by the researcher and the supervisory team to the national headquarters of the Alzheimer’s Society and this was still not granted, due to there being no money available for this type of support.

Throughout this section, I have discussed how Deaf people tend to see their status of citizenship as a problem that is situated between the majority (hearing) and minority (Deaf) community with the former withholding rights to full citizenship and fulfilment for the latter (as being a member of the Deaf community). However, the testimony of participants, whether in individual interviews or in the focus groups, point to another key barrier in respecting citizenship for Deaf people with dementia – one that comes from within the Deaf community, not outside it. Assumptions, prejudices, ignorance and stigma displayed by Deaf people who are not living with dementia themselves need to be challenged within the wider Deaf community, before any positive positioning of citizenship can take place for the Deaf person with dementia. Only then will appropriate cultural safety measures (Hulko and Stern, 2009) be put into place. When the health and community service providers understand what positive citizenship means
for the Deaf community, Deaf people living with dementia’s cultural and linguistic requirements will be met.

8.5 Concluding Summary

- Non-verbal communication for Deaf people with dementia does not represent a transition to a new channel of available expression. It is a continuation, be it differently, of a life-long visual way of being. Therefore, its potential as a retained strength in continuation of meaningful communication should be recognised. It challenges and extends some of the assumptions that underpin the current literature on non-verbal communication and dementia because Deaf people’s language has always been embodied.

- Deaf people are resilient in desiring and wanting to understand information and gain knowledge about dementia in an accessible format. Deaf people living with dementia and their carers, in the face of diagnosis and support after diagnosis, maintain high levels of internal and external resilience in dealing with life experiences. These are not commonly recognised nor seen as a source of strength. This life-long coping mechanism of resilience, while being Deaf, enables Deaf people with dementia and their carers to deal with adversity, such as miscommunication with hearing professionals. This is the first time Deaf people living with dementia and their carers have been recognised as resilient citizens.

- Full citizenship status has never been afforded to Deaf people in mainstream society. Living with dementia did not impact on this reduced status as it has remained as a constant. Conversely, full membership of their Deaf community was effectively diminished to the point of personal exclusion. However, their resilience allowed positive management of this, reflected in the coping strategies employed. Exclusion of minority groups within a majority minority group (intra-community oppression) is not a novel concept; but this occurrence being informed (or presented) by Deaf people living with dementia and their carers is entirely unique.

- The activism of Deaf people living with dementia has taken the form of witnessing their experience to another Deaf activist (the researcher) in order to leave a legacy for the future. There is a strong collective desire to change services and improve quality of life for others in the community who will go through a similar experience. The collective, futures orientated perspective of all those who took part in the study is remarkable for its potential power as an agent of change.
Contribution to knowledge

This thesis has offered an important contribution to world knowledge from two vantage points: the Deaf community’s understanding, knowledge, and support requirements linked to dementia; and understanding, valuing and recording the everyday experiences of Deaf people living with dementia and their carers.

From the first vantage point, which is the Deaf community, it is now understood how information about dementia should be delivered to Deaf people to ensure that it is understood, trusted and valued. Deaf people do not want dementia information just in BSL, their language; they want this information to be accessible, easy to grasp and transferable to their realities. Deaf people want to know more about dementia and have demanded that more information should be delivered.

Additionally, the Deaf community wants dementia specific support services to be tailored specifically to their culture and language; they are keen to work with hearing professionals, because they know this is part of their reality as members of a minority group, nonetheless, they feel strongly that these professionals should be familiar with Deaf culture and fluent in BSL.

From the second vantage point, this thesis has explored the worldview of Deaf people living with dementia and their carers for the first time. Their stories have told what everyday life is like living with dementia as a Deaf BSL user. In their words, their worlds crucially remain the same; living with dementia does not alter this world in terms of maintaining their Deaf identity and values. What they believe is unchanged is how hearing people around them do not consider their communication needs; how hearing support services are not tailored to their specific needs; and how hearing people do not consider their cultural and linguistic differences. Deaf people living with dementia remain resilient in their citizenship, while recognising that their communication needs have changed in terms of finding it difficult to express themselves and valuing their carer’s scaffolding strategies to facilitate their expression.

However, they told us how they feel that they no longer belong in their second home, the Deaf community, because the Deaf community does not have empathy or experience in supporting Deaf people with dementia. The Deaf community has deliberately excluded its own members, not through malicious intent, but through lack of knowledge and understanding. Deaf people living with dementia (and their Deaf carers) feel like they have lost a really important component of their livelihoods, but yet remain content and happy in their familial relationships.
10 Study Limitations

10.1 Face-to-face recruitment

The recruitment strategy for the interviews was two-pronged, in order to reach potential participants within a very small community that is geographically diverse. While there were no responses for the clinical route, there were limited responses from the Deaf community route for a variety of reasons. As a Deaf researcher, it was a conscious decision to visit as many Deaf clubs as possible within the timescale as face-to-face contact with this community was paramount to build up trust and to show physically who the researcher was on this study. However, this approach was not as effective as anticipated as it became apparent that Deaf people living with dementia were not visiting these clubs as regularly as they used to, because they were either not being supported in getting to the club or had been excluded from those clubs due to their condition. This is further expanded on in Chapter 7.

10.2 Limited longitudinal approach

Two interviews were conducted six to 12 weeks apart. While the time spent with the participants was extremely valuable and afforded the opportunity to collect rich data, the constraints of the study timescale meant that there was not the opportunity to commence a longitudinal study, which would have further developed the relationship between the researcher and the participants. Additionally, the researcher would have been able to make note of any marked differences in the Deaf person with dementia's presentation over a longer period of time and elicit from close family members more comprehensive descriptions of these differences, for example, perhaps the sharing of more details linked to evidencing the actual changes in language/behaviour/personality. A longitudinal design may well help to capture such transitions and adaptations in a future study.

10.3 Timing of interviews in the personal dementia history of participants

Due to the general barriers to accessing health services, all the participants' diagnosis of dementia was received at a later stage in their condition, which meant the onset of dementia had transformed into something that became embedded as part of their identity. If the research study had commenced at an earlier stage in their diagnostic process, more might have been shared about the subtle alterations that were indicating the onset of dementia.

10.4 Being a Deaf researcher

As a member of the same linguistic and cultural community, there were natural assumptions from participants in both the interviews and the focus groups that there was already knowledge possessed by the researcher. At times, participants' ideas or experiences were not specifically
elaborated upon, as it was assumed the pre-existing knowledge the researcher possessed meant for them that nothing further needed to be said. This is common in studies where the participant believes the researcher is from the same cultural group or if the question being asked is too obvious to be answered (see Hulko, 2004, p. 248), but for the purpose of research, it has to be elaborated upon. The researcher had to directly ask for clarification or ask for further explanations to be given, sometimes to the puzzlement of the participant making the erroneous assumption.

10.5 Language of data capture in the focus groups

As previously discussed, although the data were generated in the participants’ first language (BSL), the decision was made not to capture it in BSL using video cameras. It was simultaneously translated into English and captured by a voice over from the interpreters present. While the researcher made contemporaneous notes after each session had taken place, there is awareness that the source data may not have been represented in its entirety as the voice-overs by each BSL/English interpreter will have been conducted through their own frame of reference. This may have had an impact on the depth in which the data were presented. As Temple and Young (2004, p. 164) clarify, there are challenges that stem from the acknowledgement that the use of different languages may construct different ways of representing someone’s life in a social context. In addition to this, each BSL-English interpreter will have their own social positioning, which will then colour their interpretation of first-hand information shared in BSL (Stone and West, 2012).

Also, as the focus groups were not video-recorded, there is no opportunity to visually check the source data alongside the voice-overs to ensure that the interpreters have fully reflected what each Deaf person was signing within the group. However, the researcher has been able to refer to their contemporaneous field notes as well as rely on their memory to recollect where people were sitting and who would have said which statements. For future studies in this area involving Deaf people, the use of video cameras will be employed to ensure that clear reviewing processes can be achieved for richer analysis.

10.6 Comparing geographical variations

Study 1 was a valuable opportunity for Deaf people to attend focus groups to discuss the topic of dementia and for the researcher to gauge their knowledge of the condition. The focus groups were concentrated in one geographical area. For future studies, it might be useful to consider setting up focus groups in different regions to compare, if any, the differences in knowledge and support service provision.

10.7 Interviewing professionals involved in providing support
Each interview was held with the Deaf person living with dementia and their care partner (whether this was their spouse or another family member). There was deliberately no dialogue with the hearing professionals offering support in their everyday lives (such as the sheltered housing manager for Maggie, or the nurse who worked with Harold and Pearl), as the first-hand stories of Beryl, Ernest, Harold and Maggie and their families were vital to this study. However, in a future study, meeting these professionals and exploring their perspectives on their provision of support to Deaf people living with dementia would offer a new dimension to the interpretation of meaningful and effective support.
11 Future Implications

11.1 Research studies

- From these original findings, there is an on-going research project (the Deaf with Dementia Life-Stories Project, as part of the Neighbourhoods and Dementia Study funded by ESRC/NIHR\(^{29}\)) exploring the use of technology to support the development of life-stories for Deaf people and their carers in different home environments, such as with their families, and within care homes and day centres. It takes forward a key finding from this study that connectedness with hearing carers who have no knowledge of Deaf culture is of importance. This study will pilot the impact of increased knowledge and if this supports interactions between Deaf people living with dementia and their hearing carers.

- There is therefore scope to explore further through a longitudinal study, where there could be more key junctures noted in terms of any changes brought on due to the onset of dementia whether in terms of language, communication or care needs. This will also test the conclusions drawn about the resilience responses of Deaf people with dementia and whether and how these are retained or not.

- Deaf people with dementia are geographically diverse so there is a high likelihood of Deaf people being resident in care homes where they are the only Deaf person present. They could remain undiagnosed as living with dementia as their communication needs are not being fully met. A future research study could address this very different context in which Deaf people with dementia may be living without close culturally and linguistically matched care. It is anticipated that their experiences would be very different from those who remained in their family homes. This evidence would be important both to understand this bigger context, but also to see how lessons of strength and resilience and practical support learned from the current study might be translated into the broader care environments.

11.2 Policy Development

- The All-Party Parliamentary Group on Dementia (2016) have made progress in highlighting the needs of people with hearing loss and dementia, as well as SCIE through the Dementia Gateway where they have published work on sensory loss and dementia (Young, Waterman and Ferguson-Coleman, 2013). However, there is scope to explore the development of a policy that considers meeting the cultural and linguistic needs of Deaf people living with dementia and their

\(^{29}\) http://www.neighbourhoodsanddementia.org/
carers which would encompass primary care needs throughout to end of life care (including hospital and hospice stays). Much of the current policy work on dementia undeliberately excludes Deaf people. The recent review on co-morbidities (APPG, 2016) might recognise sensory needs but does not associate deafness with BSL users; the recent policy guidance on ethnicity and culture in association with dementia (APPG, 2013) fails to recognise Deaf people as a cultural minority.

- Dementia friendly communities need to consider their accessibility for Deaf people who use BSL as their first or preferred language. These language issues are not highlighted in the Prime Ministers Challenge on Dementia or in the Alzheimer’s Society report (Alzheimer’s Society, 2013; DoH, 2012; 2015). The APPG report (2016) mentions hearing loss but does not consider the needs of this cultural linguistic minority group. This is an area ripe for development.

11.3 Training

- As part of the dissemination work for the Deaf with Dementia project, a ‘Dementia and Deafness’ training package was developed and delivered to Greater Manchester West NHS Trust (UK) staff in 2015. This package addressed issues and challenges there are in working with a cultural, linguistic minority and offered solutions for front-line staff. This package could be rolled out to other NHS Trusts across the UK.

- Training sessions are offered to MSc Dementia Care students at the University of Manchester annually. This is a key juncture where staff are able to reflect on their professional practice and consider what they should do when supporting Deaf people living with dementia and their carers.

- An online website has been developed for the wider mainstream and for the Deaf community (www.deafwithdementiahub.com) where information about dementia, where to go for a diagnosis and for support has been made available in BSL and English. It could be extended much further. Training sessions could be developed for Deaf people to become Deaf with Dementia champions so that they are reachable for their local Deaf community members should they have any concerns about themselves, their families or friends.

- Advocates for Deaf people with dementia should be trained and established within local PALS and mental health services, as there are still no specialist dementia services available to support Deaf people living with dementia and their families.
12 References


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13 Appendices (i)

A. Acceptance letter from University of Manchester Research Ethics Committee
B. Focus Group recruitment advertisement
C. Focus Group information sheet
D. Focus Group consent form
E. Topic guide for focus groups
F. Eligibility checklist for clinical route
G. Recruitment advert for community route
H. Participant information sheet
I. Carer information sheet
J. Participant consent form
K. Carer consent form
L. Acceptance letter from Research Ethics Committee Manchester South
M. Topic guide for interviews
A. Acceptance letter from Research Ethics Committee at the University of Manchester

Secretary to Research Ethics Committee 5  
Faculty Office - Devonshire House

Tel: 0161 275 0288

Email: jared.ruff@manchester.ac.uk

Emma Ferguson-Coleman  
School of Midwifery, Nursing and Social Work

22nd June 2011

Dear Emma

Research Ethics Committee 5 (Flagged Humanities) - Project Ref 10397

I am writing to thank you and your colleagues for coming to meet the Committee on 23rd May 2011 and providing follow up material to address the issues that I raised with you in my email of 31st May 2011. I can now confirm that by way of chair's action your project has now been formally approved by the University Ethics Committee 5 (flagged Humanities).

This approval is effective for a period of five years and if the project continues beyond that period it must be submitted for review. It is the Committee's practice to warn investigators that they should not depart from the agreed protocol without seeking the approval of the Committee, as any significant deviation could invalidate the insurance arrangements and constitute research misconduct. We also ask that any information sheet should carry a University logo or other indication of where it came from, and that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a university computer or kept as a hard copy in a location which is accessible only to those involved with the research.

Finally, I would be grateful if you could complete and return the attached form at the end of the project or by September 2012.

I hope the research goes well.

Yours sincerely

Jared Ruff  
Senior Research Manager  
Faculty of Humanities and Secretary to URC 5 (Flagged Humanities)  
0161 275 0288  
jared.ruff@manchester.ac.uk

UNIVERSITY OF MANCHESTER
Progress or Completion Report Form on an Approved Project

The Committee's procedures require those responsible for projects which have been approved by the Committee to report on any of the following:

* Any incident, accident or untoward event associated with the project (Please note that if the incident constitutes an accident or dangerous occurrence, the usual Health and Safety reporting mechanism must still be used)
* Any variation in the methods or procedures in the approved protocol
* A termination or abandonment of the project (with reasons)
* A report on completion of the project or a progress report 12 months after approval has been given.

The report should be sent to the Secretary to the Committee, Dr T P C Stibbs, Room 2.004 John Owens Building, University of Manchester, Oxford Road, Manchester M13 9PL (tel: 0161-275-2046/2206).

Project: Ref 10397
B. Focus Group recruitment advertisement
C. Focus Group information sheet

Deaf People with Dementia project

Focus Group information sheet

BSL version on accompanying DVD and at www.manchester.ac.uk/deafwithdementia

What is the aim of the research?

The Government has written a document about hearing people who have dementia but there is no information about Deaf people.

We want to talk with Deaf people who do not have dementia.

We want to find out:

• What your understanding of dementia is;
• Where you would go to find out information about dementia;
• If you or someone in your family has dementia, where would you get support?
• Your views and opinions about current service provision.

The research is being done so that we can understand what Deaf people’s knowledge about dementia is like, what Deaf people’s priorities are when they or their families receive a diagnosis and what services need to do to support Deaf people better when they have dementia.

Why have you been given this leaflet/DVD?

• You have registered for the Deaf with Dementia focus group.

Do I have to take part?

No. It is entirely your decision whether you want to be in the focus group. If you decide not to take part, that is OK.

If you decide to take part, but then later change your mind that is OK. You can withdraw from the group at any time. You do not need to tell us why you do not want to be involved.

If I agree to take part, what will I have to do?

You will be contacted to take part in a focus group, which will be delivered in BSL. We will ask you about your knowledge of dementia, what you think should happen for Deaf people to get appropriate support and to review existing service provision.

Will I receive payment for taking part in the study?
You will receive travelling expenses from your home/workplace to the place where the focus group will be held.

**Who is organising and funding this research?**

Emma Ferguson-Coleman (see photo) is carrying out the research as part of her work at the University of Manchester. The project is funded by the Alzheimer’s Society. Her supervisors are Professor Alys Young and Professor John Keady. The research has ethical approval from The University of Manchester Ethics Committee.

The Royal Association for Deaf people is supporting this project by organising the focus groups at different venues in the UK.

Emma’s role is a researcher. She will ask you about your knowledge and experiences. She is collecting information about different Deaf people’s views about how people understand dementia, how Deaf people would recognise dementia, where they would get information and support if they or their families are diagnosed with dementia.

**What happens to the information from the groups?**

The discussions will be voice-overed by BSL interpreters. The information will be recorded onto an audio-tape. Emma will transcribe this data from the discussions on a password-protected computer. She will analyse what people have said about dementia and what their views are.

**How will confidentiality be kept?**

The audio-recordings will be kept on a password-protected remote data storage server which is not kept in Emma’s office. Any notes will be kept in a lockable file that is in an office on a different floor in the same building.

Emma's academic supervisors at the University of Manchester (Professor Alys Young and Professor John Keady) will listen to some of the audio-recordings and read some of the notes.

It is also possible that a person from an Ethics or Clinical Governance office in the University of Manchester, in a regulatory authority or in an NHS Trust may want to listen to the audio-recordings to check that the researchers are carrying out the study in an ethical way.

If you want to see photos of the two supervisors, these are on the website www.manchester.ac.uk/deafwithdementia

When the project is finished and the research results are presented to the public, no audible material from the audio-recordings or names will be used, so you will not be identifiable. If any quotes are presented in the results, English quotes will be anonymous and BSL quotes will be signed by an actor. Information collected may be used again in the future for different studies. You will be asked for your
permission for this. Any information gathered will be kept confidentially and securely for ten years. It will then be deleted.

**Will the outcomes of the research be published?**

We will write about the research results for professional research journals and Deaf publications like *British Deaf News*.

The results will be presented in BSL and English on the study website. We will present the results at academic conferences and conferences that link service users with service providers and researchers, like Alzheimer’s Society, National Dementia Congress and INVOLVE.

We will offer to talk to Deaf organisations and social groups. Finally, we will create a summary of the results and recommendations for Alzheimer’s Society and other service providers to use.

The results will be available from late 2012.

**What are the possible disadvantages and risks of taking part?**

The researchers think it is unlikely that you would come to any harm through taking part in the group. However, it is possible that asking you to talk about difficult experiences could be upsetting for you. The guide for what to talk about is very open so you can choose what experiences you feel comfortable about sharing.

**What are the possible benefits of taking part?**

There is no specific benefit to you through taking part in the research. However, you may enjoy knowing that you are contributing to the potential improvement of services in the future.

**What if something goes wrong?**

If anything about the study upsets you or raises questions for you, while you are taking part or afterwards, please email Emma at dwd@manchester.ac.uk or text her on 07500 126219. She can then talk with you in BSL via webcam if you prefer. If you need more information or help that she cannot provide, she may ask you if you would like her to put you in contact with someone else.

**Complaints**

If you have questions or concerns that the researchers cannot answer or if you want to make a formal complaint about the research, please contact a University Research Practice and Governance Coordinator by email on research-governance@manchester.ac.uk or via phone using Typetalk on 0161 275 7583 or 0161 275 8093. If you need to speak to someone in that office face to face through a BSL/English interpreter, this could be arranged.

**How long will the study run for?**

The study starts in June 2011 and the project will finish in October 2012.

**Who can I contact for more information?**

If you have any questions or concerns about the research, please contact Emma at dwd@manchester.ac.uk. You can then arrange to talk to her in BSL via webcam if you prefer. There is also more information on the study website at www.manchester.ac.uk/deafwithdementia.

If you have questions, but would rather contact one of the project supervisors, you can email Professor Alys Young at alys.young@manchester.ac.uk. Alys would also be happy to answer questions in BSL via
webcam. Alternatively, you can contact Professor John Keady by email at john.keady@manchester.ac.uk

What happens next?

If you are happy to be involved in the focus group, please complete the enclosed consent form and post it to Emma Ferguson-Coleman, Research Assistant, at:

Social Research with Deaf People Group (SORD),
School of Nursing, Midwifery and Social Work,
The University of Manchester,
Room 4.312, Jean McFarlane Building,
Oxford Road, Manchester M13 9PL.

The consent form is also available to view in BSL at the end of the DVD. If you prefer, you can complete the consent form online on the website www.manchester.ac.uk/deafwithdementia.

Emma will then contact you to arrange a date for the focus group.
D. Focus Group consent form

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<tr>
<td>1.</td>
<td>I have read the Deaf with Dementia Project information sheet or I have watched the BSL video explaining the study.</td>
<td>YES/NO</td>
</tr>
<tr>
<td>2.</td>
<td>I have received enough information about the focus group.</td>
<td>YES/NO</td>
</tr>
<tr>
<td>3.</td>
<td>I am happy to have my views audio-taped in the focus group.</td>
<td>YES/NO</td>
</tr>
<tr>
<td>4.</td>
<td>I understand that the information from the focus groups may be used in the project’s publications and presentations. I am aware that my name will not be used.</td>
<td>YES/NO</td>
</tr>
<tr>
<td>5.</td>
<td>These audio-tapes will be kept safe at the University. I am happy for them to be used again in the future in a different study.</td>
<td>YES/NO</td>
</tr>
<tr>
<td>6.</td>
<td>I understand that I can withdraw from the group at any time.</td>
<td>YES/NO</td>
</tr>
<tr>
<td>7.</td>
<td>I agree to take part in this study.</td>
<td>YES/NO</td>
</tr>
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Name of participant:  
Signature of participant:  
Date  

SCHOOL OF NURSING, MIDWIFERY and SOCIAL WORK  
PARTICIPANT CONSENT FORM
E. Topic guide for focus groups

**Topic guide for Focus Groups 13th – 15th September 2011**

Ensure that people have watched the video or read the info sheet and collect all **signed** consent forms.

**Intro:** 5 mins One hour for each group, food and drinks, comfort breaks. Ensure confidentiality – explain my role as a facilitator – no pressure if they don’t want to share anything, be comfortable.

5 mins: Introductions (name, where from etc)

5 mins: Explain what project is about (brief!)

**Questions to ask the group:** (will put up on flipchart too)

- **10 – 15 mins:** What their understanding of dementia is?
  - Word means what?
  - What signs do you use for the word? (need to plan on how this will be voice-overed!?)
  - What happens when a person has dementia?
  - What signs (as in clues) would you think means someone has dementia?
  - Experience of living with or caring for someone with dementia?

- **10-15 mins:** Where they would go to find out information about dementia?
  - Who provides information?
  - Which type of information is better, who helps you understand it?

**Check for comfort breaks**

- **10-15 mins:** If they or someone in their family has dementia, where would they get support?
  - Who would support you?
  - Where would you get help from?

- **10-15 mins:** Their views and opinions about current service provision
  - What’s out there now? How far? Easy to find? Easy to travel to?
  - Names of organisation(s)?
  - Good service? Have access in BSL?
  - What would be better for Deaf BSL users?

**Break for food and drink**

- **10 mins:** Review of Alzheimer’s Society website with support from RAD staff (if needed)

- **10 mins:** Feedback from group

- **5 – 10 mins:** Any final comments/thanks for attending.
F. Eligibility checklist for clinical route

John Denmark Unit current caseload screening checklist

Is the patient:

☑ Aged 55 years or above?
☑ With a suspected or current diagnosis of dementia?
☑ Currently on the JDU’s caseload?
☑ With capacity to participate in this study?
☑ Able to make an informed decision to accept information about the study?

If so, with their permission, please suggest offering the person with dementia or their carer the information pack about this study.

They can then decide for themselves if they wish to make contact with the researcher, Emma Ferguson-Coleman.
G. Recruitment advertisement for community route

Image of recruitment advertisement:

- Alzheimer's Society
- Funded by Alzheimer's Society

**Why do we want to meet you?**

This is a research project about older people who have been diagnosed with dementia and their carers.

- We want to find out:
  - How do you find out you had dementia?
  - What is daily life like for you?
  - What kinds of services are important to you?
  - What has changed and what has stayed the same for you and your family?

The research is being done so that we can understand more about the needs of older people with dementia and their carers and improve services in the future.

**We would like to meet people who are:**

- Aged 55 years and over
- British Sign Language users
- Diagnosed with dementia in the last two years

If you would like more information about this study, please contact Emma Ferguson-Collman, Research Assistant, at

Social Research with Old People Group (OROG),
School of Nursing, Midwifery and Social Work, The University of Manchester
Orchard House, Oxford Road, Manchester M13 9PL

Telephone number: 0161 306 7711
Mobile number: 07790 028219
email: emma.ferguson-collman@manchester.ac.uk

Emma will then contact you by your preferred method: email, SMS or telephone to arrange a convenient time and place to visit you.

Emma will ask you and your carer some questions to see if you are happy to be interviewed about your experiences of living with dementia.

There are no medical tests involved.
H. Participant information sheet for Deaf people living with dementia

Participant information Sheet

Why have you been given this leaflet/DVD?

- You have told us you have dementia (or)
- Your carer told us you have dementia (or)
- You told us you would be interested in more information.

Emma Ferguson-Coleman (see photo) is employed to carry out this research with the University of Manchester. The project is funded by the Alzheimer’s Society. Her supervisors are Professor Alys Young and Professor John Keady. The research has ethics permission from National Research Ethics Committee.

Emma’s role is a researcher. She will come to interview you about your experiences. She is collecting information about different Deaf people’s views about living with dementia. Emma will make sure you are happy to do the interview with her and she will respect your choice if you want to carry on or not. She is responsible for keeping your information confidential.

Why do we want to meet you?

This is a research project about Deaf people who have been diagnosed with dementia and their carers.

We want to find out:

- How did you find out you had dementia?
- What is daily life like for you
- What kinds of services are important to you?
- What has changed and what has stayed the same for you and your family?

The research is being done so that we can understand more about the needs of Deaf people with dementia and their carers and improve services in the future.

What do we want to do?
Emma will come to your house
(or a different place of your choice)

At a time that suits you and your carer

Emma will use video cameras for our chat

Emma will come to see you twice in nine months

**What will we do with your information?**

We will write a report about what everyone tells us.

Your personal details will be kept confidential.

Emma's academic supervisors at the University of Manchester (Professor Alys Young and Professor John Keady) will see some of the videos and some of the notes.

**Nobody else** will see the information you give us. It is important that you know who will see the information because you are using BSL and so these people will see your face too. You will not be anonymous.

*If a major concern arises from the interviews, Emma will discuss these with her two supervisors. Contact may then be made with your GP (We will ask your permission for this.)*

**What happens next?**

You choose if you want to be involved **YES or NO**

If you say yes, we will give you a form where you will tick a box to say you want to be involved.

If not, that is fine. We will not ask you again.

If you want to take part in the study, you can contact Emma Ferguson-Coleman, Research Assistant, at:

**Social Research with Deaf People Group (SORD),
School of Nursing, Midwifery and Social Work,
Room 4.312, Jean McFarlane Building, The University of Manchester, Oxford Road, Manchester M13 9PL.**

Emma will then contact you by your preferred method (email, SMS etc) to arrange a convenient time and place to visit you.
Where will the research be published?

This report will be given to the Alzheimer’s Society

The report will also be included in professional research journals and Deaf publications like British Deaf News.

The results will be presented in BSL and English on the study website www.manchester.ac.uk/deafwithdementia

The results will be presented at academic conferences and conferences that link service users with service providers and researchers, like Alzheimer’s Society. National Dementia Congress and INVOLVE.

We will also talk to Deaf organisations and social groups.

The results will be available from late 2012.

If you are not happy with the research?

You can contact:

Professor Alys Young or Professor John Keady

alys.young@manchester.ac.uk or john.keady@manchester.ac.uk

telephone 0161 306 7747 or telephone 0161 306 7854
fax 0161 306 7707 or fax 0161 306 7894
What is the aim of the research?

This is a research project about Deaf people who have been diagnosed with dementia and their carers.

We want to find out:

- What is daily life like for you?
- What kinds of services are important to you?
- What has changed and what has stayed the same for you?

The research is being done so that we can understand more about the needs of Deaf people with dementia and their carers and improve services in the future.

Why have I been sent this letter and DVD?

- We are contacting you because you have told us you are a carer for a Deaf BSL user, who has dementia.
- The Deaf BSL user that you are caring for has agreed to take part in this study.
- You have told us you would be interested in taking part.

Who can take part in this study?

We want to meet people who are:

1. Carers who live with and care for a Deaf BSL user with dementia
2. Willing to talk about their experiences of living with a Deaf person with dementia

Do I have to take part?

No. It is entirely your decision whether you want to be in the research study. If you decide not to take part this will not affect in any way the services you receive.

If you decide to take part, but then later change your mind, that is OK. You can withdraw from the study at any time. You do not need to tell us why you want to stop the interviews.

If I agree to take part, what will I have to do?
The researcher, Emma Ferguson-Coleman, will contact you first to arrange to visit you at home or in another place that is convenient for you. This visit will take about an hour and will take place in BSL. If you cannot sign, please let us know and we will bring an interpreter with us to facilitate communication.

This is an opportunity for you to find out more about the research and ask questions and get to know the researcher. Emma is Deaf herself.

You can choose whether you wish to be interviewed with the person you care for, if you prefer, or on your own.

If after this first visit you want to continue, then Emma will come and see you two times in nine months to find out how things are going for you. She will ask you about what has been happening for you and what you think about the help you are getting from services in your area. These conversations will be recorded on video tape.

**Will I receive payment for taking part in the study?**

No. The researcher will visit you at home or at a different place of your preference. This means you will not need to pay anything out of your pocket.

**Who is organising and funding this research?**

Emma Ferguson-Coleman (see photo) is employed to carry out this research with the University of Manchester. The project is funded by the Alzheimer's Society. Her supervisors are Professor Alys Young and Professor John Keady. The research has ethical approval from a National Research Ethics Committee.

Emma’s role is a researcher. She will come to interview you about your experiences. She is collecting information about different Deaf people’s views about living with dementia. Emma will make sure you are happy to do the interview with her and she will respect your choice if you want to carry on or not. She is responsible for keeping your information confidential.

**What happens to the information from the video tapes?**

Emma will analyse the video tapes from the interviews on a password-protected computer. She will analyse what people have said about living with a person with dementia and what their views are.

**How will confidentiality be kept?**

The videos will be kept on a password-protected video library server which is not kept in Emma’s office. Any notes will be kept in a lockable file that is in an office on a different floor in the same building.

Emma’s academic supervisors at the University of Manchester (Professor Alys Young and Professor John Keady) will see some of the video data and some of the notes.
It is also possible that a person from an Ethics or Clinical Governance office in the University of Manchester, in a regulatory authority or in an NHS Trust may want to see the videos to check that the researchers are carrying out the study in an ethical way.

**Nobody else** will see the information you give us. It is important that you know who will see the information because you may be using BSL and so these people will see your face too. You will not be anonymous.

If a major concern arises from the interviews, Emma will discuss these with her two supervisors. Contact may then be made with your GP (we will ask your permission for this.)

If you want to see photos of Emma’s two supervisors, these are on the website [www.manchester.ac.uk/deafwithdementia](http://www.manchester.ac.uk/deafwithdementia)

When the project is finished and the research results are presented to the public, no videos or names will be used, so you will not be identifiable. If any quotes are presented in the results, BSL quotes will be signed by an actor. Quotes in English will be anonymised. Information collected may be used again in the future for different studies. You will be asked for your permission for this. Any information gathered will be kept confidentially and securely for ten years. It will then be deleted.

**Will the outcomes of the research be published?**

We will write about the research results for professional research journals and Deaf publications like *British Deaf News*.

The results will be presented in BSL and English on the study website. We will present the results at academic conferences and conferences that link service users with service providers and researchers, like Alzheimer’s Society. National Dementia Congress and INVOLVE.

We will offer to talk to Deaf organisations and social groups
Finally, a summary will be written with recommendations for Alzheimer’s Society and other service providers to use.

The results will be available from late 2012.

**What are the possible disadvantages and risks of taking part?**

The researchers think it is unlikely that you would come to any harm through taking part in the study. However, it is possible that asking you to talk about your experiences could be upsetting for you. You will not be forced to discuss anything you are not comfortable talking about and it is up to you what you want to share.

**What are the possible benefits of taking part?**

There is no specific benefit to you through taking part in the research. However, you may enjoy knowing that you are contributing to the potential improvement of services in the future.

**What if something goes wrong?**

If anything about the study upsets you or raises questions for you, while you are taking part or afterwards, please email Emma at dwd@manchester.ac.uk or text her on 07500 126219. She can then talk with you in BSL via webcam if you prefer. If you need more information or help that she cannot provide, she may ask you if you would like her to put you in contact with someone else.

**Complaints**
If you have questions or concerns that the researchers cannot answer or if you want to make a formal complaint about the research, please contact a University Research Practice and Governance Coordinator by email on research-governance@manchester.ac.uk or via phone using Typetalk on 0161 275 7583 or 0161 275 8093. If you need to speak to someone in that office face to face through a BSL/English interpreter, this could be arranged.

How long will the study run for?

The study starts in May 2011 and the project will finish in December 2012.

Who can I contact for more information?

If you have any questions or concerns about the research, please contact Emma at dwd@manchester.ac.uk. You can then arrange to talk to her in BSL via webcam if you prefer. There is also more information on the study website at www.manchester.ac.uk/deafwithdementia.

If you have questions, but would rather contact one of the project supervisors, you can email Professor Alys Young at alys.young@manchester.ac.uk. Alys would also be happy to answer questions in BSL via webcam. Alternatively, you can contact Professor John Keady by email at john.keady@manchester.ac.uk

What happens next?

If you want to take place in the study, please complete the enclosed consent form and post it to Emma Ferguson-Coleman, Research Assistant, at:

Social Research with Deaf People Group (SORD),
School of Nursing, Midwifery and Social Work,
The University of Manchester,
Room 4.312, Jean McFarlane Building,
Oxford Road, Manchester M13 9PL.

The consent form is also available to view in BSL at the end of the DVD. If you prefer, you can complete the consent form online on the website www.manchester.ac.uk/deafwithdementia.

Emma will then contact you by your preferred method (email, SMS etc) to arrange a convenient time and place to visit you.
J. Participant Consent Form

Please put your initials in the box if you agree.

1. I have read the Deaf with Dementia Project information sheet or I have watched the BSL video explaining the study.

2. I have received enough information about the study.

3. I have been able to ask any questions I have about the study.

4. I am happy for my carer to be present at the interviews.

5. I am happy to be videoed in my interviews with the researcher.

6. I am happy for my anonymous quotes to be used.

7. These videos will be kept safe at the University. I am happy for the videos to be used again in the future in a different study.

8. I give permission for you to contact my healthcare professional to inform them I am involved in this study.

9. I understand that I can withdraw from this study at any time without my medical care or legal rights being affected.

10. I understand that some of my information may be seen by responsible people from the University of Manchester, from external authorities or from the NHS Trust. I am happy for these people to have access to my information.

11. I agree to take part in this study.

Name of participant:……………………… Name of person taking consent……………
Signature of participant:……………… Signature of person taking consent …………
Date …/……/….. Date ………/……/…. .
K. Carer Consent Form

<table>
<thead>
<tr>
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<th>PLEASE PUT YOUR INITIALS IN THE BOX IF YOU AGREE.</th>
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</thead>
<tbody>
<tr>
<td>1.</td>
<td>I have read the Deaf with Dementia Project information sheet or I have watched the BSL video explaining the study.</td>
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<tr>
<td>2.</td>
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<td>3.</td>
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Name of participant:…………………………………       Name of person taking consent
…………………………
Signature of participant:……………………………..       Signature of person taking consent
....………………...........
Date  …/……/….                       Date …/……/…. .

PLEASE PUT YOUR INITIALS IN THE BOX IF YOU AGREE.
27 October 2011

Professor Alys M Young
Professor of Social Work Education and Research
University of Manchester
Jean McFarlane Building
Oxford Road
Manchester
M13 9PL

Dear Professor Young

Full title of study: The experiences of Deaf people with dementia: a narrative study
REC reference number: 11/NW/0669

Thank you for your letter of 27 October 2011. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 13 October 2011. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering Letter</td>
<td></td>
<td>26 October 2011</td>
</tr>
<tr>
<td>Participant Consent Form: Carer</td>
<td>2</td>
<td>20 October 2011</td>
</tr>
<tr>
<td>Participant Consent Form: Participant</td>
<td>2</td>
<td>20 October 2011</td>
</tr>
<tr>
<td>Participant Information Sheet: Carer</td>
<td>2</td>
<td>20 October 2011</td>
</tr>
<tr>
<td>Participant Information Sheet: Participant</td>
<td>2</td>
<td>20 October 2011</td>
</tr>
</tbody>
</table>

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor’s responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

11/NW/0669 Please quote this number on all correspondence
Yours sincerely

Miss Rowen Callaghan  
Committee Co-ordinator  

E-mail: rowen.callaghan@northwest.nhs.uk

Copy to:  
Ms Lynne MacRae – University of Manchester  
Ms. Jenny Walker, Adult and Youth Specialised Services Directorate, Greater Manchester West Mental Health NHS Foundation Trust, Bury new Road, Manchester, M25 3BL  
Emma Ferguson-Coleman, Room 4.312, Jean McFarlane Building, University of Manchester, Oxford Road, Manchester M13 9PL
M. Topic guide for interviews

**Interview Guide for Deaf with Dementia**

This interview guide is compiled with a view to interviewing Deaf British Sign Language users, thus questions will be asked in BSL (not English).

There will be a short period of 'establishing dialogue' that will take place before any questions are asked. This is in order to engage with the participants and may include sharing cultural norms, such as which school each person attended, where they're originally from and which Deaf club they attend. This assists with beginning to understand each other’s communication register, different signs that may be used (as British Sign Language is not a standardised language and has its own regional dialects) and is a building block for developing trust in the Deaf researcher. The researcher may need to clarify that the information shared is confidential and that if both parties were to bump into each other at a future social event, that there should be no concern that their information will be inappropriately divulged on the researcher’s part.

Process consent will be completed before the interview starts – the researcher will ensure that the person’s consent has been recorded on the video camera. If the person says they no longer wish to take part, then the meeting will be brought to a close and the person thanked for their time.

The person’s carer may or may not be present in the interview – this will be established before we start. If the carer asks for some time alone with me, then this will be checked with the person with dementia; as I would not wish to lose their trust. (Danger of losing trust is embedded in the Deaf community; if you go off to speak in private with someone close, it can have negative connotations and trigger paranoia, therefore creating unnecessary breakdowns in communication.)

**Themes to be covered**

The starting theme will be around dementia and understandings

Prompts: What is the person’s understanding of what this means? What is their understanding of this word (in BSL?) What is the (hearing) doctor’s understanding? What does dementia mean in terms of the person’s and their carer’s lives? Is dementia a label?

**Events leading up to diagnosis**

Prompts: How was your dementia noticed? What happened next? (this is one prompt that will allow the researcher to identify if there are any social networks present outside of the home) Who knows about your dementia? How have they responded to this?

**Is life the same or different?**

Prompts: what is life like after your diagnosis? What do you do differently now from before? What is good example of your life being different or still the same? A bad example, what is different that you find hard or difficult? Is the Deaf club the same or different from before? Why? Do you still have the same hobbies? If not, why?

**Contact with professionals**

Prompts: who is involved with you because of your dementia? Hearing or deaf? How do they communicate with you? Do they book an interpreter? Do you understand what they say to you? Give me a good example of how that professional helped you? Have you had any problems with anyone? Has anything been frustrating for you? How long have you been seeing this person? Do you feel you have had the right support? If not, what would have been better for you?

This dialogue will be conducted for up to two hours. There will be a break after 45 minutes and measures will be taken to ensure the participants’ comfort throughout.
The interview will be closed by thanking the person for their time. I will ask them if it is OK for me to come and visit them again in 2 months’ time. If they consent to this, I will check what dates are suitable for all of us. I will fill in a follow-up appointment card which has my name and contact details on.

I will then write to the person afterwards (within a week) to thank them for their time. I will also send another letter (or use a different preferred method of communication) one week before the next appointment as a reminder that I will be visiting again. This also allows for them to inform me if they cannot make this time for whatever reason.

**FW: Response to enquiry regarding Diagram for use in PhD thesis (due for submission) (our ref EH68527)**

Iain Moir [Iain.Moir@nice.org.uk]

**Sent:** 07 April 2016 17:35

**To:** Emma Ferguson-coleman

Dear Emma

Thanks for your email.

NICE has no objection to your request and a licence follows below:

We are happy to grant you permission on the following conditions:

1. These non-exclusive English language rights are not transferable and refer only to reproducing the material listed below as part of your dissertation. You will need to re-apply for permission if you wish to reproduce the material in any other format or future publications.

   **PMG 4 Methods for the development of NICE public health guidance** (3rd edition)

   ‘Selected content’

2. The licence is granted in perpetuity.
3. There will be no fee charged for the rights granted under this licence.
4. The rights do not include permission to reproduce either the former National Institute for Health and Clinical Excellence logo or the National Institute for Health and Care Excellence logo. Please note that NICE changed its name and status on 1.04.13.
5. The granting of these rights does not confer an approval or endorsement of your dissertation, and no such inference should be given to intended audiences.
6. The material should be appropriately referenced wherever it is mentioned. Our suggested wording for referencing this is as follows:


Please let me know if you are happy with these terms.

Best wishes and good luck with your dissertation.

Iain

Iain Moir
Senior Service Development and Contracts Manager
Evidence Resources
National Institute for Health and Care Excellence
10 Spring Gardens
London
SW1A 2BU

Tel: 020 7045 2208
Email: iain.moir@nice.org.uk
Appendix O: Confirmation of permission rights from Elsevier to use excerpts from Young, Ferguson-Coleman and Keady (2014) Understanding the personhood of Deaf people with dementia: Methodological Issues.
14 Appendices (ii) Video Clips for BSL representations.

All clips are on www.vimeo.com and the password to view these is dwd2016.

Please type each hyperlink into the search address bar and press Enter. You will then be asked for the password to view the video. Please note each video has its own unique link.


Video 5 (V5): Dementia-brain changes  https://vimeo.com/169758307

Video 6 (V6): Losing contact  https://vimeo.com/169758858

Video 7 (V7): Fingers-up-arm  https://vimeo.com/169758866

Video 8 (V8): Perservperservperserv  https://vimeo.com/169759196

Video 9 (V9): Signing space changes  https://vimeo.com/186317743
(This demonstrates the usual signing space of BSL, and then the change in Beryl’s signing space)

(This demonstrates the BSL manual alphabet letter E, then the school-specific sign for E)

Video 11 (V11): The sign for move, correct and erroneous  https://vimeo.com/169759683
(This demonstrates the correct BSL sign for move, then the way that Ernest signs move)

Video 12 (V12): The sign for ‘fading away’  https://vimeo.com/169759874