The Deaf collective: Opposition, organisation and difference

by

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Acknowledgements

Abstract

UK society and the mainstream social sciences typically share the assumption that people need to hear and speak in order to function effectively in the social world. Hence, d/Deaf people are perceived as vulnerable individuals with sensory impairment, social disability, and biological invalidity; d/Deaf people are accordingly eligible for individualised welfare intervention. By contrast Deaf Studies, which this thesis draws upon, critically explores the relativity of linguistic conceptualisations and cultural norms and asserts that Deaf people are members of a purposive, political culture, with an independent British language and identity, comprising a British as well as an international collective, and are without impairment, disability or invalidity.

The key research question that my research asks is what is the social position of Deaf people within British society and likewise what is the social position of the Deaf collective in the UK policy-making and political arena? That is, on whose terms is the societal inclusion of Deaf people and the broader Deaf collective to be based and understood? The scope of my inquiry comprises primarily (a) the personal views and professional ambitions of 13 senior executive office-holders of Deaf-led third sector organisations across Wales and England, and (b) the perspectives of 9 senior officers of relevant hearing institutions, and their understandings of their institutions' policies and funding practices in regard to Deaf people and Deaf organisations. Data from these organisational elites was subjected to detailed narrative and thematic analysis which drew upon key concepts within interactionist and post-modernist thought.

The thesis will uncover how third sector Deaf-led organisations face fundamental dilemmas in asserting their collective presence in order to promote their political aims. Deaf organisations operate to an extent by government funding streams which typically impose conditions upon their actions. Those organisations without funding conditionality can promote their chosen agenda; they may also struggle to operate or to survive where funding cannot be secured. By contrast, those who accept conditional funding also must accept the externally bestowed status of representing the 'medical deaf model' whereby they are deemed to be operating within a welfare/ disability frame of reference and allied actions. Also, the welfare system as mediated in the views of key hearing respondents fails to question the objectivised values that inform the 'medical deaf model'. The analysis will suggest that the

Deaf Collective both intellectually and operationally exists in a relatively non-intersecting system, without the wider institutional world noticing its presence. The thesis considers the consequences of this for policy and practice and offers suggestions for a more progressive understanding and involvement of Deaf people and their collective.

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Chapter 1

Introduction

> (At) a world [Deaf] congress a couple of years ago, ...as an opening gesture, the President grasped a hearing-aid and smashed it on the lectern with a hammer!

This extract from an interview with a Deaf respondent aptly introduces the topic of this study. It is about being 'Deaf' and being a member of the Deaf community or collective in the UK. It is about a cultural world of different social and political values which rejects the norms of wider society in relation to being Deaf. In order to explore this world, about which there has been relatively scant research, this qualitative study examines the perceptions of Deaf elite proponents of a Deaf collective agenda, contrasting this with the views of hearing elite welfare policy-makers who represent institutions that daily affect the lives of Deaf people. The meaning of 'D'eaf is further defined on page 5.

The key research questions that are addressed are:

- On whose terms is the societal presence of Deaf people and the broader Deaf collective to be based and understood?

- What is the nature of Deaf led membership organisations, and what is their purpose and authority in relation to the Deaf collective?

- What is the understanding that hearing elites of public sector welfare institutions possess of Deaf organisations and their collective?

- What typifies the normative relationships between hearing institutions and Deaf people and their representative organisations?

- Why do the two worlds of Deaf-led services versus hearing-led services for Deaf people appear not to overlap?

- How far are these matters of concern to either party, and in what ways?

The study was shaped by narrative research methods and the use of in-depth qualitative interviews. Conceptually, the study drew upon the core influences of interactionism and post-modernism in exploring and challenging available literature, as well as adopting methods,

approaches of reflexivity and deconstruction, in analysing findings (Lilleker 2003; Fine 2001; Lyon 2000). The study explores aspects of the social world of Deaf people and their particular cultural and political identity. A key element defining this world is their use of the third British language, British Sign Language (BSL) (www.bda.org.uk 2012). These people class themselves as living within the British Deaf collective who use this language as well as an international 'Deaf collective' (Lane 2005). This British collective claims a clear, cultural and political identification whose largely tight knit but relatively small membership often know of each other locally (UK) and to some extent internationally (see FDP 2000).

Two contrasting purposive samples in the research are represented by elites of their respective domains, by senior Deaf people holding office as chief executives or chairs of third sector Deaf led charitable membership organisations in England and Wales, and by senior hearing public sector professionals who work within four key public sector spheres of governance and administration in Wales which influence the welfare and equality process; the Welsh Government, the Welsh civil service, statutory adult social services, and the (umbrella) third sector in Wales.

Background

I first encountered Deaf people at an early age, when I was a Brownie Guide, and another Brownie was Deaf. I became aware at that time of the peculiarity of the way in which Deaf people are treated by hearing society – by typically treating them as hearing individuals whose responsibility it was to speak and hear, and to 'keep up'. ("She can lip-read so well", personal communication a: 2012). I started learning BSL in 1995 through attending evening classes, and later became familiar with swear signs used by Deaf teenagers when I secured voluntary work experience; this was my initial involvement in and early awareness of the world of the Deaf collective, and I began to accelerate in my absorption of both language and culture. My interest in this world deepened with exposure to a challenging but persuasive literature by Deaf Studies academics from both the UK and America who gave both intellectual and moral weight to the claims to a distinctive non-disabled identity for the Deaf. My subsequent training in Wales as a social worker included practice learning in a statutory social services sensory impairment team where my colleagues were hearing and relatively medically focused. This contrasted markedly with my second placement at a national Deaf organisation where my work colleagues were Deaf and comparatively much more politically

focused in terms of Deaf identity and interests. At the first placement during my first week, I assessed Deaf individuals for their interpreting needs as well as for their need for me to visit them to explain various official letters that they had received. At the second placement during my first week, I attended a national campaign forum organised and attended solely by Deaf people except for the presence of myself, an inhibited hearing student. The two placements, both about helping Deaf people, could not have been more different and gave me much food for thought about the appropriate role for social work with the Deaf community.

I qualified and became a social worker with deaf people. During this time I became quickly familiar with a 'disability' led approach to 'the needs of deaf people', and familiar with routine categorising of people such as 'deaf with speech' or for the more 'disabled', 'deaf without speech' (see RNID 1999; SSIW 2004). I subsequently sought employment with the same national Deaf organisation where I was a student social worker and quickly became involved in policy creation, fundraising and marketing. During this time, I attended an absorbing world congress and various conferences on the state of the international Deaf collective. This and other influences nurtured a growing interest in conducting research into this area. I became increasingly aware of two polarised worlds – the Deaf and hearing worlds – in which it became apparent there were fundamental issues of social justice with intriguing, contradictory approaches of welfare support pulling in opposing directions between the aspirations of the Deaf and the approach of a hearing majority. Traditionally, Deaf people have been educated to learn to lip-read and speak English (or Welsh), but have not achieved educational or social status on a par with their hearing peers in either a hearing mainstream or Deaf education system (Lane *et al*., 1996). Hence, the socio-economic position of Deaf people, as we shall see in Chapter Two, has been one of under-employment and under-education and long term exposure to a depressed economic condition and political profile together with their primary categorisation as likely in need of some form of welfare assistance.

Two contrasting alternative theories offer explanations for Deaf people's inability to function and develop within the hearing system as their hearing peers can. The first is, their hearing incapacity is defined as a medical impairment (they 'can't hear'). Hence they do not hear in social contexts or in risk situations, and also their (social disability) of having a little-known minority communication system or sign language does not enable them to socially integrate or to avoid those risks which require communication. They are therefore in need of (hearing)

intervention to assist their functioning in society, whether through social services, disability policies or grants to d/Deaf charitable organisations (SSIW 2004; Young *et al*., 2004; WCVA 2011). The second and opposing perspective is that Deaf people have institutionally not been allowed to be culturally or linguistically different - only to the extent that they are seen as a disability group with 'cultural needs' to hear and speak English (or Welsh) in order to function independently in mainstream society. Whereas Deaf people claim they have different 'needs' that include mainstream recognition of what they assert is their valid minority national language. It follows that should their education be based on the understanding of those values and language, they might then develop academically in a different manner from past patterns (Roots 1999; Lane 1996; Ladd 2003).

Much research has been and is being done by the academic Deaf Studies community on Deafhood, culture and history, as well as on linguistics, but often without making effective links to the hearing world and its welfare institutional systems (Ladd *et al*., 2003; Batterbury *et al*., 2003). (Research into the political component of the Deaf collective however appears limited to the main protagonists' work discussed in chapters 1 and 2). Equally, much social services research continues to maintain a focus on d/Deaf people and their need and eligibility for services (Young *et al.*, 2004; RNID 1999). There do not seem to be bridges between these two research traditions and their respective disciplines. Neither does there appear to be much research into the position of Deaf people and their organisations within the generic third sector. Deaf Studies do not appear to overlap with the academic studies of social work, or of sociology, just as the latter do not appear to consider Deaf Studies. Arguably, Deaf academic studies and the existence of the Deaf collective cannot become a part of mainstream society, or the wider social science research community, if the mainstream knows little of the other's existence.

Minority groups are often widely researched and as a result society can at length change the way it operates to incorporate acceptance and understanding of diversity (Thompson 2001; Pestello and Saxton 2000). However, in the case of the Deaf, the body of current research has not yet been able to reverse a societal perception of a group labelled as needing a medical cure in order to become a majority citizen. Such a perception may cause a sense of inequity and unfairness to the Deaf minority who are politically self-established but regarded as standing outside the mainstream institutionally. They may wish to be recognised differently from their deep-rooted welfare institutional image and to be allowed to contribute differently

as citizens. Some however may assume that there is little point in arguing with powerful hearing institutions where their given label appears fixed and unchangeable.

Deaf people, as the thesis will demonstrate, can experience markedly different upbringings. Those who have Deaf parents will likely have as their first language BSL through which they communicate and affirm a sense of shared familial bonds. Through BSL they can accelerate in concept development, learn written English fluently as primary plus aged children, and secure a confidence in themselves and their identity as Deaf (Lane 1995). This mode of upbringing stands in some contrast to those who are Deaf but who have hearing parents and typically are urged to seek in their early years a hearing identity whereby they struggle to speak and to hear and in doing so can feel isolated and different, and learn to be impaired. Those Deaf in this study (the majority) often did not have an opportunity to learn BSL until they reached their teens or later and it is then that they feel 'Deaf' (Lane *et al*., 1996). This notion of becoming Deaf is now explored in more detail. Key terms Deaf, deaf, d/Deaf, Deaf community, Deaf collective, hearing colonisation, Deafhood, audism, disability and impairment, and the models of disability will appear frequently throughout the thesis usually linked to data and literature and require some preliminary elaboration at this point to discursively locate the enquiry.

Definitions of 'D'eaf, 'd'eaf, and 'd/D'eaf

'Deaf' denotes an evolved state and identity, the result of which is a self-ascribed label to characterise the political and communal nature of a purposive group. The label indicates an independent culture with respect to people who use signed language and who function differently, where shared heritage and language have set such people apart from a mainstream cultural identity. From the perspective of Deaf people, they do not have 'sensory impairment', or any medical issue, neither do they experience social disability in attempting to fit into society. Instead, Deaf people are independent in their collective functioning, using a visual (as opposed to audio) focus, and using independent language which invites traditional Deaflore (folklore) and other representations through sports, arts, history, politics and academic study. This captures the tradition and feeling of their collective (see below). Deaf people experience collective disadvantage in society in those instances when cultural mainstream systems exclude culturally different modes of functioning. They are

misrepresented institutionally as individuals with invalidity as hearing people (Ladd 2003; Ladd 2006a; 2006b; Roots 1999).

By contrast, 'deaf' is a label which describes people who have medically defined deafness, where 'ness' implies measurability (Ladd 2003). This is understood by welfare services, other public bodies, and by these deaf people themselves. They tend to live as culturally hearing people, often struggling to hear and speak the majority language, and tend to use equipment to help them to hear. They would probably choose to be hearing given a choice – their social networks consist of hearing people and those other deaf people they have been introduced to for social purposes. They are individuals who do not necessarily have anything in common with another deaf person or the Deaf collective (Harris 1997; Sainsbury 1986, Mindess 2006).

The label 'd/Deaf' (a distinction introduced for the practical purposes of this thesis) denotes the way commentators (or respondents in this study) speak of a 'generic' community of all deaf and Deaf people without realising this includes two distinct groups of people (cultural hearing deaf and cultural Deaf). An undifferentiated d/Deaf labelling often stems from traditional welfare assumptions as well as the dominance of oralist assumptions too, namely that all these individuals are impaired because they 'can't hear' and yet need to hear and speak to function independently in society. Thus when respondents (particularly the welfare elites in the second phase of interviews) referred to "the Deaf community" and yet implied sensory impairment as a key characteristic of the community, in these cases I applied the 'd/Deaf' label and likewise in other instances where it was unclear if an interviewee understood the significant differences between deaf and Deaf. Thus it was sometimes difficult to know which rendering of 'Deaf' / 'deaf' / 'd/Deaf' to allocate to someone's speech. This has therefore been a discretionary process, using the assistance of background biographical and organisational context provided by the respondent (Metzger 1999; Sutton-Spence and Woll 1999).

Terms used to locate Deaf / deaf / d/Deaf people

Within the study, Deaf and deaf people are described, following the conventions of sociology, according to their cultural and /or language allocation in terms of how they represent themselves, or are represented and categorised. Labels used include: cultural Deaf, Deaf signers, politically Deaf, medically deaf, hearing impairment, and deaf with /without speech, to name but a few descriptors applied by very different constituencies of interest. According

to the distinction between cultures, a hearing person and a medically deaf person share the same culture – that is, hearing culture, whereas, as has been stated above, a Deaf person experiences a distinctively different cultural Deaf identity. The adoption into law of Clause 14, of the Human Fertilisation and Embryology Act 2008, which indicates that where an embryo (and future life) is known to be deaf, it may be destroyed, supplies a clear indication of the institutionally perceived invalidity of Deaf people. Thus Deaf Studies academics assert with much emphasis that Deaf people are misrepresented institutionally as individuals with invalidity as hearing people (Harris 1997; Mindess 2006). By contrast, it will be shown how Deaf community (respondents) members who have a shared culture and language and are a part of their collective, claim an authentic social status by dint of their being Deaf collective members. Indeed, the many different ways of describing Deaf and deaf people (which are employed in this study) stem from different and sometimes contrary movements assuming responsibility and involvement with Deaf and deaf people, for example, welfare systems as opposed to Deaf representative bodies.

Definition of the 'Deaf community'

The 'Deaf community' is applied here to those cultural Deaf people of a single country or region who use sign language. The label defines Deaf people as a particular category for the period ranging from the Paris Banquets (see chapter 2) to the present day, spanning some 200 years. It defines Deaf people according to how they see themselves as authentic members of a distinct collective and denotes links of lesser attachment to Deaf members who have internalised values of hearing colonisation. It alludes to subjective links to previous generations of Deaf people who struggled to survive, so providing an example for future generations. The term however is also used by welfarists asserting a contrasting meaning of hearing-impaired individuals who may be at risk of their own independence, who use sign language if they cannot use speech. The term has multiple-meanings, which could arguably weaken any single, core meaning. For example, a Deaf Studies academic may understand their 'Deaf community' identity to be quite different from that of a member who has a social worker for deaf people visit them on a weekly basis. Yet the term has its key significance in its historical origin as indicating (the first) meaning of 'Deaf strength', prior to the rise of oralism and welfare colonisation (Ladd 2003; 2006a). However Deaf people's self-allocated label is in conflict with the welfare definition, and institutionalised policies that relate to Deaf people (Mindess 2006; Lane *et al.* 2006) where the meaning of 'Deaf community' for society

is not one of 'Deaf strength' prior to the misguided pathologisation of Deaf people. Equally, lay academics might imagine that the term could describe any group of d/Deaf people, whether they are known to one another or not; hence one's response to the notion of such a community would not create immediate empathy or interest. The struggle over label or identity is thus critical to understanding the movement of the Deaf collective as is discussed below.

Definition of the 'Deaf collective'

The term 'collective' refers to those people comprising 'the Deaf collective' and is used in preference to the terms 'community', 'linguistic minority', or any other group label. The Deaf collective is defined as such for several reasons: First, Deaf respondents adopted this term themselves when discussing the constituencies of interest that they and their organisations typically represented. Secondly, as argued by Ladd (2003:37), self-consciously Deaf people adopt collectivist values over self-oriented ones: '(Deaf people have)... their own languages..., organisations, history, arts and humour... It is having... high quality *collective* life' (emphasis original). Ladd (2003:167) also writes of a 'recognition that this culture is one impelled by collectivist values, which therefore stand in contrast to Western cultures' essentially individualistic values'. The third reason for the 'collective' label is its implication of shared political intention. The Federation for Deaf People (1998:12) asserts that political organisations do not represent a *community*, as this word implies passive grouping; rather, they work for their *collective*: hence they argue 'a 'Deaf community' is all fine but is of minimal relevance unless it actually influences policies in society. Deaf people (are working hard to) participate fully and influence policies'. Cohen (2003:98) supports this notion, in that: 'the community as experienced by its members – does not consist in social structure or in 'the doing' of social behaviour'. Cohen remarks that a 'community' is more of a symbolic construct, whereas a collective could incorporate a political construct in addition to the components of a community whereby specific aims are generated and advanced by the membership. A fourth reason, and prerequisite of a collective, is that all members *know, or know of each other* (emphasis original) (see Anderson 1999:6).

The collective could be seen as a social movement, in that 'a strain (in society) is recognised, (and the Deaf collective) try to deal with it', thus motivating their interest in social change (Sandstrom *et al*., 2006:194). Over the past few centuries however, Deaf people did not join

together because of their being collectively pathologised (such being the motive for the formation of some social movements), but rather, the collective evolved gradually through individuals recognising shared characteristics and similar experiences of being controlled by hearing institutions, through to learning the Deaf language and absorbing Deaf culture (Johnston and Klanermans 1995; Branson and Miller 2002; Lane *et al.*, 1996). The question remains (as discussed in later chapters) about how independent and purposive can the Deaf collective be when their representative organisations are often publicly funded with grants which stipulate their purpose in alleviating disability.

How the 'Deaf community' relates to the 'Deaf collective'

The purpose of the 'collective' is not to exclude any Deaf members of the community, but rather to embrace all cultural Deaf people who use sign language, and to move the Deaf community forward to securing a positive public profile and representing themselves as a tangible, visible minority group. The replacement of 'community' by 'collective' is not to displace or denigrate the category of 'Deaf community'; instead it is to identify cultural Deaf people in both social science and normative terms, and to validate their purposive and meaningful group presence. The term 'collective' has increasingly been used throughout Deaf history by prominent Deaf intellectuals and activists and suggests that the term is intended to more directly oppose the notion of 'colonialism', and would be more effective in this ambition than the more neutral or passive signifier that is sometimes attached to the notion of 'community'. 'Collective' suggests an immediate and apparent sense of a purposive group, implying solidarity around a shared identity and position. The point of 'collective' is *not* that Deaf people who are members of this have to become 'political'; Deaf people can enjoy social membership alone, yet still be aware of their positive presence and shared, mutual identity. Instead, the use of the term 'collective' suggests more of a natural link to the notion that all Deaf people can become mindful of their own Deafhood, a context where they are consciously aware of their positive, collective identity (Lane 2005; Branson and Miller 2002; Cohen 2003; Anderson 1999). It is also likely that welfarists could not co-opt this term in order to describe Deaf people in traditional welfarist terms. Thus, importantly, the meaning of 'collective' is not fundamentally different from the common-sense meaning of 'community' understood by Deaf people, but rather serves to distinguish a self-allocated Deaf meaning around identity and membership from a welfarist notion of deafness.

Hearing colonisation

Ladd (2003) argues that the hearing colonisation of the mind is an effect with some parallel with the colonisation by imperialist countries over previously independent native ones in the 17th to 19th centuries, where the power relationship was one of almost total control by one over the other, and where the coloniser sought to impose their normative systems of rules and language upon the other. Ladd (2003) detects two types of parallel hearing colonisation: welfare and linguistic. Welfare colonialism is the hearing imposition of individualistic norms from the mainstream culture, and where the idealised individual is one who is culturally hearing as a prerequisite to being able, functioning and independent. Linguistic colonialism refers to the traditional hearing belief that British Sign Language as an educative medium ought to be deleted (a European decision that took effect 130 years ago, see Jackson 1990), and replaced with an oralist method of education for d/Deaf children. In consequence such children learn to become cultural hearing individuals with impairment, instead of Deaf people able to learn their natural language as well as the majority language. In short it was and remains presumed by many that Deaf people need to speak in order to participate 'in their evolution to full human status' (Ladd 2003:114).

Deafhood

'Deafhood' as coined by Ladd (2003) is a response to the imperialist tendencies of a hearing society as noted above. 'Deafhood' is a term contrary in meaning to 'deafness', the latter implying medical measurement according to an individualising and pathologising order. Deafhood describes the personal, cultural, language and political purposive identity of a Deaf person, attributing their natural membership to a collectivist arena. Ladd (2003:81) emphasises that this term focuses on 'Deaf people's relationships' with one another. Deafhood denotes a British as well as international collective of shared values and ambitions that seek the recognition of Deaf people as authentic citizens in a diverse late modern society. Yet Deafhood does not only incorporate politically active values around which Deaf people can campaign but also the cultural values of those who wish only to coexist socially with other fellow Deaf people and to remain socially distanced from the judgements of those who would see them as socially and intellectually impaired (Ladd 2003:8). Deafhood is about self-actualisation within the collective, in recognising and developing confidence in one's own Deaf norms which become taken for granted and easy to operate socially. It is also about

collective confidence that may advance Deaf interests in negotiations with mainstream policy and public service institutions.

Social science disability literature

Social science disability literature while briefly noted is not drawn upon or applied in the analysis. This is in line with the conceptual orientation of the thesis which seeks to understand the world of Deaf people from their perspective, that is, their rejection of any link to themselves with disability or medical impairment. Social science disability literature is typically developed from a cultural hearing perspective, researched and written by mainstream social scientists, and all too often assumes that 'd/Deafness' is some form of disability (Mindess 2006). Legally, Deaf people in the UK are defined as individuals with deformity and handicap and thereby classed as at risk and unlikely to engage fully and independently in society (Clements 2000; SSIW 2004; Cardiff Council Unified Assessment 2012). By definition they are eligible for a social care assessment and potentially can receive statutory social services community care (CSDPA1970s2; see www.justice.gov.uk/law commission/areas/adult-social-care 2012). By contrast, Deaf academic studies view such definitions and treatment of Deaf people as wholly inappropriate and dissent from any such position. They promote an alternative orientation which seeks to offer a view of being Deaf and the Deaf collective as authentic ontologies whereby a minority culture and membership claim a distinctive identity and rightful place in society as full and unimpaired citizens (Ladd 2003; Roots 1999; Monaghan 2004; Doe 2007).

Medical, social and cultural/ linguistic models used to describe Deaf people

The above models are utilised in this study, particularly in chapter 7, in regard to hearing elite respondents who tended to invoke medical and social models to categorise D/deaf people via a 'medical model of (hearing) impairment', and /or the 'social model of disability (deafness)'. The former focusses on the audiological state of a person's hearing in terms of decibels. 'Impairment' suggests dysfunction, and implies a notion of cure. In general terms this is how culturally hearing deaf people may consider their own hearing position. The second model is politically pivotal to both the Welsh and UK governments in their adoption of this model of disability and in their aims for societal inclusion of all disability groups. In this model 'disability' suggests societal barriers which prevent individuals from physically accessing for example buildings or services. Those applying the model attempt to provide opportunities for

disability group representation through which they can lobby for societal access and resources. From a Deaf Studies perspective, this model cannot possibly assist culturally Deaf people, who in their view had their full citizenship removed by the introduction of Oralism. It follows that Deaf people are under-represented in society, and to fit them into the social model of disability would be to misrepresent them further. A third model perceives Deaf people to have an independent culture and language which can define their identity, that is, the 'cultural / linguistic model of being Deaf', more recently labelled as 'the cultural model of collective disadvantage'. The former description of the third model focuses on the distinct culture and language of Deaf people; however this has been replaced by Deaf bodies with a focus on the collective disadvantage of minority groups in general. Deaf people more recently identify with parallel minority ethnic, cultural and linguistic groups. This model however is yet to be recognised or awarded weight in mainstream terms (see BDA 2004; Ladd 2003; WAG 2008; BDN 2003; Equality Policy Unit, WG 2012).

Gender neutral terms

Throughout the thesis I have for various reasons avoided mentioning gender specific information about the Deaf respondents. According to grammatically correct British Sign Language when one signs 'his' or 'her' referring to a particular person, one actually signs 'their' because their gender is not typically signified in BSL conversational structures (Sutton-Spence and Woll 1999; Metzger 1999). In a parallel manner, instead of specifying gender with regard to particular respondents, terms such as 'her /she' or 'him /his /he' were avoided, and replaced with 'their /they' to remain more faithful to the language traditions of the Deaf interviewees. In a similar vein, Deaf Studies assert that spoken English implicitly maintains 'audist language' that reinforces mainstream values of speech and hearing, thereby further excluding or 'othering' difference.

Audist language and audism

Use of everyday words and phrases of speaking and hearing are used where the meanings are quite different: examples such as 'sounds like' (meaning), 'active listening' (consideration), giving 'voice' (representation), 'I hear you' (understanding), 'nice to hear from you' (appreciation) and 'I said' (reportage of written statements) all reinforce an objectivised way of functioning, involving hearing and speaking, even when neither speech nor hearing is literally present or required. Such audist traditions and structures have no similar counterpart

in the visual language system of BSL and it is this failure by mainstream society to recognise and affirm the profoundly different language system of signing that discriminates against the Deaf (Ladd 2003; Mitchell 2006). This is because much of society perceives 'being Deaf' as '*deafness'*, which only describes someone's level of auditory capacity that they have in medical terms and thereby reinforces the assumption that deaf and Deaf people are all the same, in that they are all hearing impaired individuals. To Deaf people, this is as logical as measuring the extent of someone's Welshness or Blackness or maleness. Audist language serves to reinforce audism, according to Deaf Studies academic Bienvenu (1993:8), which is as powerful and destructive as bigotry in accepted mainstream forms. Presenting at a conference to a Deaf audience, Bienvenu signed:

> The fight against racism, sexism, anti-Semitism and homophobia continues. Today you are truly disabled. They believe we are lacking intelligence and that all Deaf people long to become hearing. (Bienvenu 1993:8).

Ladd (2003) and Mindess (2006) argue that this perception remains, given that no obvious social change has occurred. It is therefore important to remain conscious of the associations and underlying presence of audism, however tangible or nuanced. I have therefore attempted to avoid any inappropriate use of audist language in the analysis of data (see chapter four) in an effort to avoid collusion with audist assumptions.

Thesis Content

We now turn to a brief description of the content of the thesis chapters. Chapter 2 follows and is the first of two reviews of literature, and introduces fundamental notions of culture, language, identity and the welfare system, a brief documented history of Deaf people and the structural opportunities and limitations experienced by them, linked to Deaf academic perspectives on social justice. Deaf Studies literature is contrasted here with social work research and welfare policy, where the welfare ethos maintains a medical focus on d/Deaf people, risk and dependency, and need. The procedural guidelines of social work with d/Deaf people, as well as social work research relating to d/Deaf people are explored. Both of these sources are debatable in view of the mainstream perspectives from which they are conducted, and would arguably be distorted accordingly. A Deaf Studies perspective draws attention to

the possibility of political motivation on the part of Deaf people to negotiate their collective presence as society's citizens, with a valid, distinct position.

Chapter 3 is the second review of literature and contrasts the respective institutional positions of public welfare and Deaf organisations, focusing on issues of profile, power, and their relation to one another in 'implementing' and 'receiving' social justice for d/Deaf people. The social science literature in relation to policy making and implementation typically observes public sector institutions without there being any direct links to or conception of the Deaf collective. Hence, the authority and governance of varying public sector bodies is explored, and particularly their impact on the position and visibility of third sector Deaf organisations, and then community bodies' own self-governance. The attempts of UK governments to modernise their objectives in considering the politics of change are discussed and the question is put as to whether these are sufficient in contributing to the visible presence of the Deaf. An exploration of public sector literature would suggest that Deaf people are not recognised as a cultural or linguistic minority other than by Deaf Studies academics, or by Deaf people themselves.

Chapter 4 describes the research process at a theoretical as well as administrative and practical level. The methodologies of narrative research and analysis, interactionism and post-modernism are focussed on, from their shaping of data collection through to the producing of analysis. The data were co-created by researched and researcher in the production of narrative research. Research design aspects relating to ethical and political concerns, elite interviews, insider-outsider issues, the relative status and relationship between the researcher and researched, and the involvement of two languages are also considered. The process of research from initial design, operation, analysis and presentation are described, enabling an independent researcher to reproduce this study according to their own interpretations. Practical explanations of sample, interview method, interview recording, translation, and methodological analysis are given. Analysis was conceptually shaped by narrative, reflexive and deconstructionist methods. This meant first, having an awareness of one's relationship with the researched which contributes towards engineering the shaping of the data and its analysis. Secondly, deconstructionism invites the continual questioning of assumed cultural values and norms.

Chapter 5 is the first of three findings chapters and concentrates on the personal backgrounds of Deaf elite respondents (as outlined above). Respondent data revealed shared and polarised classifications demonstrating distinctive life patterns and key events. Their formative early experiences influenced all respondents into aiming to become role-models for the members they subsequently represented. Classifications into groupings were driven by the data, according to the parent type of respondents, that is, whether their parents were Deaf or hearing. This seemed to affect significantly long term outcomes for individuals. The second grouping was school type, that is, whether respondents attended residential Deaf school or mainstream local hearing school. The third grouping was the age that respondents learnt BSL, and the point at which they felt they had established their Deaf membership and believed themselves to be culturally different. Respondents themselves generally considered that those who had Deaf parents and were therefore able to learn BSL and to gain a secure cultural Deaf identity at an early age were considered to be the more fortunate few, whereas those with a largely culturally hearing up-bringing and who learned BSL in adulthood were deemed by respondents as the least fortunate.

Chapter 6 goes on to explore the professional lives of Deaf respondents in holding elite status, with particular focus on their third sector organisations and the impact that they secure in working with their fellow Deaf collective members, as well as with hearing policy making and their welfare administrative institutions. The data were divided into different groupings from those of the above chapter. These were based on different types of organisational funding and commissioning arrangements. The first grouping denotes organisations that are financially 'self-sufficient' in not being tied to funders' conditions, without however always being financially stable as a consequence. The second grouping consisted of organisations with service level agreements with local adult social services. The funding was stable, yet to an extent this required some compromising of the values of Deaf as independent and non-disabled. When local authority social services fund d/Deaf organisations this funding invariably underpins the hearing cultural view of the impairment of Deaf people. The third group similarly comprised Deaf organisations holding financial partnerships or merger agreements where they have medically deaf service users with cultural hearing identity, as well as culturally Deaf participants. Such organisations were able to maintain their Deaf projects but may have risked an undesired organisational profile being ascribed to them of being a medical deaf body rather than a preferred Deaf cultural profile.

Chapter 7 follows the institutional perspectives of hearing elite policy makers and funding allocators, with regard to the third sector bodies of the Deaf collective and regional Deaf collective, and their varying relationships to one another. The data demonstrated the basis from which policies and funding decisions are made, according to the 'knowledge' that individual public sector respondents have of Deaf people, and of the Deaf collective, and third sector operational Deaf organisations. The categories emanating from this data derived from the particular public sectors, comprising: politicians of the Welsh Government, principal officers of the National Assembly for Wales (including both the political and administrative arms of the Welsh Government), senior officers in adult social services from local authorities in Wales, and leading officers of third sector coordinating bodies. The respondents of the political class, civil service and social services put forward more traditional mainstream understandings of Deaf people as individuals with medical impairment and social disability, and requiring appropriate treatment. Third sector respondents generally held more diverse understandings of Deaf people as members of a collective, although no role of seeking to raise the Deaf profile had been adopted. Generally Deaf organisations were not recognised in policy and funding terms, except as fitting into the institutionally maintained categories of hearing impairment.

Chapter 8 comprises discussion of aspects which arise from the three findings chapters and summarises the key points of each. The chapter examines how 'common sense' views prevent the exposure of alternative perspectives concerning the Deaf held by people with contrasting cultural norms, values and experiences. The general views of those from phase two (chapter 7) would seemingly for example not anticipate that a Deaf child might not believe themselves to be impaired, or that a Deaf organisation would not want funding, or Deaf adults would not want to become hearing. The title quotation of chapter 7 is made by a phase two respondent, who makes a typical statement defending their mainstream policy decisions as rendered credible by public approval, and therefore legitimised. The chapter focuses on core underlying concepts of 'hearing colonisation' and of 'Deafhood', coined by Ladd (2003), and the ways in which findings relate to these.

In the concluding chapter I explain my original research interest in an 'invisible' minority, as well as in my exploring the perspectives of such a minority. I list the limitations to the research relating to scale, time, my position as an outsider, and to the limits contained within mainstream academic and policy sources as well as the emerging social science and Deaf

Studies fields. The chapter summarises responses to the core research questions as stated at the start of chapter 1. The point is made that the data indicate the lack of social inclusion of the British Deaf collective rather than any substantial societal recognition of their presence; the collective themselves consequently asserting their own identity. Deaf organisations presented their purpose and authority as co-ordinators of their regional and national collective. Of the respondents, hearing elites largely maintain an understanding of Deaf people as medically 'deaf' and have limited knowledge of Deaf organisations; the notion of the collective is largely dismissed as unviable. Long-standing institutionalised beliefs may shape the perceptions of hearing people and their estimations of Deaf people in the possibilities for structural change. Involved bodies may not challenge normative assumptions on either side of their mutually exclusive world-views because of their insulated positions that lack meaningful overlap. It is observed that if Deaf organisations accelerate their political ambitions and if they develop like-minded mixed sector partnerships then they may enhance their potential to forge links with hearing policy makers as willing participants in initiatives to generate the equalities sought by the Deaf collective.

I make recommendations relating to Deaf Studies research, Deaf sector partnerships, and social science research. I suggest attendance by prominent hearing policy makers and members of the social science academy at the Istanbul World Congress for the Deaf in 2015 to witness the political and intellectual standing of the international Deaf collective, with a view to furthering elite hearing recognition of Deaf people, benefitting both the social and economic make-up of society, and Deaf people themselves.

The thesis now turns to chapter 2, the first of two reviews of literature. This chapter considers the social positioning of Deaf people and the contested nature of their identity, particularly in respect of welfare/ disability labelling and the counter claims of the Deaf collective. Contrasting perspectives are examined in relation to Deaf Studies, mainstream social work theory, and those of welfare policy commentators more generally.

Chapter 2

Deaf Communities and Social Welfare Provision – The Historical Background

Introduction

In this chapter 'traditional' welfare policy is examined from the perspective of a Deaf critique and in particular the argument that welfare policy represents a colonisation of the mind (Ladd 2003; Batterbury *et al*., 2003); this perspective will be considered and critically assessed. In doing so the experiences and treatment of Deaf people across five particular eras of Deaf history are explored. The chapter also addresses contemporary perspectives on welfare, disability and corresponding social work research, and the suggestion that the welfarist emphasis on community care diverts attempts by Deaf people to have positive political recognition. The chapter will critically examine relevant welfare policy and the available evidence-base for social work with Deaf people. A key argument that will be developed in this chapter is that Deaf research and political action sit uneasily within disability theories and the disability movement. Whilst it may be assumed that Deaf people are a disability category in welfare literature (Corker 1998), the literature in Deaf Studies does not assume any connection with disability at all (see Lane *et al*., 1996). Disability and welfare perspectives however are perforce discussed because Deaf people are typically placed within a 'sensory impairment' category, and thereby seen as having 'individual need' by health and social services.

A pivotal consideration is whether the welfare 'safety net' maintains and reinforces what some commentators would argue is the discriminatory treatment of the British Deaf collective. In other words the chapter explores whether application of the disability label to Deaf people, together with investment in cultural hearing institutions such as social work, creates a paternalist system (see Rutherford 1996). The question thus arises whether a modernised role for social work with deaf people can provide an appropriate interventionist service, in the language of Deaf people, to those Deaf individuals who need it. However if the Deaf academic community does not engage with mainstream academic debates about welfare will they be able to assert the political relevance of Deaf people to a global intellectual and

policy constituency? Should they be inside or outside current academic discourses on welfare and disability?

It will be argued that there is no simple consensus in an often vexed and contested debate between Deaf Studies perspectives, cultural hearing social science researchers and welfare policy commentators. The chapter explores the disparate theoretical literature on cultural identity, social justice and social capital and will compare and contrast the ways in which these apply to Deaf and to hearing people. The chapter will further explore notions of culture and identity in both hearing society and the Deaf collective. The linkages and distinctions between Deaf culture and politics are assessed. In terms of social justice it will go on to explore ideas of social recognition and redistributive justice as a means of assessing the structural opportunities and limitations experienced by Deaf people. The widely used social science concept of social capital will help provide an outline of the structural, socio-economic position of Deaf people. Deaf people do not appear to be included in the social system sufficiently to gain adequate social capital, or indeed cultural capital, thus rendering their societal position under-educated, under-employed and collectively socially marginalised. This review of literature offers a balance of traditional perspectives that welfare institutions have of Deaf people, contrasting this with views that Deaf people have of themselves, and of the history of Deaf and hearing people's interactions, which continue to shape the way Deaf people are treated in modern times.

Deaf communities across key eras

What is this community?

Deaf people traditionally have become members of the Deaf community through attending residential schools and after leaving school maintaining these links with fellow Deaf school leavers. Deaf clubs have traditionally been viewed as the core of the Deaf community where fellow Deaf people can socially interact freely after undergoing the constraints of fitting in with hearing people for the rest of the week. Deaf people tend not to have been introduced to their Deaf club through relatives, at least where they are the only Deaf family member. If they are fortunate to be one of the ten per cent who come from previous generations of Deaf family, the path towards Deaf community membership occurs sooner in their lifetime, and is more straightforward. Deaf people who cannot sign can attend Deaf club and learn from peers. The mutual aspects which Deaf people share are language, culture and membership,

experience of schooling, experiences of difference, isolation and social upbringing, shared values, pride and humour, and offering of mutual support, friendship and release, and autonomy. Prominent aspects which stem from sign language are creative storytelling and poetry. Traditionally, missioners, and later welfare officers and (less so) social workers have held a permanent position within a Deaf club, with varying levels of control. Hearing relatives are often members of the Deaf community; particularly hearing children of Deaf parents (Lawson 1981).

What does the community consist of?

The size of the Deaf community in the UK remains unknown, because the ten yearly Census still does not ask specific questions relating to Deaf people, or to sign language users. RNID statistics, which are re-used by social services departments (RNID 1999) estimate that there are 70,000 Deaf people in the UK, based on certain audiological levels of deafness. The BDA (2012) estimates that there is a Deaf population of 400,000 in the UK. Geographically, Deaf people have tended to move to a town or city with a large Deaf community so as to become an integral part of an established network and to increase thereby their social contacts. Many of their new neighbours may have gone to school together. Another alternative is that Deaf people have tended to leave school and return to their home towns, and then regularly travel a long way to meet up at social or cultural events.

Historically, as a result of oral deaf education, many Deaf community members were semi-literate and in modern times Deaf levels of education, skill and employment remain low. Social activities offer opportunities to interact in which most are thought to partake. Arranging sporting events led the way to Deaf independent control and organisation. Missioners in control of Deaf clubs and communities would allocate the organisation of sporting events to the control of Deaf people, which they would savour. Deaf people have thereby had the chance to excel at sports. Deaf people who were not particularly interested in sports would still attend in order to see and make new friends. Whole communities would visit one another, so that larger close-knit connections were maintained. These types of event would have an outward aim of sociability however it also reinforced the cultural and mutual nature of the community, as well as signifying a more subtle political aspect that Deaf people enjoy autonomy and evince strength by organising such events. This motivated some Deaf people to promote their rights further and to advance their community's position. Deaf clubs

have traditionally arranged outings or holidays and in doing so offer opportunities for socialising with friends and peers, and reinforcing a sense of membership and pride in one's Deaf club. Likewise, the opportunity to meet fellow school leavers from different geographical areas while intrinsically enjoyable can also be an indication of membership of a large and bounded community, which embraced all its members (see Padden 1994; Taylor 1986).

An historical overview of five eras of Deaf community history

Pre-education to 1760

Historical recordings of Deaf people and sign language in the period before 1760 are extremely limited. Deaf people appear to have been educated in monasteries in France, Spain and Italy where sign language was valued by monks who had taken vows of silence. Recordings suggest that a French Deaf man Etienne de Fay (early 1700s) was brought up in the Abbey of Amiens. He was taught to sign and was educated comprehensively. He became an architect, artist and teacher of deaf children. He in turn taught children to sign, but more authoritative educators took over seeking to teach the deaf children to speak. Another French Deaf citizen Pierre Desloges (mid 1700s) became a bookbinder in Paris and wrote books about sign language that became well known. At a similar time in Britain, (hearing) political writer Daniel Defoe, writing in the early 1700s, wrote about a Deaf character Duncan Campbell. He wrote about the significance of deaf education, and the importance of sign language. For a relatively brief period Deaf people were regarded as eloquent in their writings, despite being mute. However in Britain Deaf people were more regarded as interesting 'scientific' cases, where one could assess and experiment over their potential to learn (see Branson and Miller 2002; Dimmock 1993).

Sign language education with Deaf teachers 1760 – 1880

The first Deaf schools were established in Edinburgh and Paris in the 1760s. These used sign language as their medium of communication. The Scot, Thomas Braidwood, set up his school for the Deaf in 1760. The aim predominantly was to teach deaf children to read English and to express themselves through writing and artwork and design. A second focus was to teach them to speak, but this was not as important as their academic development in the sciences, and study of their surrounding world. They learned through sign language. Sign language was

also interchangeably called 'natural language' by commentators of Braidwood's teaching methods, and in observing his pupils. At the same time in the 1760s, Charles Michel de L'Epee, a priest and lawyer, established the Paris school for the deaf. This lasted until the early 1800s. L'Epee was interested in sign languages and understood their potential to become a universal international language. Following this, similar-minded educators established Deaf schools in Europe and America. As a result Deaf people became educated, bi-lingual and literate, and they established positions in society for themselves, for example becoming artists, architects and publishers. This was not to last for long however, as Deaf people began to be 'medicalised' and seen as disabled, and educators would face the increasing pressure of Oralism.

The annual Paris Banquets of the early 1800s reinforced the then growing intellectual developments among Deaf academics. Deaf and hearing people would travel from America to attend these. Deaf philosophers made signed speeches which were recorded in written French, about the natural gift of sign languages, and of the intellectual potential of Deaf people. They invited Deaf people from all countries to come together collectively and to spread their sign languages (Ladd 2006a; 2006b).

However in the early 1800s, science was focussing on the ear, and experimentation on medical cures for deafness, without much concern for people's lives. Even though Deaf people had achieved prominent social status, and become educators themselves, their schools began to be taken over by hearing bodies. Throughout the early to mid-1800s deafness began to be seen as a pathological condition. Schools began to try to cure deafness through violent treatments and even causing death (Itard, early 1800s). Philosopher and philanthropist Joseph Marie, Baron de Gerando was the Director of the Paris Institute in 1820. De Gerando believed that Deaf people were inferior and dependent on their intellectual superiors. He believed sign language to be primeval and unrefined, and Deaf people to be sub-normal. He fought against his prominent colleagues who advocated sign language in education, to replace manual teaching with an oralist method, of 'teaching' pupils to hear and speak. He used and promoted (the then late) L'Epee's views of actually believing that Deaf people could never be on an intellectual par with hearing people. Parallel changes in intellectual direction followed in Britain (Branson and Miller 2002; Lysons 1977).

A missionary influence began to shape the focus of education by the 1830s. Missioners were also educators, so that the primary aim was to uplift Deaf people spiritually, to feel equal with hearing people (even though they were labelled as lacking capacity to be 'normal') and could somehow become 'literate' in relation to God and the religious word (Clarke 2001).

Oralist and social welfare colonisation century 1880 – 1970s

Darwin published his theory of evolution in 1859. This was used by others to justify the colonialist treatment of vulnerable groups, where the ethic of 'survival of the fittest' was applied to humans, as opposed to animals. The subsequent eugenics movement supported beliefs that Deaf people ought not to marry or to produce more 'dysfunctional' members of the population. Alexander Graham Bell of the eugenics movement supported this view, and believed that only speech could enable individuals to compete in the survival of the fittest. Oralism was gaining in credence and popularity amongst hearing leaders. The Milan Congress of 1880 was a culmination of these philosophies. At this congress, oralism was famously agreed to be the only method to teach deaf children, so they would learn to lip-read and speak. This had enormous destructive consequences for adult Deaf people, as well as for future generations of the Deaf. Deaf teachers were dismissed after much united protest, and became unemployed and poor. Deaf adults slowly lost their place in the professions, and deaf children became illiterate adults with limited prospects. Another aim of oralists was to prevent deaf children from communicating with one another at all, perhaps to avoid collective rebellion. Deaf people often became dependent on social welfare, lost motivation to challenge the status quo, and suffered from mental ill health (Dimmock 1993).

At the same time, Deaf clubs were being influenced by missioners, both Deaf evangelical Christians, and hearing missioners with philanthropist and spiritual concern for poor Deaf people. After the banning of sign language, Deaf missioners were slowly replaced by their hearing children upon adulthood, or by other hearing missioners, who gradually took control of British Deaf clubs. However in 1880, there were a few radical Deaf activists, who attempted to challenge the infiltration of hearing control. The National Association of the Deaf was set up in America in 1880 by Deaf and allied hearing people. In the UK in 1880

Deaf activist Francis Maginn attempted to set up a strong Deaf organisation with colleagues from which to directly counter hearing control and oralism. However the ensuing organisation was established as the British Deaf and Dumb Association in 1890, with hearing missioners as well as Deaf members, and control was assumed by a hearing leader. Maginn was allocated a subsidiary role of responsibility. He resigned shortly afterwards, and set up his own organisation in Ireland. The BDDA was controlled by hearing people until the 1970s. Missioners in control of Deaf clubs, and the linking BDDA generated the establishment of welfare colonialism. It was not until 1971 that the BDDA deleted the D for 'and dumb' and changed their name to the British Deaf Association (Ladd 2003; Dimmock 1995).

The 1948 National Assistance Act introduced local authority welfare officers; however the result was largely ineffectual as local authorities allocated power to missioners to continue with their control over Deaf clubs and their members. The Seebohm report of 1968 professionalised social work with deaf people; missioners were removed from control and social workers with deaf people took over the responsibility for the Deaf. The change however meant a new individualised welfare focus, and also as social workers could not sign, missioners became interpreters. The new individualised focus on Deaf individuals and an ignorance of the collective created a disjunction which continues in modern welfare. This role of intervening to support Deaf people as people 'in need' remains a pivotal aspect of statutory welfare as well as elements of independent third sector Deaf organisations. In a report commissioned by the BDA (Lysons 1977), the BDA were reported as claiming that they realised Deaf people needed to be supported by interventionist hearing welfare officers. This indicates an example of a Deaf body that would seem to have internalised colonialist values by accepting the view that the Deaf could not enjoy independence or control. For several British Deaf people in the 1970s the negative treatment of colonisation and hearing control was unacceptable, leading to a short period of political action as noted below (see also Ladd 2003; Cooper 1983).

The Deaf resurgence from 1975

The post-missioner age involved several important corresponding aspects of social and cultural change, and Deaf radical members were able to take advantage of changing social structures. Academic research into BSL formalised the significance of Deaf people and their language. An exploration into Deaf history developed confidence in Deaf clubs as well as in

radical members, and also Deaf people became nationally visible through being represented on the TV programme 'See Hear'. Deaf people began to challenge the institutionalised order of colonialism around the same period as the abatement of missioner power. Deaf school leavers communicating with older Deaf members established older people's views which were derogatory of hearing controllers, missioners and even of welfare. Deaf young people received their first Deaf education as to the potential capacity and independence of Deaf people, and their contrasting and hidden history. Some attempted to influence their local Deaf clubs towards more Deaf influence but hearing controllers used their authority to prevent this. Deaf young people resorted to establishing meetings in pubs (where there still may have been connotations of colonialist internalisation, because Deaf people were still meeting with hearing people), and these became widespread in the UK (Jackson 1990).

Finally, in 1976, some of the more activist and purposive Deaf members of the pub groups established the National Union of the Deaf (NUD). Leadership and representation on the part of the NUD were of pivotal significance, as individuals had to be prepared to stand up against missioners, as well as rooted Deaf members of local Deaf clubs. The link with Deaf history was persuasive to younger Deaf club members. People were interested in how Deaf people had historically maintained their independence and defended their rights against oralism, and had held strong Deaf views which amounted to membership of a collective. The development of the professionalisation of social work with deaf people was to be fortuitous to the NUD and Deaf rebels in that welfare reforms would allow Deaf clubs superficially to run themselves. Deaf people with Deaf families joined Deaf activists in supporting the BDA to change its focus, and in supporting the BDA hearing leader (Arthur Verney) who wished the organisation to give way to Deaf control. In 1983 a Deaf person was finally appointed as chair. (This process is indeed reminiscent of the employment of subsequent Deaf leaders in some of the thirteen Deaf led organisations of this study; this will be addressed in chapter 6.) However Deaf control does not necessarily mean that hearing internalised values had been removed from leadership styles or Deaf organisational culture as we shall see in later chapters (Taylor 1986).

The rise of two Deaf bodies from the 1970s to the 1990s demonstrates the emergence of a Deaf political movement which evidently lasted during that time. The National Union of the Deaf (NUD) was established by a small radical group of British Deaf people to be a more 'dynamic and go-ahead group' (Ladd 1992a:8) which aimed to unite the previously

fragmented and different apolitical Deaf groups (Jackson 1990). It was the first Deaf organisation to be Deaf-led. The reaction to the NUD by the then Deaf community was not widely one of acceptance. Many Deaf people instead accepted the dominant hearing welfarist values of society and did not wish to pursue such radical ambitions. The NUD however became a significant body of a few hundred members, which would influence the values of later Deaf organisations (Ladd 1992a). The vision was to campaign amongst both hearing and fellow Deaf people (by Deaf and some hearing members) for the reversal of the colonialist, negative way in which Deaf people were perceived in society, in fields ranging from education, employment, medicine and welfare, to mainstream politics. The initial aims for Deaf people were to run local grass-roots groups, organise national campaigns, and to develop private businesses. The underlying political values were to be commonly agreed and understood, and a newspaper would document Deaf life, political values, activities and opinion (Dimmock 1992). The ultimate aim was to be recognised by dominant society: 'we need to be seen' (Ladd 1992a:12). Academic Deaf Studies centres were established in a few universities during this period. The NUD was wound up twelve years later due to financial challenges, barriers in terms of access to information and knowledge of societal systems and networks, and weariness on the part of its leaders (Ladd 1992b:169).

The Federation for Deaf People (FDP), a similarly radical Deaf body, was formed in the wake of the NUD. The FDP, established in 1998, ceased to function after some four years. The aims were to challenge the mainstream status quo but also the non-political nature of other national prominent Deaf bodies, and to motivate Deaf members into realising an underlying political core to their culture (Jackson 2001). The focus was providing education about legislation and employment, and to invite Deaf members to become politically motivated in publicly representing themselves. They did not accept charitable status, and women formed a large proportion of FDP leaders. The FDP partnered with parallel politically active minority groups in holding conferences (FDP 2000). It exploited core aspects of Deaf culture in uniting members, adopting the Deaf Arts and Deaf spiritual beliefs at conferences, as well as exploring the concept of the 'Deaf identity' (Jackson 2001). The FDP faded in 2002 when the chair resigned, the organisation experienced financial problems, and weariness again arose among leaders. No national Deaf organisation appears to have significantly adopted the role of either the NUD or the FDP since; regional organisations however have to varying extents

implemented visions of their political ideals (see chapters 6 and 8), but Deaf politics have not become resonant in mainstream society.

The need for Deaf Studies

Stokoe (1960) made the first assertions that signed languages had independent grammar and structure, and were indeed independent valid languages. The study of sign language linguistics evolved into university research centres. This allowed the way forward for Deaf activists to develop academic concepts of the Deaf community as linguistic minorities. Further research into Deaf communities co-existing with hearing mainstream society meant recognition of bi-cultural and bi-linguistic identities (Padden 1996), as well as a focus on Deaf culture and the history of Deaf communities. Deaf Studies departments in a few English universities existing as an intellectual independent discipline secured credibility. Three universities in America, and several Deaf Studies centres in England started to encourage Deaf students to enrol on courses to study academic concepts opposite to the fixed views of oralism, and to challenge traditional internalised hearing values. Deafhood, as it is defined in chapter 1, was the internal exploration of one's self-identity and one's recognition of a shared ownership of this identity, in the form of a collective. Arguably, Deaf Studies needs to engage further and more critically with the social sciences (particularly social work and social policy) in order to challenge the status of welfare colonialism and audism, as well as to educate hearing policy makers in the ways in which Deaf people wish to be independent and to secure contributory citizenship status.

The Neo-colonialist backlash of mainstreaming, cochlear implantation and genetic engineering

The increasing closure of Deaf schools in contemporary UK, and the advent of 'Partial Hearing Units' in mainstream day schools using oral education has contributed to a reversal in the education of a Deaf culture in society. We have also seen a new medical emphasis upon the 'cure' of deafness with a significant investment into cochlear implant programmes in the UK and globally. Indeed, Lane *et al*., (1996) reveal the indignation of Deaf people about the preoccupation with cochlear implants as a routine 'cure' for (d/)Deaf people to become 'hearing'. They observe: 'It must be an unparalleled event in medical history for organisations of adults to raise such an outcry against medical intervention for children like themselves' (Lane *et al*., 1996:112). Demonstrators protesting against cochlear implants

however have been continually denied the opportunity to open up the debate based on fundamentally opposing values with hearing medical advocates of 'corrective' surgery whose investment into this intervention worldwide is sizeable (Lane and Bahan 1998).

The recent UK development in genetics indicates an institutional view of Deaf people similar to that of Itard and De Gerando from the early to mid-1800s, as discussed above, where deafness is seen as a pathological condition which must be experimented upon. Modern day developments go further in that deafness is seen as an avoidable condition which must be prevented as far as possible. Scientific biologism can be seen as political in that it was based on 'unfounded beliefs about the superiority of one group over another on the basis of inherited biological characteristics' which, Skinner argues, 'came to look increasingly irrelevant' (Skinner 2006:467). However, these same presuppositions can be seen in more recent medical discourses in the promotion of cultural hearing values and an auditory focus (Dawkins 2006; Skinner 2006; Lane *et al*., 1996). There is a now a re-established biologism, in which biology and culture are linked, based on a new emphasis on the value of genetics and specifically the search for a deaf gene. Some might term this as cultural racism in the way it threatens the assertion of a Deaf culture by focusing on deafness yet again as a disorder to be avoided (see Skinner 2006; Wade 2002). Currently, 'in a setting where "whatever the question is, genetics is the answer" there is a real possibility of the rebirth of scientific racism grounded in the objective truth of DNA' (Skinner 2006:471).

The social welfare context within which Deaf organisations are situated

Missioner control of Deaf clubs varied from spiritual support from 1830, through to maintained control until the 1970s. Deaf clubs had been originally set up by Deaf people, and their control was gradually removed once Deaf children were viewed as being incapable of fully functioning and so could not become priests themselves. The role of missions evolved throughout their reign. Evangelism and religious instruction was replaced with a welfare role by the 1950s. There was less preaching, but they retained overall authority, and continued to organise all aspects of social and spiritual life. They held the roles of social worker and interpreter, provided spiritual guidance and organised social events. They also interpreted in court for Deaf people, as well as supporting them and their families. They visited people in hospital and also interpreted for hospital staff, and they even made psychiatric assessments of Deaf people's behaviour. They counselled Deaf people's parents when their children left

school and realised they could not secure employment. They significantly advised Deaf people not to marry each other, indicating the corresponding rooted views of Alexander Graham Bell in the 1860s. This view clearly indicates the extent of the authority missioners held, as well as their views about the sub-normal status of Deaf people. New missioners were typically trained by previous ones, so that their stance would tend to be traditionalist. Missioners maintained contact with oral deaf organisations such as the RNID and the BDDA, which had also been set up by hearing welfarists.

Some Deaf people throughout this period, who had attended deaf schools that allowed some group presence among children, remained unaccepting of the status quo of Deaf clubs, and attempted to negotiate their power and control. When they were defeated, they left to set up independent Deaf controlled clubs, and some Deaf peers went with them. Such examples provided motivation to Deaf activists in the 1970s and continue to do so. This is a clear example of the non-internalising of hearing colonialist power and the full knowledge of (small-scale) possibilities for change. Had more Deaf activists taken this option, if it had been financially realistic, an organisation such as the NUD might have had the opportunity to be established at an earlier time.

Such welfare colonialism, accepted as paternalist authority on the part of many Deaf members, appeared to be a 'trade-off' for the provision of opportunity and security. This view was challenged by the then minority of Deaf activists in the 1970s who did not wish to 'trade-off' their independence, or be supplicants for opportunity and security, but to create and establish this for themselves (Lyons 1977).

The sentiments and disabilist language of the National Assistance Act 1948 and the paternalism seen in the missions appear to survive, albeit subtly, in the policies of some contemporary statutory public services today. Service Level Agreements between Deaf-led third sector organisations and social services means that statutory funding will ensure that service recipients will be treated according to predefined (welfare colonialist) methods which categorise Deaf people as hearing-impaired and to be treated accordingly. Welfare colonialism can arguably be said to be alive and influential and this raises questions about the value base of statutory agencies as well as the alternatives to social services funding for the Deaf third sector – a point that is explored in chapter 6.

The body from which the RNID originated was set up in 1911; it was named 'The National Bureau for Promoting the General Welfare of Deaf People'. The RNID has more recently changed its name to 'Action for Hearing Loss'. The organisation was established by an oral deaf wealthy merchant banker, Leo Bonn. He and his fellow missioners' concern was oralism, and the welfare of oral deaf people, but they also claimed to represent Deaf people who signed. The BDDA immediately sought to emulate a wealthy seemingly like-minded organisation, and provided Leo Bonn the support he needed with which his organisation could shape colonialist direction over Deaf clubs (Branson and Miller 2002). The RNID (renamed in 1961, and then in 1992) have maintained their national profile as representative of d/Deaf people, however their aims would be seen as audist according to the view of the Deaf Studies community. It will be seen that some of the Deaf-led third sector organisations explored in this study tend to replicate some of the motives and aims of organisations like the RNID. For example, two of the Deaf-led organisations sampled in this study accepted partnership funding with medical deaf organisations and thereby appear to bear some resemblance to organisations such as the RNID (or Action for Hearing Loss) whereby a purely political Deaf agenda is not claimed (see also Branson and Miller 2002).

We now turn to culture and language, which are often regarded by policy makers as less significant compared to welfare priorities of care and support, which are deemed necessary to assist the independent functioning of those with sensory impairment. The Deaf Studies community by contrast assert a contrary perspective of Deaf people already functioning independently with their distinct language and culture, as we explore below.

Culture and Language

Grosjean (1996:28) argues that culture 'reflects all the facets of life of a group of people: its organisation, its rules, its behaviours, its beliefs, its values, its traditions…'. Blee (2007:124) discusses how a distinct cultural system works through cultural practices which 'create bonds among members and normalise (their) ideas and actions'. Distinctive collective values are thereby increasingly reinforced. Culture reinforces 'normal' behaviour and identity, enabling both group and individual validity and collective self-recognition of natural social organization and activity. A culture evolves, in parallel to changes in society, through, for example, changes in education, the economy, employment, technology and social attitudes, and in turn through changing understanding of that culture (Parasnis 1996).

Gone *et al*., (1999:371) discuss cultural identity as deriving from an individual's experience, and the social norms and rules according to which they interact, and which influence their routine life. The 'conceptual self as normatively oriented is designated a cultural identity and defined as a form of …the self which knowingly commits itself to the shared values and practices of a particular cultural group'. Also those routine values and practices which reinforce norms, are self-replicating and recurrent: 'Culture is historically reproduced in that subsequent generations are socialised into using the intelligible practices of their communities.' (Gone *et al.,* 1999:373). Roots (1999:39) states that:

> …a culture is a system that explains things and how they can be known. The literature of the culture – its stories, legends, and folklore – not only passes on the community's history but teaches the wisdom of the group. In the case of Deaf people, it teaches them how to cope with and understand the hearing world.

Deaf culture has long enabled close-knit bonds, robust social links, shared heritage, and recognition of collective exclusion, with a distinct language at its cohesive core. The collective have not struggled to exist, rather, it has not succeeded in persuading the dominant culture of their different cultural existence. Culture also enables regulation: 'Like hearing society (and culture), Deaf culture has its rules and standards, and they include rules governing who belongs, who does not, and who deviates' (Roots 1999:39). Accordingly, 'adjustment to another culture demands direct experience with various conceptions of reality, various ideas and their values, and various ways of meeting environmental demands… and consequent reflection of a cross-cultural experience' (Brislin 1996:13). Knowledge of two diverse cultures invites comparison of status, and in this case re-evaluation of judgements of 'disability', plus recognition of the relativity of society's norms. Cultural anthropologist Hallowell (1955) wrote of the five orientations of culture in analysing the self. These are: self, object, and spatio-temporal, motivational, and normative orientations. Orientations include factors of social action, events and language, consequent reflexivity, a 'behavioural environment', location, and influence. The normative orientation is the most evident factor influencing social behaviour, shared values and aspirations in the maintenance of order, demonstrating the inherent formally established and enveloping nature of culture. It is this which 'most conspicuously provides the self with an explicit awareness of the moral order of things' (Gone *et al*., 1999:374). An example of the normative orientation can be seen in the

'embedding of historically constituted practices in what feels "normal" and natural – produce(ing) feelings of cultural lack among (outsiders)' (Perry, 2001:57).

As a culturally sensitive language, British Sign Language (BSL) informs behaviour such as etiquette, humour, and the conduct of informal gatherings and formal meetings; that is, the management of relationships and socialization (Lucas 2001). Sign languages have a long history (see above) and literature on their development tends to be North American, and therefore based on American Sign Language (ASL) – an independent language, grammatically different from BSL:

> ASL was recognized as a true language following psycho-social and linguistic studies in the 1960s. It was claimed that a true, evolved, natural language is nurtured by its culture, which means that culture will simultaneously nurture its core bond, of language (Stokoe 1980:42).

Roots (1999), goes further to claim that ASL is a natural language, as opposed to spoken English, which is a learned skill. A visual /spatial communicative environment is natural for Deaf people and ASL is its logical reflection. Speaking, however, has to be taught. Deaf people tend only to meet other Deaf people upon leaving school, after having been denied the opportunity of using their natural language. They tend to switch from struggling to use English as a cultural hearing person, to acquiring and using BSL as a cultural Deaf person (Ladd 2003). It is recognized by cultural hearing, speech and language researchers of the English language, that: 'ASL is a full and formal language with a grammar and morphology all of its own. Because it does not parallel English, one cannot be signing fluent ASL and speaking or mouthing fluent English at the same time' (Campbell, Dodd and Burnham 1998:245). Language and culture mould one's identity:

> Language and identity are intimately linked. Use of natural sign language is the primary identifying criterion for membership of the Deaf community… Use of natural sign language is a defining and non-disposable part of being "ethnically" Deaf (Kannapell 1994:198).

Signed languages have spread globally in line with the spread of spoken languages through colonialism. Signed languages in Australia, New Zealand, India and South Africa derive from BSL (Woll, Sutton-Spence and Elton 2001). This exhibits the nature of an evolved natural language, with identifiable linguistic roots, parallel to spoken languages. Ladd (2003), and Lane (2002) write of the ironic situation that d/Deaf children face throughout their education,

of hearing colonialism (see chapter 1, page 7), and of the first aspect, oralist colonialism in particular. The European conference on education, and speech and language in 1880 (Jackson 1990) implanted the strategy of oralism, where d/Deaf children would no longer be taught the grammar and structure of their country's signed language and indeed would not be allowed to use it at all. D/deaf children would instead be 'taught' to hear and speak in order to behave like their hearing peers, and to become culturally hearing (Pickersgill 1998).

A Denial of Deaf Culture

Ladd (2003) defends the notion of a Deaf culture according to the minority value that Deaf people exist as functional individuals, and members of a purposive, cohesive group, who are linked by their distinct language and related different norms, practices, heritage of growing up together and subsequent traditions, and both historic and current means of socialisation. Ladd (2003) presents arguments from academics which criticise the idea that Deaf people have a distinctive culture. The first argument (exemplified in personal communication c: 2007) is that a claim of 'Deaf culture' somehow trivialises the mainstream culture. This suggests, on the one hand, that there is a mainstream singular culture and, on the other that its position is under threat.

The second argument is that Deaf culture does not exist just because Deaf people assert it. This argument may somewhat underestimate research and writing on Deaf culture and the strength of the arguments offered in its support (see Lane 2002). This argument has two variations. The first is that Deaf people's agenda is political, and so they assert a cultural identity in order to avoid what the critics regard as their 'actual' position as unfortunate impaired and ill people. This argument is flawed in that the critics themselves assume or presuppose objective knowledge as to the social position of this group of people, compared with the rest of society. The minority group are also assumed to be 'political' when they defend cultural characteristics, whereas the majority universal norm is not so perceived and they do not have to defend anything (Ladd 2003). The second variation of this argument is that justifications of cultures which focus on symbolic practices are not sufficient, whereas cultures may be validated by investigation of a culture's structure. Some research has been done on the structure of Deaf culture, for example on organisation and system (Padden and Humphries 2005). Ladd (2003) proposes that what may not have been researched from a post-structuralist perspective, however, is the structure of Deaf culture.

The third main argument levelled against the existence of a Deaf culture presented by Ladd (2003) is that ethnography cannot itself validate Deaf culture, as one risks losing objectivity once one has internal access (see for example Huspeck 1994). This argument may embody imperialist tones in suggesting that only non-insider researchers (and by extension people who are *not* culturally Deaf themselves), have an impartial basis from which they conduct observation and interaction. Alternatively, ethnographic research remains valid where some aspects are acknowledged as non-objective, and where a researcher acknowledges that their interaction with the studied stimulates their own ideological social attitudes and assumptions, whether they are culturally Deaf or not; such research may remain independent and compelling (see Fielding 2001).

Finally other sources (Tucker 1994; www.deaflinx.com 2012; Seligson 2011) assert that Deaf 'culture' is in fact a sub-culture, based on the notion that mainstream society is not included in the identification of 'Deaf culture', leaving Deaf people to be isolated by this category. This argument again may be interpreted as expressing a threat to the hearing majority, where it is made clear that a minority has a distinct identity. Definitions of Deaf culture however tend to acknowledge that its members also live within wider society. This therefore may not be a sufficient argument against the notion of Deaf culture (Ladd 2003). A connected argument fears that advocates of Deaf culture reject hearing people to the extent that hearing professionals will no longer be able to meet the 'needs' of Deaf people (see further below). This assertion may be somewhat paternalist in nature, assuming that Deaf people *need* to be repaired and supported, by 'natural' hearing society (Lane *et al*., 1996). Against this complex and contested background, I now turn to the processes of labelling and the construction of identity.

Identification and How Identity is Constructed

Jenkins (1996) argues that the notion of identity is useful for members of a social environment, where a label is required, and thereby where it is socially constructed. Jenkins observes 'the interaction between (internal) self-definition and definition by others (externally) as a process of internalisation' (Jenkins 1996:22). According to this notion, internalisation takes place under an established order. Barth (1966) suggests that identity has two separate aspects, nominal identity (one's name) and virtual identity (one's experience). The two can conflict in terms of allocated label, and the group's own understanding of the

nature of their existence. In terms of outside control held by the majority, systemic treatment of a group follows the label allocated by that majority and in terms of the majority's understanding of that group. Thus, 'the traits attributed to Deaf people by the "psychology of the deaf" reflect not the characteristics of Deaf people but the paternalistic posture of the hearing experts making these attributions' (Lane 2002:39). Lane presumably means social workers and the like. Much is written about Deaf culture, and yet this literature appears to be closed off to a system where hearing professionals 'helping' deaf people is perpetuated (Lane 2002):

> Among the more important contexts within which identification becomes consequential are institutions. Institutions are established patterns of practice recognised as such by actors, which have force as 'the way things are done' (Jenkins 1996:24).

That is, the weight of established systems imposes the way Deaf people are labelled and consequently treated and enables further unquestioned structural assumptions. Consequently, the more established the system, the more radical a challenge appears.

Cohen (2003) considers the symbolic construction of a collective. The conditions that contribute to the belief in and make-up of a collective are: mutual shared ownership, inviting community loyalty and support, and shared behaviour and norms, involving an underpinning of community symbols. To be part of a collective membership requires the belief and use of symbols which represent the collective and determine a sense of belonging and communicate the strength of its membership. Also the labelling of one's own collective mobilises belief in an oppositional identity and highlights a separation of the internal from the external. The reinforcement of the identification process occurs where there is external interaction (Cohen 1985). However the insiders or outsiders with the larger power create a label which determines how the group is treated. This can be applied to Deaf people, where an established label of 'hearing impaired', or 'deaf with /without speech', or 'individual with need', or of 'can't hear' is difficult to challenge. A reinforced label has increased power. The label made credible by law and policy 'objectivises' Deaf people as having impairment, and being disabled. Deaf people are labelled with encompassing categories, such that it may be understood that their identities *are* medical issues and measurement (Lane 2002).

Cultural Invisibility and Culturelessness

Rosaldo (1989) argues that all individuals have culture, and as such are shaped by their surrounding cultural values, norms and social understanding. What is changeable is the transparency of one's culture, so that according to differing social status, culture may be visible or invisible. Where one's culture is invisible, one belongs to the culture of the powerful rule maker. Significantly, 'cultural invisibility' implies 'rational' and superior, as opposed to 'cultural' and inferior. According to this idea, one can draw a parallel between hearing and Deaf people. Hearing people are not assumed to have a culture, whereas at most, Deaf people may be 'permitted' a culture – which would suggest acceptance that they have a different status from (hearing assimilated) disabled individuals (Parasnis 1996). This could then mean that the hearing cultural majority norm reinforces the rational, logical and objective nature of the structural treatment of a minority - here, of Deaf people. The 'objective' nature of the supposed encompassing description of Deaf people as medically impaired, as well as their consequent treatment, would be presumed without having to be justified (Grosjean 1996). This is 'the crucial distinction between majority and minority cultures – the former are under no obligation either to make explicit the beliefs which drive their actions, let alone have to justify their actual existence' (Ladd 2003:21). Deaf people have not succeeded in widely persuading the majority that they have an independent culture, let alone persuade the majority that they too have one, in attempting to explain the equal validity and rationality of both groups (Grosjean 1996; Perry 2001).

A recycled argument rooted in 'biologism' has supported 'evidence' of the medical identity and non-culture of Deaf people (Lane 2002; Wilson 1975). Biologism interprets the notion of natural selection as our genes organising our behaviour and then being replicated, so that genes determine social phenomena. Biologism assumes an inherent link to the dominant population, where minorities are thereby not envisaged to be an obvious part of natural selection but instead are seen as biologically distinct (Dawkins 2006; Rothman 1998). The discussion has stemmed from arguments about the majoritarian universal norm and racial difference, where ethnicity - or minority ethnicity - is itself seen as biological distinction; 'notions of biological difference and connection have figured in (medicalised) discourse in variable ways' (Skinner 2006:464). Skinner (2006) discusses how 'objective' science previously concealed a political agenda, in promoting scientific racism. Deaf advocates argue that this is paralleled in medical science today, with the promotion of pro-oralism and medical cures, ignoring the views of cultural Deaf opponents of this view (Branson and

Miller 2002). Genetic identities may become increasingly foregrounded, with race identities becoming forgotten. For cultural Deaf people this could, as noted earlier in this chapter, mean a transition from racism to geneticism: 'Biologism, with its novel new ways of thinking about the self, the body and society allows the social diffusion of genetic ideas and practices. (There is) a growing dominance of biological determinism' (Skinner 2006:472).

Whilst there are interesting developments such as in the Human Fertilisation and Embryology Act 2008, which will be discussed in chapters 5 and 8, scientific study which is either 'racist' or 'eugenicist' is considered to be immoral and is given no academic status (see Hull and Ruse 2007). So for example:

> white culture *is* Western European rational culture and whites (white, propertied males especially) are the unconditional beneficiaries of rationalism in that they are constructed as the most rational and, therefore, the most superior of all peoples (Perry 2001:62).

Whilst this may be seen as an example of a racist proposition this kind of argument can also be used in a hearing/non-hearing context. In a direct parallel, one can apply hearing culture to this idea of majority-ness, and replace 'whiteness' with 'hearingness'. Thus, being rational, (*hearingness*) must deny culture to the extent that culture is understood as sets of practices that carry affective and valued continuities with the past. 'Rational (*hearingness*) is postcultural. It is (an illusion of) anticulture' (Perry 2001: 62) (my substitutions in italics). Thus, hearingness can be seen as parallel to whiteness, where the universal norm is assumed (Cutler 2006). Being 'hearing' does not need to be labelled, and subsequent study, action, or treatment is not required. 'Cultureless (*hearingness*) is a form of hegemonic power and, therefore, widespread. …the naturalization of (*hearingness* appears to) most easily occur where (*hearing*) cultural practices are ubiquitous and self-confirming' (Perry 2001: 62; Lane 2002) (my substitutions in italics). In the same way as with whiteness, hearing culture is not defined as culture; it may be seen to be an anticulture, and post cultural. The status of Deaf culture may therefore be two stages behind the hearing majority 'rational' position, in that first, Deaf individuals are perceived as assimilated members of the majority with inferior individual medical status, quite apart from the fact that Deaf culture is not acknowledged by government, policy, or in mainstream social science academic circles, and secondly, that the irrationality of Deaf people as a collective could be supposed once 'their culture' is

recognised (Ladd 2003). Mainstream acknowledgement of Deaf culture may attract anthropological study where irrationality is often standardly assumed:

> Western rationalism exiles tradition and culture from the realms of truth and relevance and replaces them with reason. Whiteness (*or hearingness*) benefits from hierarchical …values of orderliness, self-control, individualism, and rationality, which are recognised as standard or normal behaviour. Otherness is defined in terms of that which is passionate, chaotic, violent, lazy, irrational, and – since marginal to the norm – cultural (Perry 2001:81) (my substitution in italics).

Superficial knowledge of a minority may inadvertently promote the majority 'known' standard norm, where learning about the attributes of an 'Other' reinforces a reluctance to define one's own majority. Members of the hearing majority, irrespective of their gender and ethnic origins, may be educated by default to believe that their identity is beyond culture (Perry 2001). It follows that if Deaf people claim an independent culture, in so doing it may mean that they elect to be seen as irrational and inferior. The culture of society goes unlabelled because it is assumed to be normal, where 'normal' does not need a label; that is, there may be an idealistic assumption that diversity is understood, and that notions of monolithic culture and normativity are more hidden (Thoutenhoofd 2000). Were it to be both accepted that Deaf people and hearing people each have a culture, the polarised relationship of power might be lessened. Cutler (2006: 698-9) discusses the situation where a majority culture is 'unlabelled' because it is assumed to be the socially reinforced norm:

> Christian is an unmarked category in United States culture much the same way white or heterosexual is – it is assumed of others by those who occupy it, uninterrogated because of its normativity, and largely invisible in its power to structure the lives of those who are the other.

Cultural Hearing Norms

Hearing culture can be typified by a systematic preoccupation with speech and hearing, for example society's dependence on audio intercommunications, a weighty music industry, and underlyingly an audio and spoken language system (Roots 1999). The tendency of hearing culture may be towards such a projection of the need for speech and the hearing of language as the ideological norm for society. Society is measured against an 'ability' to hear (Parasnis 1996). Default normative cultural assumptions can be reinforced through the cultural sensitivity of language. Garot (2007:51) discusses 'the power of language in the doing of identity and emotional manipulation', where language is core to the shared identity. One can

observe for example, cultural hearing use of 'hearing' or 'speech' terms in, say, English, which are also used for other meanings of receipt, production or consideration of knowledge or information, and also when corresponding through written text) (See chapter 1, page 9). This is implicitly a shaping process that underlines the dominance and normative functioning of speech and hearing (Baker-Shenk 1986). Consequently, Deaf people also learn to use such language when growing up as cultural hearing individuals with impairment, that is, when using the English language. Hearing cultural values are likely to continue to influence their application in the learning and use of BSL on the part of these people, that is, terms and meanings associated with conventional understanding of the verbs 'to speak' and 'to hear' may become preserved, so that the merit of speech and hearing may become internalised. It may be difficult to culture-neutralise one's language where such values are dominant (Roots 1999).

Lawson (1981:161) uses outdated language, but describes a societal hearing assumption about Deaf people which is possibly maintained and current: 'Deaf people are separated from the hearing society around them, and from the culture that belongs to that society, because of a physical feature: *lack of hearing*' (my emphasis). Instead, Deaf people have a visual /spatial language and environment; therefore they do not need to hear in order to function collectively (Lane 1984). Accordingly, Deaf people can communicate through noise, silence, distance, glass and water, and thereby can be classed as being able to communicate in multiple spheres. Whereas cultural Deaf people may be assumed to have sensory impairment because they '*can't hear*', similarly, cultural hearing people (who can't sign) are incapable of multi-sphere communication. That is, cultural *hearing* people find that they cannot hear each other through glass and other media and therefore cannot communicate. 'Can't multi-sphere communicate' however is not taken to imply that cultural hearing people have impairment or disability, because by default the majority are not labelled as non-able (Branson and Miller 2002).

It is a cultural hearing norm that society *needs* to hear. A legitimate conclusion that one can draw from this is that Deaf people are disabled (Grosjean 1996). Lawson (1981:161) continues, 'the desire to belong to a group, the desire for social contact, is no less strong in deaf people than it is in *normal* hearing people' (my emphasis). Hearing people may be considered to be 'normal' according to their membership of the cultural majority, which shapes hearing cultural influences encompassed by society. As Blee (2007:124) comments, majority cultural identity enables normalized values and behaviour '..cultural practices

…normalise ideas and actions'. Ladd (2003) uses the term 'subaltern' derived from Gramsci to refer to Deaf people in general, because it cannot be assumed that they fit into the class system. 'Subaltern' refers to a group of people who do not own or have access to any meaningful power in society, do not share the dominant language, and are not considered to be a part of the 'norm'. This suggests an understanding of the class system as a conditional cultural hearing institution, which excludes Deaf people because they do not have the 'normal' (and essential) credentials required to gain social membership. Where Deaf people are systematically seen at their most powerful - as 'service users', their potential to participate may be reduced to token involvement as 'disabled' informant, and effectively to being collectively excluded (Ladd 2003).

Social Injustice

Cole (1998) argues that the exclusion of social groups should be seen as a form of social injustice. Deaf people are excluded where their position as full citizens and membership of society is undermined. 'The response to this exclusion now cannot simply be compensation for its effects - it must be a positive programme aiming to restore or create the positive conditions of participation' (Cole 1998:52). Structural redistribution ought to occur in order for Deaf people to be able to access and contribute to society in the way in which the majority has the potential to choose to participate, and to secure and maintain social status according to the autonomy and power available to them. 'Coercive paternalism' may have prevented minority groups from free social interaction, and been used to justify social injustices. The reason why choices are not available to those in receipt of labelling, measurement and treatment may be that rules are made by the rational majority with power (Cole 1998). Both Deaf and hearing people however are socially influenced and restricted to different extents:

> The heteronomous chooser, chooses for themselves, but the standards by which they choose, the reasons they have for choosing, are given to them by others… they are not truly theirs… the reason why they value this end has been accepted by them uncritically without examination (Cole 1998:96).

Life chances may be available through historical processes. Each individual has an anchored place in society, which determines their levels of membership, inclusion and position. All citizens are (unconsciously) restricted by the social structure which determines normative action and process (Jenkins 2006). Secure membership of society allows powers and

capacities. Lack of membership means marginalisation and emptiness of position where an individual does not have influence and therefore has limited life chances. Social position is pivotal. Individuals are dependent on social cooperation and position, leading to material rewards and established status. A person is therefore deprived of liberty if they do not have genuine and active membership of the community. According to the above theory, superficial compensation in terms of allotted welfare may therefore be unable to compensate for a lack of full citizenship (Shklar 1990; Cole 1998).

Young (1990) discusses the 'five faces of oppression' where any of these five is a sufficient condition to define a group as oppressed. These are: exploitation, marginalisation, powerlessness, cultural imperialism and violence. Exploitation involves control of the means of production, and the generation of value and profit. As outlined earlier, a cultural Deaf person may be a 'subaltern' excluded from the class system and thereby oppressed (Ladd 2003). Marginalisation is 'perhaps the most dangerous form of oppression (with linking) severe material deprivation' (Young 1990:53). The argument that cultural Deaf people as a collective are under-educated and under-employed demonstrates their systemic marginalisation whereby they do not experience opportunities to gain social competences, and where dependency on welfare denies many rights and freedoms (see below). Powerlessness applies to Deaf people where they systemically lack authority or power (Young 1990). Fraser (2009:21) discusses two types of injustice, socio-economic (including exploitation, economic marginalisation and deprivation), and cultural (including cultural domination, non-recognition and disrespect). Of culture as an example Fraser writes: 'it encompasses both political-economic dimensions and cultural-valuational dimensions, which implicates both (rights of) redistribution and recognition'. However 'whereas the logic of redistribution is to put (culture) out of business as such, the logic of recognition is to valorise (cultural) specificity' (Fraser 2009:21). Since the Deaf collective may be invisible in the mainstream, recognition would need to occur before redistribution.

Shklar (1990:66) describes a parallel experience of a 'minority power'. Women experience social injustice because they remain judged by the 'dominant power' as a 'physically and culturally defined group of inferiors'. Where a woman has a career and marries resulting in enhanced status, she remains a more fortunate individual within the same minority power:

Childbearing can be done artificially and parenting left to those people who want to do it and who are especially qualified for this most demanding of tasks. From that point of view, being a woman was indeed a misfortune once upon a time and is now an injustice (Shklar 1990:66).

Shklar (1990) considers that legislation created by the majority with power may be one of the causes of social injustice, through an inadvertent paternalism. The idea of Deaf people qualifying for social services *because* they are Deaf may be one such example. Legislation passed in 1948 (the National Assistance Act) remains the current legislative framework which directs Deaf people into the welfare system. Rather than legislation being passed to protect and promote the Deaf cultural British language, Deaf people are (still) *legally* 'handicapped', and may well remain so in the proposed Care and Support Bill to modernise the welfare system in England (Clements 2000; Care and Support Bill 2012). Subsequent welfare legislation appears to have backed up the fundamental paternalistic direction, whilst modernising social services. The maintenance of the status quo may justify the absence of perceived societal need for collective recognition of a minority, and its redistribution. This may partly be attributed to the lack of social capital Deaf people own, and society's consequent unclear mandate towards Deaf people as valued citizens (Ryan *et al.*, 2008). This is explored in-depth in the following section.

Social Capital

Whilst the concept of 'social capital' may be variously used in social science and interpreted in contrasting directions, it is arguably useful in this context as a gauge to illustrate the position of the Deaf collective. One criticism of the application of the concept is that social capital advocates have been accused of diverting away structural and individual political challenge through their assurance that voluntary participation and membership of one's community will offer sufficient wellbeing (Harris 2001; Fine 2001). Another critical interpretation is that social capital addresses only 'civic culture' without addressing economic social relations (Harriss 2001; Edwards and Foley 1998). However the concept of social capital is used here to illustrate that Deaf people collectively are 'invisible' in terms of their lack of social capital *and* their effective participation in the economic and political mainstream, *pace* the views of Coleman (1988), Putnam (2000) and Portes (1998). That is, Deaf people cannot contribute to voluntary participation and membership in their society where they do not experience even rudimentary social inclusion, and thereby have nothing to

improve. Their 'social capital' does not therefore divert them from creating political challenge.

Social capital amounts to the nature and quality of the potential for social relationships. Therefore not only is the source of social capital important to analyse, but the relationships between the claimants of social capital, the enablers of social capital themselves, as well as the capital in question. Coleman (1988) maintains that to have social capital, one needs information channels available to them, and one's presence in society involves social expectations, obligations and norms. This arguably cannot be described as applying to Deaf people. Putnam (2000) describes how bridging social capital invites relatively weak (compared to bonding social capital, described below), inclusive networks of different groups. An illustration of the bridging impact on Deaf people in their networks within mainstream society is the probability that neither the Deaf collective nor its members' individual existences are recognised or acknowledged in relation to academic social science, or in institutional policy or welfare legislation (Jones 2006; Ladd *et al*., 2006). A Durkheimian explanation for the sourcing of capital is that all actors are evenly involved in a mutually shared structure, and contribute to the common good. This would suggest that Deaf people are entirely excluded from this structure as they are a seemingly invisible subclass (Parasnis 1996; Portes 1998). Data relating to the socio-economic status of Deaf people is presented below, followed by discussion of debates among theorists as to the most useful and indeed reasonable interpretation of social capital.

Society's progress means that cultural hearing people benefit at a far higher level and at a more accelerated pace from influences which are designed according to a cultural hearing focus. Examples demonstrate the structural opportunities and limitations of cultural Deaf people according to these effects. The treatment of cultural Deaf people collectively has traditionally been led by hearing cultural norms. An example is the functional illiteracy of culturally Deaf Canadians:

> This might be as high as 65%; [this is] not out of intelligence or capability of the Deaf themselves, but on an education system which, by denying them a natural language and culture within which they can function capably and comfortably, in effect socialises them into stupidity (Roots 1999:31).

Similarly, 'only 2 percent of Deaf Americans go on to University, compared to 40 percent of hearing Americans' (Roots 1999:32). This has not been researched, but if one were to compare the number of people in Britain with a PhD with the miniscule number of Deaf holders of PhDs and their proportion in the population as a whole, this could suggest the collective under-education of cultural Deaf people (Padden-Duncan 2007; www.bda.org.uk 2012). Thus cultural Deaf people's education teaches them how to speak and hear English, and to *be* culturally hearing, rather than to be fluent in understanding and writing English, or in academic conceptual development. Instead of an attempt at integration through mainstream education, the system appears to be more of an attempt at assimilation because it involves 'one-way integration, forcing Deaf children to integrate with hearing children on hearing people's terms' (Lee 1992:160). Ladd (2003) discusses the employment position of cultural Deaf people. They tend either to be unemployed, or to be employed in manual unskilled work. A tiny minority are in positions of management and most of these tend to be in cultural Deaf organisations. This suggests the collective underemployment of cultural Deaf people. The all-conquering medically influenced philosophy of state social systems does not appear to be questioned.

Jenkins (2006:121) considers the social capital secured by individuals and accessible resources available to them, depending on the social relationships they are intimate with. This informs their social abilities and competence which establish their position in a social framework. This leads to 'the ability to influence both the expectations which other people have and their 'objective probability' of fulfilling them'; they are positioned in a social hierarchy with conditional power and political ability. 'Social networks are not a natural given and must be constructed through investment strategies oriented to the institutionalisation of group relations, usable as a reliable source of other benefits' (Portes 1998:3). Redistribution is possible according to the changing nature and subjectivity of social groups, and to wider structural influences. Ryan *et al*., (2008:677) assess the position of Polish migrants relating to social capital, and the extent to which their gaining status is subject to the political climate:

> Migrants' ability to mobilize social capital and to successfully engage in bridging may thus depend on their cultural capital (language, skills and educational qualifications) at their disposal. This ability is also conditioned by wider social processes such as policy towards migration and the rights attached to particular migration status.

This assessment however does not positively apply to Deaf people, who have a low status minority British language, and usually do not have formally recognised skills and qualifications of any sort. Their cultural capital may therefore not become transferable currency. Current policy towards Deaf people involves the assumption of an automatic link to the welfare system; they do not have recognition of collective rights (Roots 1999). In comparison young minority ethnic workers in the late 1970s lacked social capital. Yet their income inequality in many cases changed despite the seemingly rooted permanence of young minority ethnic workers' parents' poverty, their own poor connections and their opportunities in the labour market. A seismic shift in societal attitude and legislation had altered the position and social capital of new generations of young minority ethnic workers (Ryan *et al.*, 2008).

Portes (1998:5) explains that 'equally important is the distinction between the motivations of recipients and of donors in exchanges mediated by social capital. …(donors) are requested to make these assets available without any immediate return'. Portes suggests it may be that the providers of social capital accrue reciprocal social capital in the form of obligations owed. This explains the intangible nature of social capital, and its role as power. In terms of Deaf people, they may not be in a position to be empowered with social capital, and thereby not develop into a position where they owe obligations to providers (Lane 2002). The Marxist explanation in terms of the social relationship between the enabler and receiver is that community strength will determine group self-identification and subsequent support. This would explain the recurrently invested roots of power being situated in certain social sectors (Burke 2005; Harriss 2001).

Putnam (2000) describes how bonding social capital enables strong, select ties amongst in-groups. Bonding social capital however is potentially only useful when a group can secure symbolic and cultural capital, that is, tangible aspects of language, education, parental bonds, empowerment, social interaction - and thereby social ties with which to lever. Portes (1998) refers to Bourdieu's understanding of social capital as 'assets gained through membership in networks'. This means that an excluded group's community membership and social capital is non-substantive, because it does not collectively own power. The Deaf collective may experience low levels of social capital, because they are socially excluded from the majority in the immediate term without symbolic or cultural capital. Deaf people may thereby not have employment or vertical economic mobility opportunities where there is a severe lack of social

links (Portes 1998; Jones 2006). Deaf people may seem invisible, so that links of low social capital are reinforced. Ryan *et al*., (2008) in their study on Polish immigrants and social capital discuss a male Polish immigrant who does not use English. His limited social contacts outside his own family may mean that he experiences 'network closure'. Deaf people may similarly experience this sense of 'network closure':

> [Deaf people] have historically been squirrelled away in isolated schools and kept out of the media: they lived largely in hospitals or group homes, and worked either in sheltered workshops or in menial labour where they were unlikely to be seen by others (Roots 1999:24).

The intended purpose of social capital as an indicator of social inclusion is useful here. The notion demonstrates both the position and potential of Deaf people in structural terms. At its most advantageous interpretation, social capital indicates a collective existence of subaltern level from the perspective of the Deaf Studies community, and illustrates some of Ladd's (2003) description of the hearing colonisation of Deaf people. I now turn to the modern welfare system, and the way in which Deaf people are understood and accordingly treated in welfarist terms.

Underpinning Principles of Welfare Service Provision

Under the NHS and Community Care Act 1990 section 47, Deaf people's entitlements are individually assessed, predominantly for domiciliary care needs. Domiciliary care entitlements are laid down in two previous Acts, the National Assistance Act 1948 section 29, and the Chronically Sick and Disabled Person's Act 1970 section 2 (NHSCCA1990). Clements (2000: 135) states that in the 1970 Act, Deaf (and hard of hearing) people are defined as 'other persons who are substantially and permanently handicapped (and who have) a disabling loss of hearing'. The administrative individualised model of social care has directed community care legislation, where difficulty and dependence are assumed:

> The construction of disability as dependency has been a recurrent and pervasive feature of community care policy making… This way of speaking about disability implies a unidirectional and causal connection between impairment and dependency. This obscures the possibility that the dependency of people with perceived impairments might also be culturally produced (Priestly 1999:44).

The legal status of Deaf people (described as deaf /hard of hearing people) is as individuals with impairment and with needs (NHSCCA1990; Clements 2000; RNID 1999). Their legal

status places them in a dependent position where they can call upon social services for assistance. All Deaf people are entitled to a social work assessment and appropriate service because they are seen as cultural hearing individuals with impairment, therefore having need and dependency (Young, Ackerman and Kyle 1998). The care system is designed to meet 'needs' rather than 'rights' and the objectivity of that 'need' is assumed. The disability movement maintains that independence for disabled people is more than just 'care' services, and that a quality service recognizes its obligation to the service user, including the challenging of structural barriers:

> Community Care should be seen, within local authorities, as a 'corporate approach' to local need. This transcends the socially and bureaucratically constructed boundaries of 'service' provision altogether, in favour of one based on a social model of disability and barrier removal (in society) (Priestly 1999:205).

Priestly argues that 'need', as determined by welfare legislators, primarily identifies the domiciliary assistance required according to a person's physical ability, which, when addressed, achieves 'normality'.

This implies that the identification of communication difficulties would illustrate disadvantage, which cannot be addressed. 'Need' therefore excludes the identification of societal communication barriers. Deaf Studies literature argues that as people who are culturally different from the mainstream culture, Deaf people do not logically fit into welfare legislation which is designed for cultural hearing individuals with impairment. From a Deaf view, Deaf people are 'normal', and therefore do not have 'need', communicative or other support needs (Roots 1999; Emery 2009). Sainsbury (1986:15) writes of 'deaf people… whose impairment might be expected to create severe communication difficulties, namely profoundly prelingually deaf adults'. Sainsbury, with possible connotations of control, questions:

> …how do doctors, psychiatrists, teachers, housing and employment authorities know how to *deal* appropriately with *people dependent on sign language?* Our carelessness and ignorance conspire to ensure that many deaf people experience considerable deprivation and suffering (my emphasis) (Sainsbury 1986:15).

What is interesting is the comment that there is 'dependence' on the use of a minority language, as opposed to dependence on the use of the majority, i.e. hearing, language. The notion of a hearing language is not acknowledged and it is assumed that it is not desirable to

use a minority language which is different from the mainstream mode of communication in society. There is also a direct implication that professionals such as 'front-line' operational workers and implementers of government policy are default majority people, and not 'deaf', and that it is for those professionals to *deal* with the minority.

Sainsbury (1986) compares 'deaf' people to blind people, in terms of limitations to expectations of individual advancement, and observes that it is for social workers to classify whether 'deaf' people fit into the categories of 'deaf with speech', 'deaf without speech', and 'hard of hearing' (see Young *et al.*, 2004). This suggests a lack of consideration of any kind of collective status, or of cultural difference. It is assumed that 'deaf' individuals are as disadvantaged as blind individuals. According to a hearing cultural perspective, 'deaf' people *are* in a corresponding position. However from a Deaf view, Deaf people are a naturally evolved collective with a distinctive culture, whereas visually impaired people share the majority culture and language, and acknowledge that they experience individual impairment and disability (www.bda.org.uk 2008; RNID 1999; SSIW 2004). The categories of 'deaf with speech' and 'deaf without speech' are clearly based on measurement of use of spoken language and extent of ability to *be* hearing. The labels are 'one-way', in arguably suiting the purpose of the cultural hearing professional's plans for 'support' according to hearing cultural terms. Sainsbury concludes, 'if deaf people are to achieve… they will require the services of the trained specialist. The deaf community is dependent on... provision of social workers for the deaf' (1986:245). This view is often maintained in current social work with deaf people (RNID 1999).

Likewise, Harris (1997:26) some years back observed with regard to the welfare of deaf people, that: 'Hearing people are frequently ignorant of the communication needs of deaf people, and they react to deafness in unhelpful and stigmatizing ways.' Ironically, this statement may be unhelpful to Deaf people in that it is assumed that 'deaf' people have communication needs; it is not acknowledged that they have a valid language, or that cultural hearing and cultural Deaf people between them have two diverse languages. The term 'deafness' implies medical (audiological) measurement, and thereby deficiency, potentially presupposing a cultural hearing understanding of the status of Deaf people. Harris (1997:30) similarly states:

..deaf people are relatively powerless. If communication is to be meaningful, the hearing person must adapt to the needs of the deaf person… The social relations between deaf and hearing people *depend on the good will and adaptation of hearing people* (my emphasis).

The assumption (above) that Deaf people are completely reliant on cultural hearing people to permit social change implies that cultural Deaf people indeed experience disability in having 'needs', need help in progressing forward, and that they are under the control of cultural hearing people who must be prepared to let go of some power to enable some authentic cultural Deaf self-expression and self-development. Arguably, social change can only occur when an excluded group gains sufficient recognition and strength to campaign against the status quo (Ladd 2003). A not dissimilar example could be the Welsh language campaign movement Cymdeithas yr Iaith Gymraeg which successfully sought Welsh language legislation, and which continues to work towards protecting and promoting the Welsh language and culture. It was arguably not centrally due to English language speakers that Welsh Language Acts have been passed (www.cymdeithas.org/deddfiaith/ 2008).

Current Welfare Policy Guidance

The Social Services Inspectorate for Wales *Inspection of services for people with a physical or sensory impairment* (SSIW 2004) summarises the current (2012) policy assumptions underlying social work with deaf people. Point 4.75 acknowledges Deaf categories of self-claimed labels and identities, but thereafter refers to them in traditional ways: Deaf people are described as 'deaf people who use British Sign Language (who) describe themselves as being part of a cultural and linguistic minority and reject the concept that they are disabled'. Further on in the report, however, they are described as 'possibly using a hearing aid', or as having 'some form of hearing disability', 'Deaf with speech' or 'Deaf without speech', as having 'severe /profound deafness' and being 'hearing impaired'. Again, this demonstrates an ongoing hearing cultural gauge of the ability to use spoken language and the extent of hearing 'loss.' Again there is the assumption that lack of speech and hearing is a loss. Point 4.77 discusses 'specialist workers'; the report does not define 'specialist', but appears to imply the difficulty of their task because their service users have speech and hearing loss. Point 4.78 states '…authorities should give consideration to the professional support needs of specialist workers'. The report does not state what these professional support needs are. Presumably their support needs arise because of their difficult work.

Point 4.81 proceeds to affirm that 'local authorities should ensure appropriate provision of communication support'. However it is not clear what is meant by communication support. Does this mean recognition of BSL as an independent language? Or does 'support' here imply helping someone to use or access English? It continues: 'the roles of specialist worker and interpreter have now become *more* distinctive, although specialists may act as an advocate' (my emphasis). This suggests that specialist workers can still interpret, and that there remains no clear segregation between roles. Could this add to or reinforce dependency? Also the idea that specialists can act as an advocate is questionable, given that they are statutory workers, whose role is to carry out a legislative obligation.

Point 4.82 states 'social services help deaf people get interpreters in different ways'. This directly implies that it is 'deaf' people who need interpreters, suggesting that there may not be recognition of English /Welsh and BSL as equal languages. There is a Standards checklist question 'Does the policy recognise that being able to communicate in a language does not automatically mean that you can interpret it?' An assumption however is made here of social services departments' responsibility for providing interpreters. Under the specialist worker's role, the list includes 'helping children with a deaf parent or parents'. This assumes that (hearing) children who have a deaf parent or parents have a disability or disadvantage, and thereby have need. The list also includes a traditional role for social work with deaf people, according to hearing cultural assumptions that the main focus should be enabling access to English or Welsh. It could be argued that this role actually creates dependency, and diverts a service user from recognizing their own cultural and language identity: the social work role is to provide help with one-off tasks, so that a service user may not be in a position to do tasks independently of the social worker. Point 4.87 advises that the standards in the 'Best Practice Standards' manual (RNID 1999) are 'essential for …reviewing and developing services for deaf and hard of hearing people'. This arguably demonstrates an upper limit to what is achievable by way of the scope of social work by specifying operational standards for practice, as well as preventing consideration of practice led by the different values of the Deaf collective.

The Best Practice Standards (RNID 1999) is a Government sponsored manual of nine standards to which local authority sensory impairment services should (still) conform. These cover: information, access to services, communication services, assessing and identifying appropriate services, equipment assessment and provision, accessible services at home and

outside the home, planning, service procedures and procedures for joint working /managing responsibility. The report states that 'it is designed for practitioners identifying an acceptable level of service based on legislative intent… It is hoped that the standards will contribute to clearer, more transparent services' (RNID 1999:1). This summarises the boundaries of the underlying policy for social work with Deaf people. The Best Practice Standards report (RNID 1999:4) states that senior managers 'are responsible for developing strategy, policy and good practice in all areas of social services, including deaf and hard of hearing people, they will need an understanding of deafness and hearing loss'. This suggests a required knowledge of Deaf people in terms of a medical and /or social understanding according to hearing cultural values, that is, a requirement to understand cultural Deaf people's 'impairment' in terms of fitting them into hearing cultural society.

The National Occupational Standards (Care Council for Wales 2007) are required standards to which all social workers should conform. There are six 'key roles' of a social worker which set out their 'indicative knowledge base'. These areas comprise: preparation and assessment, engaging and planning, support, managing risk, accountability and evaluation. These currently apply to all social workers in Wales. A 'specialised' set of National Occupational Standards has however been produced, although not circulated to sensory practitioners focusing on sensory impairment (personal communication b: 2012). This would seem to suggest that a separate, narrower set of standards is required because the generic standards may not be sufficiently applicable. The Care Council for Wales Code of Practice (2007) is an obligatory code of professional ethics which sets out the boundaries of ethical social care practice. These appear to overlap to some degree with National Occupational Standards. The core elements are: protection, engaging, promoting independence, respect, accountability and upholding of the standards of social care services. The inclusion of the final element is interesting, in view of its being classed as a value. It may be that the focus of these obligatory values and ethical practice is to enable maintenance of professional status, as well as to implement fundamental social work core values. The Code of Ethics for Social Work (2007) is set by the British Association of Social Workers; the guidelines are not obligatory, and may be less known by social workers (personal communication b: 2012). 'The primary objective of the Association's Code of Ethics is to express the values and principles which are integral to social work, and to give guidance on ethical practice' (www.basw.co.uk 2007:1).

In Wales, individual need is assessed via the statutorily required Unified Assessment Process (Cardiff Council Unified Assessment 2012), whereby priority is awarded in response to an individual's 'risk to independence' and need of intervention in order to fit in with society as an independent person. There is a change in focus away from identifying 'need', perhaps in parallel with a change in financial priorities, and commitment to a higher threshold for the level where need will be matched with service provision. The specified domains are: service user and carer perspectives, medical background, physical and emotional well-being, senses and mental health, safety, and the local environment and available resources. There is an option for a linked specialist assessment through referral by a social worker (for example: see Cardiff Council Unified Assessment 2012).

More recent developments include the Welsh Government's *Benchmarking on Hearing Impairment* guidelines (www.ssiacymru.org.uk 2012), although this also has not been circulated to sensory practitioners (personal communication b: 2012). Care Council for Wales (2007) have developed a change in direction to collaborative working amongst agencies, and a focus on 'outcome based services', according to what an individual service user wants to achieve (funding permitting). The new 'personalisation' adult service user budgets focus on 'citizen directive support', that is, achieving independence. A social worker refresher qualification in sensory services is being developed, as a 'Level 5 QCF diploma' (www.tutorcare.co.uk/NVQ-Training/Level-5-Diploma-in-Health-and-Social-Care   2012). The Welsh Government have commissioned training (personal communication b: 2012) for sensory impairment social work practitioners relating to the medical and social models of disability, and on mental health issues and deafness (personal communication b: 2012). The fundamental values of the Best Practice Standards (RNID 1999) remain: of d/Deaf people as having individual, sensory impairment and need, and at risk to their own independence - measurement of these is according to the likelihood and severity of risk, as assessed by the individual social worker.

Social Work Research with Deaf People

Evidence-based practice is the research process involving systematic checks of evidence, linking cause and effect, and concerning effectiveness, including cost-effectiveness (Humphries 2003). It involves 'locating empirical evidence about an intervention, carefully appraising the validity and utility of this evidence, and applying the results of such an

appraisal in an ethical fashion' (Jenson 2005:133). Two examples of relevant research are discussed that arguably challenge this perspective and which indicate ways in which studies may collude in majority cultural oralist assumptions about need and identity for Deaf people and which therefore require us to think critically about what stands as 'fact' or evidence in research. Firstly, Young *et al*., (2004) conducted a quantitative study of fifteen social work services with deaf and hard of hearing people in England'. They adopted the criteria in the 'Best Practice Standards' manual (RNID 1999) to compare their data.

Their research is perhaps conceptually limited because it assumes beforehand that the set criteria list the best possible outcomes. Moreover the study may be inadvertently led by hearing cultural values. Even though there is recognition of 'Deaf' people as 'having' a culture (as if hearing people do not), there is no questioning of *why* 'Deaf' people have a social worker. 'Deaf' people are assumed to come under the umbrella category of having 'hearing loss'; there is no questioning of why 'Deaf' people have the same social worker as people who are oral deaf /hard of hearing. The terminology of Best Practice Standards is followed without question; the category of 'deafblind' appears to label cultural hearing blind people who have become hard of hearing. It does not acknowledge its tacit inclusion of Deaf people who have become blind. It is accepted without question that it is the need of 'Deaf' people for interpreting services that is referred to and that 'need' is not in question, even though it is acknowledged that 'to be Deaf is no longer regarded as a sufficient reason to be in need of services' (2004: 34). This point would appear to be in conflict with the legislation. However evidence based the study is, ideological hearing cultural norms appear to shape the research design and outcomes (O'Brien and Penna 1998). Indeed, Butler argues that we need to be sceptical about the possibility of studies that claim to be purely scientific and value free:

> Such scientism tends to the depoliticisation of both social work and social work research. A narrowly conceived, contemporary understanding of what constitutes evidence (and hence legitimate forms of research) means that ...questions concerning ultimate causes and final purposes are more or less unanswered …such scientism also claims to be value free (Butler 2003:22).

Secondly, Crowe's (2003) study using focus groups to promote HIV prevention material for Deaf people seems to have conceptual weaknesses on a comparable level to those of Young *et al*., (op cit). Crowe's research seems similarly paternalistic in the 'othering' of the researched (Fine 1994). It appears that the researched are written 'for'. Crowe's perspective does not

acknowledge the (different) cultural identity of the participants (they are classed as 'deaf'); assumes lower language levels of the language involved in the research (the natural language of participants); explains apparent basic detail in engaging with participants, as if that is all that is required in securing data from this type of people and expresses a low expectation of the capabilities of 'deaf' people and their contribution to society. Such inadvertent hearing cultural influences in research can mean that qualitative enquiry misrepresents 'knowledge' of socially constructed reality; this could mean that for purposes of evidence-based practice, so-called 'best quality' evidence would be used to reinforce legitimated social work practice. Indeed much of the literature in this field needs to be read with a critical eye.

Conclusion

Differing cultural perspectives offer different understandings of the everyday practices and processes that are fundamental to the workings of society. The influential norms of society appear to belong to the dominant culture (Perry 2001). The state approved principles of social justice in advanced liberal democracies are understood to mean that 'all members of the community are in a position to be equally active choosers, doers and participators' (Cole 1998:56). The state recognises that 'intervention can be incorporated in enabling freedom, to promote and protect well-being', given justifiable grounds. It 'ensures that the welfare of each person is equally realised' (Cole 1998:92). 'Justifiable grounds' by default have normative underpinnings and therefore are 'fair' according to subjective norms and rules. It is in this context that this chapter has sought to argue that welfare assumptions about the medical and legal status of Deaf people result in a form of hearing colonialism (Ladd 2003), legitimising a paternalistic safety-net mentality. Welfare policies and guidance run in parallel with welfare legislation which reinforces and dictates a societal assumption that Deaf people are individuals with impairment. There arguably remains a gap between up to date social work research with deaf people in conjunction with welfare policies /guidance, and Deaf Studies literature. Social work research with deaf people may have gone through gradual changes in parallel with societal trends and attitudes towards Deaf people, whilst the philosophy behind welfare legislation appears to remain unchallenged.

There is therefore a significant gap between the Deaf collective's view of itself, as evidenced by Deaf Studies research and literature on the one hand and mainstream research into social work with deaf people on the other, and indeed welfare legislation as a whole. Deaf writers

and activists have argued that they do not to wish to be assimilated into the majority of the population as culturally hearing pathological individuals with disability; instead they assert that their collective, language and organisation are different (Batterbury *et al.*, 2003). A poignant example of how cultural hearing is ingrained in professional assumptions about desirable outcomes is in the arguments about communication between hearing and Deaf people. As Lane writes: 'Many professionals claim that Deaf children need to be taught speech so that as adults they will not appear 'disabled' and will be able to talk and mingle with hearing people on an equal basis' (Lane *et al.*, 1996: 216). This and related contrasting cultural judgements are expanded upon in the findings of chapter 5.

In the following chapter the exploration moves to the literature relating to issues of governance, the discursive and ideological positions of Deaf controlled community organisations providing welfare and empowerment, the nature of organisational structures for power, and the determinants of survival and growth of such organisations in the contemporary UK public policy climate. It also considers the strategies of mainstream public bodies who directly or indirectly affect Deaf led charitable organisations' positions and viability. Here, issues of authority, standing, intention and investment by governmental bodies in Deaf agencies are examined in relation to the aims of UK and Welsh governments in modernising their objectives and prioritising the equalities agenda and the politics of change.

Chapter 3

Structure, Policy and Possibilities: Social Justice and the Deaf Collective

Introduction

The research parameters for this chapter allow an investigation into the institutionally held views about the Deaf, specifically affecting third sector Deaf-led organisations, their members, and the Deaf collective they seek to represent. The following bodies of literature not specifically relating to third sector Deaf-led organisations are explored for relevance: social justice, aspects of policy and participation, governance and self-governance, and issues of identity and language. The chapter covers key aspects of a growing literature about policy decisions made mainly in Wales by mainstream hearing elites which directly or indirectly affect Deaf organisations and which relate to hearing elites' authority, standing, policy and investment. This chapter does not directly address the Deaf collective or Deaf organisations as the available policy literature does not engage in significant detail with the interests of this minority community in UK society. This is made apparent, as the chapter will show, in Welsh Government policy documents which refer to equalities strands. The Deaf collective is in fact institutionally understood in legal welfare terms not as a purposeful collective but as hearing impaired individuals who slot into the category of disability as sensorily impaired.

The chapter in considering relevant policy, gives particular attention to attempts by governments to modernise society in relation to key ideas around equalities, inequalities and the politics of change, and also the fundamental ideal of the equality of outcome. The reader may be enabled thereby to understand the social and political context that underpinned the interviews with the two respondent samples which feature in chapters 5, 6 and 7. The ambitions, interests and potentialities of the two samples (hearing elites representing public service institutions and leaders of third sector Deaf organisations) are variously interlinked through systems of governance. The hearing elites and their institutions (government politicians, civil servants, providers of local authority statutory social services and third sector umbrella organisations) have considerable influence in terms of policy design and implementation and funding allocation vis a vis the Deaf collective and its representative bodies. The chapter will consider the types of governance that regulate the relationships between these bodies and which both profile and position what it is to be d/Deaf.

In applicable UK public policy literature, the Deaf collective are assumed to be a population of individuals with a physical and social disability and are unavoidably constructed in terms of how they can conform to public rules and systems which directly and indirectly affect them. Those policy systems and rules do not directly recognise the notion of a minority Deaf collective in UK society. Neither is the policy literature likely to acknowledge an existing but differently encultured group which uses a different British (or indeed world) language. Such policy sources, which will have a strong Welsh flavour, are relevant nonetheless in order to help reveal the policy discourses likely to inform the institutional elites who lead the public services in Wales that participated in this study. The themes which are now explored are: social justice, social policy, third sector development, governance and identity. In exploring these inter-linked themes it should be possible to grasp the Deaf collective in the way they are constructed by and respond to the 'rules' of mainstream policy discourse. This in turn will reveal something of the institutional complexity that is the context for this study.

Social Justice

In discussing an idealised notion of social justice and by extension of governance, Cooper (2004: 78) writes about the fundamental ambition of modern economic society and the equality of power:

> it is ultimately... unattainable... but the normative premise is that nobody has an inherent right to impact more on their social and physical environment than anyone else.... (This) includes a more radical emphasis on equalising participation within the making and operationalising of collective decisions – political, economic, environmental and social.

The drive towards equality and the above ambitions for greater participation in decision making to tackle a democratic deficit in public life has in many respects accompanied the devolution movement in the UK. For example, Williams (2007: 142) asserts that the newly devolved Welsh Government is uniquely advanced in its institutional position of recognising diversity and the allied need to advance equalities across the public policy spectrum: 'The range of legal, constitutional, governance and structural arrangements unique to Wales indicates that Welsh policy in respect of equalities has a significant degree of divergence from practices elsewhere in Britain'.

Drakeford (2007) argues the case for devolved governance principles of social justice and the implications of these for meaningful public advancement in Wales. The first principle

justifying government presence is where public investment can enhance social justice. This of course stands in some contrast to the political default system of laissez faire, or of privatised institutions and deregulation as a way to deliver social goods (Heinrich 2010): 'The history of collective effort retains a vitality in people's minds which translates into a belief that, when competently organised and delivered, Governments represent the best vehicle through which social improvement can be achieved' (Drakeford 2007: 5). The second principle that Drakeford advances to promote equalities in Welsh policy is that 'universal services are preferred, where possible' over means tested services otherwise, 'services which are reserved for poor people very quickly become poor services' (Drakeford (2007: 5). Drakeford goes on to argue that universal services enable all to share in and feel involved conjointly in society. Could the operation of these principles then allow the Deaf collective to articulate a case of discrimination, of denied equalities, and to then seek some form of compensation or remedy, for example an independent television channel and an accessible film interpreting relay service alongside recognised cultural and language status? (see Ladd 2003; Agboola 2006; Roots 1999). Such a response seems unlikely in Wales or the wider UK in the current climate of austerity coupled with the yet to be realised ambition of BSL to attain an equivalent status to other recognised minority languages such as Welsh.

Drakeford (2007: 7) asserts the aim of devolved Welsh policy to substitute where possible competition with collaboration over the delivery of public goods, so that a partnership basis is a preferred system of funding and implementation, where: 'the ethic of consumerism has been rejected in favour of an ethic of citizenship. (Instead of a) 'high-trust' relationship culture, (there is) the incorporation of collective and co-operative operation.' This position may not necessarily benefit Deaf led organisations, which may remain categorised as medically 'deaf' entities, working with people with hearing impairment, as well as those 'deaf' who use signed language. This in turn may have resulted in the medically focussed 'deaf' organisations securing funding in regard to a 'disability' agenda. Whereas, Deaf led organisations might remain invisible behind these larger agencies and where Deaf members participate tokenistically on committees of mainly hearing governing bodies and unable to generate policy focus or bias towards their collective (Turner 2007).

It may be added, in connection with Cooper's (2004) ideal of 'equality of power', that contemporary Welsh Government policy of 'equality of outcome' (www.wales.gov.uk/ topics/equality 2012) has replaced the former (and widely deployed) concept of 'equality of

opportunity'. The aims of the former include a more determined attempt to equalise the outcomes for poorer sections of society by addressing all aspects of public policy and energising greater citizen participation. Could this be seen to include members of the Deaf collective, where they can freely apply for education courses, training and employment without assumptions of 'their' need for interpretation between British languages, and where a Deaf individual is not held responsible for this in terms of 'their' budget-limited grant, in either, for example, Disabled Student Allowance, or Access to Work packages? (see www.bda.org.uk 2012; Mindess 2006). The answer is 'unlikely' given the way policy is presently configured. However, a petitions committee has been set up to enable: 'accessible campaigns, to support ease of engagement, in addition to the public access arranged for Government debates and discussions' (Drakeford 2007: 7), and this may offer further routes to the Deaf collective in Wales.

The incorporation of voluntary bodies and their collective involvement in policy formation and negotiation invites consideration as to how far the integration of Deaf led organisations could proceed. Could Deaf led organisations and the collective be recognised as having mainstream 'weight' so that they could be a valued political contributor and influence? In relation to this, Cooper (2004: 83) raises an interesting question as to whether minorities having become visibly mainstream and holding contributory positions as collective as well as individual citizens, continue to be seen as less empowered minorities able to claim social distinction thereby? Thus, 'Can gender, and race remain as meaningful, but non-pernicious, forms of difference?' Those minorities with diverse languages and cultures could be cases in point. In such an ideal form of society, Deaf members with their unique minority language would enjoy bi-lingual status in which their language would be more widely used and accepted as native to the UK, and therefore they would not need to claim social distinctness (Grosjean 1996).

On this point, Cooper (2004: 83) illustrates a possible underlying difficulty using gender as an example (and which might allow some cognate distinctions between Deaf and hearing):

> While certain injustices, such as economic class, require category elimination, others such as (gender) are perceived differently. ...(A) commonly held assumption (is) that equality between men and women is possible: gender can, indeed should outlive its relations of production. For some, this position is predicated in a separation of the biological from the social; while the latter is historically contingent and as such

amenable to change, *this does not undo the biological difference upon which relations such as gender are predicated.* (Cooper 2004: 83) (author's emphasis).

The differences could be claimed to be biologically and significantly integral because of the gendered roles men and women play in producing children. In parallel, a societal integration of Deaf collective language and culture would mean that equality between hearing and Deaf people is possible, and that the hearing and Deaf distinction could outlive its relations of production. However the separation of the biological from the social depends on the majority normative value of the need to hear, so would acceptance of Deaf minority language and culture mean that the majority norm of needing to hear be somehow dismissed? Not according to the argument of Cooper (2004). The normative fundamental that is hearing culture is seen as an unquestionable imperative whereby d/Deaf people who 'can't hear' really do need to hear, and that biological 'impairment' causes this inability (Sainsbury 1986; SSIW 2004).

Gwilym (2007) outlines details of the implementation of the policy of the social model of disability to be applied to all disability groups adopted by the (then) Welsh Assembly Government in 2002. By 2006, all Welsh Government departments had an established programme to mainstream disability equality. The Assembly were forward in accepting responsibility for English/BSL interpreting costs for Assembly debates and political involvement. In this context the Welsh Assembly Government (www.wales.gov.uk/topics/ equality 2008) appeared to recognise that the Deaf collective have an independent minority British language *as well as* a social disability. The Welsh Assembly Government (WAG 2008:148) claims an incorporated 'mainstreaming approach to the development of its equalities strategy'. This means formal consideration of minority group inclusion at the start of policy design. The stated aim is for a long-term equalities initiating strategy which will remain beyond the duration of particular governments. The introduction of an Equality Policy Unit in Welsh Government which commissions monitoring, evaluation, and training adds to an institutional openness to difference. Also:

> the cross party committee on equal opportunities... has set up engagement and consultation forums to secure the perspectives and experiences of less visible social groups in Wales. These cover the social strands of ethnicity, sexuality, women, disability, and religion.... A strategy for older people has also been established. Further research demonstrates that forums for each of these social groups have opened up accessibility to related policy development (WAG 2008: 149).

Yet, it would appear that the Deaf collective have not been considered to be a modern equalities strand under the new powers of the Welsh Government. Barnes *et al.,* (2010) argue that barriers remain which prevent real opportunity for meaningful participation. Lack of cultural knowledge and engagement with a minority group could contribute to this. The Deaf collective for example have conceptually different norms and values and language based on cultural bonds, politics, history and a collective tradition. Recognition of the Deaf collective as a minority that requires both attention to and investment (conceptual and practical) in their language and culture as a means to advance participation and to mainstream equalities is likely therefore to create challenges. As Barnes *et al*., (2010:254) observe more generally:

> in spite of broad acceptance of user and citizen participation in the governance, design and delivery of public services, there are a number of issues that continue to offer conceptual, practical and political challenges in terms of the way in which opportunities for participation are designed.

In looking more broadly at the future of UK welfare Fitzpatrick (2005: 86) stated that '...a consensus has emerged that the era of welfare state and public sector expansionism is now well and truly over'. But in a future with a more marginalised and minimalised 'safety net' welfare system would it be possible to consider that a sector such as the Deaf collective could be recognised in wholly different terms. For example, instead of being seen as welfare users could a different investment be made with a view to setting up a springboard for Deaf education thereby facilitating a collective Deaf economic contribution and membership of mainstream society (see Agboola 2006; Mindess 2006)? Such a consideration, however feasible, may be limited in a period of restricted public investments.

Additionally, as Fitzpatrick (2005:86) states: 'where social democratic principles and systems are already firmly entrenched they continue to thrive since the opportunity costs of abandoning them are potentially higher than the gains which would arrive from doing so'. That is, it would indeed be an expensive process for institutional bodies to change their fundamental policy rationales, hence welfarist and oralist traditions are likely to be dependent on an established path and objectivised over the long-term. Accordingly there would seem to be an extremely slim chance of recognition of and resources for the third British language in the way that there has been for the second British language - Welsh (see www.cymdeithas.org/deddfiaith 2008). To reiterate, could a modernising UK or Welsh state allow the Deaf collective to be removed from its policy location within a welfare institutional

ambit and become a more participative and productive societal sector enjoying thereby a more valued identity in a more knowledge based, networked and progressive society? (see also Esmark and Triantafillou, 2009). In the short to medium term there seems no easy or encouraging answer to this question.

Friedman (2002:27) writes that 'economies are likely to grow if the institutions and ideologies that shape economic actors' behaviour lower the cost of transacting.... The arena in which the pre-conditions for creating – as well as distributing – wealth is, therefore, the political'. Normative values therefore would appear in large part to shape economic outcomes; the political values of a society arguably may facilitate the conditions in which those with authority become the forerunners of policy, and in which conditions for economic advance are assisted. Friedman (2002:32) asserts that much writing on 'the identity of society' assumes a united whole, rather than anticipating difference amongst groups who live alongside the majority: 'Literature... assumes that there is a homogenous "public" whose participation can be sought and secured'. This might suggest that with the Deaf collective, were their values and attributes to be accorded a higher and positive profile then 'public' perception might somehow be swayed. Yet we must first ask, if the Welsh Government and other institutions are not aware of the Deaf collective and its many virtues, how then could a new broader public understanding be secured? The chapter addresses this question next.

Aspects of Policy and Involvement

Norris (2002:155) discusses the relevance of social patterns and cultural norms which contribute to structural and cultural aspects of social capital: 'Those societies rich in social capital are all established democracies with some of the most affluent post-industrial economies in the world... social capital (is) consistently and positively associated with many indicators of socioeconomic and human development'. Norris explains how rich communities are those with complex layers of social networks, where members have overlapping access to resources. In such cases, one 'would expect to find the strongest culture of mutual respect, tolerance, and cooperation, as well as of civic engagement'. Wallace (2009:250) asserts that the two majority political parties of the UK advocate the involvement of a part private system in terms of welfare service provision. The third sector which is considered to cover the space in vague terms between statutory and private sectors is allowed to fill-in-the-gaps as well as to pacify community groups by establishing political links and community specific provision:

Both Labour and Conservative parties... favour the use of the private sector and quasi-markets, but have increasingly softened the edges of their pro-market thinking by claiming it as only one part of the mixed economy of welfare provision and presenting the amorphous 'third sector' as a soothing balm in social policy design uniquely placed to deliver 'personalised' services.

Wallace goes on to explain the defects with the system, where local strategies, seemingly customised as solutions, are not a structural response, so that a national collective (such as the Deaf) that is so far unknown may not have the opportunity to become nationally recognised. Also any redistribution in terms of enhancing the rights and status of a collective minority through investment in commitment and resources will not materialise where this is not policy. Wallace (20009:250) explains, 'the fragmented (third sector) has thus far tended to be morally and culturally prescriptive rather than structural or redistributive... public services are increasingly provided by the market, and third sector organisations are encouraged to enhance the responsibility (of the people they represent)'. This latter requirement would fit in with the need of the Deaf collective to be recognised as a national minority section of society. Where this recognition and profile were established, Deaf representatives could enhance the responsibility of the people they represent, as an aim for achieving collective education and employment (see www.bda.org.uk 2012).

Keating (2009: 280) describes the situation of emerging minorities becoming publicly visible and claiming a status as victims of possible societal discrimination and resultant poverty: '...it seems that, where possible, regions are redefining their own 'deserving poor', with different priorities for population groups...'. The Deaf collective in different countries could be one such minority, where they claim to have been structurally and institutionally hidden behind a category where they could be labelled as individuals in need, and thereby not as a purposeful political group who know (or know of) one another nationally and internationally. One view is that due to their welfare label they have not had fair opportunities in respect of education due to a lack of recognition of and investment in their British language and opportunities to learn in this medium. They have also learned to act as individuals in need, where only limited anticipation of gaining employment has been possible. A 'collective poverty' has arisen as a result of this structural discrimination (Roots 1999; Lane *et al*., 1996). General priorities for countering such a position would need to begin with investment in the language of Deaf people, which could act as a springboard for active Deaf citizenship, contribution, education and employment (Lane *et al*., 1996).

A barrier to structural recognition in this direction is that the safety net of society lies with statutory social services. Where groups are judged to have 'fallen through the net', individuals are addressed as being in need, and are supported by a centrally governed welfare system: 'market correction, in the form of the welfare state, remains largely at the national level' (Keating 2009:275). Friedman (2002) writes about 'the state as normative ideal'. This means that the existing cultural values and norms known and historically understood by the state are likely to be those which should be implemented. Alternatively, a state with a normative ideal of challenging the status quo, and endlessly researching and engaging with 'newly discovered' minority cultures allows an open platform for negotiation. Friedman (2002:22) asserts that whatever the current policy about the engagement level of the state, 'the evidence for the decline of the state is unconvincing... not only does it remain intact but its actions continue to determine whether societies prosper economically or stagnate….. they retain significant leeway to set their own paths away from or toward growth'. Deaf Studies economists argue that the integration of the Deaf collective would mean a significant contribution to the economy, to knowledge and to production. This is an aspect which the state currently steers away from, but could be reversed (Agboola 2006).

Keating (2009:279) goes on to explain that welfare provision can become the basis of community support groups, which can in turn become more long term societal assemblies: 'welfare and social solidarity may be used precisely in the cause of region-building or stateless nation-building'. However, according to a general collective Deaf view, there may be a fundamental difference between an 'artificially' created support group for visually impaired people, introduced to one another by a social worker, and a Deaf collective based in a certain region, where the culture and language have evolved historically, against a background where signed languages were spread globally, and where members have known each other for many generations. If the intention of supportive intervention is to instigate community development, this could provide opportunities for either evolving communities led by statutory agencies, an advisory sector influenced by third sector initiatives, or self-led communities which are enabled to become formally recognised, given the opportunity for a platform. It is towards this sector that we now turn.

Third Sector Development

The third sector is supposed to engender balance in the space between the state and the market. The Welsh third sector umbrella organisation the Wales Council for Voluntary Action issues guidance as to third sector governance and achieving ambition. Guidance tends to be in parallel with government policy directives, in commenting on and advising organisations how to achieve within existent policy boundaries and incentives:

> …many community organisations work alongside and together with other organisations both voluntary and statutory. This will often be an informal arrangement in which organisations will join forces or pool resources when it seems useful. Increasingly though, organisations are entering into partnerships – the term implying a formal, or at least explicit, undertaking to work together to a commonly agreed goal (WCVA 1998: 18).

The WCVA states that partnership typically involves a plurality of organisations either from within the third sector, or in a cross-collaboration of sectors, including both private and statutory, where partners contribute different aspects to achieve a shared goal which will benefit both or all sector bodies. The report states that fundamentally, in 'an attempt to find shared solutions to shared problems, at least *one reason for the growth of partnership working is the requirement of funders*' (my emphasis) (Halfpenny 2002:535). Partnership working may have largely been shaped by the need of many organisations to attempt to survive, and thereby to accept the conditions that come with funding. Partnerships are stated as ranging from 'community initiated power holders, sharing decision making with outside forces, to manipulation (where there is an) imposition of policies and /or decisions on communities' (Halfpenny 2002:536). Of course, depending upon the aims of organisations they might either believe the system to have enabled their continued existence to deliver vital community work, or they might reject this external intervention if it requires an unacceptable compromise of their fundamental principles (see Lane *et al*., 1996). Further, Halfpenny (2002:540) includes guidance on professionalising a third sector organisation, advising organisations to consider making their standards and business aspects clear publicly, and to consider: 'effectiveness, accountability, policies, user involvement and voluntary action, governance, equality and fairness, and staff management'.

Powell and Geoghegan (2004:9) question the extent to which representative voluntary activity in civic society as a whole can match an informal and unofficially recorded need. Outside of both the state and the market, they question if voluntary activity needs to be encompassed by external sector guidance, resource and attention, or whether autonomous

voluntary action solely within a civic sector space can be self-sufficient and effective, and begin to involve political negotiation:

> Civic association envisages a deepening of democracy through the creation of counter-publics in the political realm. These create an interaction between the civic association and political association that promotes democratic dialogue. This is the essence of communicative democracy (Powell and Geoghegan 2004: 9).

Powell and Geoghegan (2004:172) state that a large proportion of community development work is based on input stemming from participation involving united group strength. Motivation for this may often be shaped by a particular identity which unites a group: 'communities of interest... (are) predominantly conceptualised within community development in terms of identity'. They go further to suggest that some minorities can achieve meaningful citizenship where they can gain profile and engagement with a political layer: '...with the significant level of activities directed along the axes of disability, ethnicity and sexuality, all these discrete identities (will) revolve around notions of citizenship' (Powell & Geoghegan 2004:172). In this context, the Deaf collective is made up of communities participating with their local organisation, where a core identity is shared among members. The identity is constituted by a shared language; the cultural influence of language makes key contributions to social interaction and behaviour, as well as cultural aspects of organisational purpose, method and procedure directing the extent of the political nature of each body (Ladd 2003; Lucas 2001).

One method of civic association involving a whole community is the idea of human capital. Here, Welsh Assembly Government (1998:10) states that 'people living ...in (situations) that are socially and economically disadvantaged can benefit from ...the recognition that what they are doing to develop and sustain their own communities has a genuine value, be it in terms of education, or training, or both'. The potential of such a community programme is that it can reap significant benefits for participating members, as well as (non-monetary) profit and community confidence generated by the project. Individual members can also learn skills relating to social inclusion and community enterprise according to Welsh Government who claim '(We want to consider) the importance of the kinds of skills that do not always get the attention they deserve. ...they include sign language learning; personal assertiveness; and money management' (WAG 1998:12). This could be an idealistic aim however where teaching about the Deaf environment and 'sign language' would be informal at best. This

inclusion and promoting of profile could possibly boost the public identity of Deaf people, but meaningful recognition of the Deaf collective arguably would be produced better by an accelerated and authoritative level of understanding linked to a commitment to public awareness of the collective.

A Wales Council for Voluntary Action report (WCVA 1998) states their now long held view that their facilitator role with individual communities is essential for addressing local and regional anti-poverty strategies of government. The WCVA state that third sector bodies need to incorporate communal systems of decision-making to promote unity, allocation of roles, and monitoring of subsequent action: '...successful (facilitator) participation requires (the initiation of) opportunities for joint decision-making, joint action and support for independent community initiatives' (WCVA 1998:5). The advised procedure is for individuals to develop in skills and confidence whilst simultaneously contributing to the development of their community: ''Capacity building' is the process which builds personal and collective skills and confidence'. The report warns of harsh and bruising realities where community groups might attempt to negotiate unsuccessfully with powerful public authorities because of lack of such competences:

> It is essential that (external facilitator) partners understand the many sources of frustration faced by community representatives when they work with public bodies – (of) being heard, (and having) confidence, (adjusting to the) skills and role of outside agencies, (and there being) community divisions (WAG 1998:9).

Another challenge faced by those community members is that external facilitator partners can themselves intimidate a less confident collective: 'The language, behaviour and expectations of [supporting bodies] can be a serious barrier to partnership with community representatives, and should be confronted' (WAG 1998:10). However a separate problematic issue that the Deaf collective face is that the cultural behaviour and actions of any facilitative partner is likely to cause a challenge for the collective, whose cultural norms and values differ, as well as language. The first likely obstacle a Deaf collective could have to get around would be persuading a power holder that having a different language should not isolate them from negotiations. Additionally, just because the Deaf collective is a minority, it should not mean that it is they that need an interpreter or should be responsible for the payment for this service (Lucas 2001). There is also the issue that Deaf collective communities might wish to

facilitate their own collective development, skills and strategies, as well as independently represent themselves to public governing bodies (Lane *et al*., 1996).

Governance and Self-Governance

Sorensen & Triantafillou (2009) argue that wider social and political forces shape the forms that self-governance can take. Self-governance by an individual or group can be classed as any distribution of power sharing for the participants' own benefit, whilst rarely being entirely autonomous. In exercising administrative responsibilities a collective or group will often be challenged by the adequacy of the powers and resources at their disposal. Sorenson and Triantafillou (2009: 2) restrict their definition of self-governance:

> to the situations in which the governing of the self is not wholly determined by forces of the self... Consequently, our notion of self-governance comprises that vast array of situations in which the self is allowed and even urged to govern itself by external, non-deterministic forces.

Wallace (2009:246) offers a view of self-governance sponsored in the UK by the former New Labour administration which is of a more fixed elite system which devolves regional power, whilst retaining core central power, even when adopted on a community level: 'Self-governance... is a top-down driven process, but one that the New Labour government has attempted to shape and implement according to a particular model of the local-social'. Sorensen and Triantafillou (2009) argue the importance of macro, meso and micro self-governance modes in illustrating the range of options, such as from centralised to decentralised, structural to individual layers, and elite to communal authority. The Deaf organisations involved in this doctoral study tended to be collectively run with a flattened hierarchy, adopting the general profile of a third sector agency (see WCVA 2001). While Deaf bodies were relatively autonomous in mandate and constitution their activities are shaped by external governance stemming from a range of dominant policy sectors including political parties, civil service, local authority statutory bodies, and umbrella third sector organisations. These externalities will briefly be explored.

Esmark and Triantafillou (2009) examine macro self-governance, particularly where modern information communication technology affects the networking of society. Here, the predominant economic mode of late modernity has led to the idea of a knowledge society, in which globalisation, complexity, risk, and multiple power formations shape structural

governance in a diverse society. Self-governance here means 'practices of freedom exercised by collective selves in constituting themselves as subjects' (Esmark and Triantafillou 2009:29). Such notions are some distance from mid-20th century theories of governance that Nagel and Mahr (1999:201) describe as comprising a 'more elite-oriented theory of democracy, which combined the insights of elite theories with minimalist requirements for a democratic political order'.

However, today's democratic processes assume much greater interface between elites and citizens. Thus the contemporary question is how 'elites can satisfy social interest group demands, and (how) civil society leaders can aggregate and effectively articulate individual interests into group demands to which government must pay attention' (Nagle and Mahr 1999: 221). To an extent this is dependent upon the political economy, and 'polarisations of opportunity' between majority and minority groups. 'Procedural democracy' is the more established elite democracy which may gradually be replaced by a more 'substantive democracy'; however power may resolutely remain with elite led systems, where markets influence distribution, private ownership reaps disproportionate rewards, and where minority groups remain as unsupported minorities. Nagel and Mahr (1999) argue that those minorities without financial strength are less likely to be taken notice by power holders, even where policy elites have had engagement with a particular minority. This situation could be seen to apply to Deaf representative organisations where their precarious financial circumstances may be both recurrent and reinforcing and where Deaf organisations are not recognised as requiring state investment to promote a more economically viable collective, but rather, as eligible for receiving grant aid for which they have applied, possibly under the category of disability. Hence Deaf collective financial sustainability would be unlikely in this context (Prior and Conway 2008; BDN 1994).

The opportunities for a minority which is not made publicly visible via social research or by public opinion formers, may not become represented, indeed, '...usually the ones who first publicly draw attention to a problem, are not the ones who experience them, only articulate them' (Kooiman 2006: 140). If those who articulate do so with some impact and success then 'others may surface who have not yet expressed themselves, and measures can be taken to ensure that these 'silent' people also get involved in the defining process' (Kooiman 2006: 142). Deaf organisations may be unlikely to be included in this process. The reason perhaps is the complexity that diversity brings. For example, if and when a minority is understood

positively and publicly then those engaged in governance need to decide whether to focus on an incidental level of interaction, or to address a structural issue relating to fundamental policy and possibly requiring a redistributive investment path (Agboola 2006). In this context, Kooiman (2006) discusses macro level regional governance where a United Kingdom parliament devolves significant budgets and legal powers to a devolved government such as in Wales. It is likely that politicians and senior civil servants will operate at a level of meso self-governance but within a formally structured elite system which can delegate authority and resource yet retain core power. These elites enjoy institutional authority and may well engage with social interest groups representing minorities. However, more fundamental power may remain ultimately with macro shaping systems whereby markets influence distribution, and where private ownership gains disproportionately from its investment and where a mass electorate is allowed to make decisions about appropriate representatives at infrequent intervals only (Esmark and Triantafillou 2009).

Sorensen and Torfing (2009) explore the meso level of self-governance, where the focus of study is the formation and reality of institutions and the authority they assume, as well as the underlying normative cultural and political values they represent, and the involved actors' interactions:

> The possibility of regulating society, through 'top-down' rule is limited. In decentred and multi-layered societies, societal regulation must necessarily involve complex processes of self-governance that cut across the institutional, political and ideological barriers that, according to traditional liberal democratic thinking, separate state, market and civil society (Sorensen and Torfing 2009:55).

The study of macro and meso levels of devolved governance is particularly pertinent to Deaf organisations and other representatives of the Deaf collective, where contrasting cultures, rules and norms may by default generate unconscious barriers (Prior and Conway 2008; Roots 1999). Whilst active citizenship 'is a constitutive feature of liberal democratic thinking where it finds its expression in the vision of self-governing people' (Sorensen and Torfing 2009:54), it involves the retention of underlying central control of branch institutions to allow regulation, albeit in complex forms of cross-institutional accounting. Here, the role of the devolved government civil servant may well engage with meso through to micro self-governance issues. This varies with the operative levels of civil servants, the more elite might act only at a meso level of governance based upon their expertise in their area and able (and expected) to act in an advisory capacity for an elected politician. Their power and authority

remains accountable to the operant systems of administrative convention and law (Sorensen and Torfing 2009).

Kooiman (2006:155) discusses the administrative governance of institutions, where a conventional system for establishing interactions for new institutions requires the consideration of a balance of social and political wishes, where institutions 'reflect broader societal governance issues, being representative of societal diversity, complexity and dynamics at large'. Thus the aim of local authority statutory social services for example is to adopt and implement policies according to pre-determined obligations, and accordingly to allocate finances from a fixed budget. Their role and significance for this study relates to the formation and operation of such institutions and the authority they legally claim, as well as the underlying normative cultural and political values they represent. Bodies such as social services contribute to the multiple layers of meso governance.

Micro level self-governance invites the representation of other bodies, through partnership and delegation, to share authority. The collective choice is expressed through individual preferences, such as the electoral system, political representation, and the system of the civil service. Micro level self-governance involves rational choice theory, and 'how to construct political authorities so that people have incentives to act in ways considered collectively beneficial: a good democratic system delivers what voters want, and the task is thus to set it up so that inefficiencies, corruption and biases are avoided' (Eriksson 2009:62). Wallace (2009:248) describes how the micro self-governance mode has been prone to delegated or devolved power through a localising system, enabling regional or local community agencies to have a visible local profile with downwardly awarded political and social credibility, and where local voice can be reflected in wider political connections.

Wallace (2009: 255) argues with some caution that 'we should of course be mindful of the critics of governance who would view 'localism' as an ephemeral discourse or a strategic retelling of government by which communities are made 'calculable' and can be more deeply regulated'. A further apparent weakness in the theory is that the representative system of civil servants acting out public preference via political decision-makers is not indisputable. The permanent civil service qua 'profession' require expertise in systems, and therefore are knowledgeable and active before a politically elected agent comes to power. The system does not allow tight control over the civil servants detailed actions, which therefore cannot be

regarded as representative of electoral preference (Eriksson 2009). Bang (2003:10) asserts that:

> (There is an) expectation that the only alternative to a politics which is exercised calmly and rationally by elites is one which is exercised agitatedly and emotionally by the masses. ...But tactics can influence strategic elite action indirectly by making new uses of manipulating and diverting existing political spaces.

Bang (2003) similarly outlines a view attributed to elites at the political centre whereby they do not give credence to an alternative power system because this would mean irrational governance by the population. Bang (2003) discusses the questioning of the state's 'automatic' power in modern times, and specifically the trend away from hierarchical systems and towards community and partnership self-governance in which the private and public sectors aim to become interrelated in the social and economic sectors. Hypothetically, such developments could open up space for the Deaf collective to develop a high profile, hold authority, and influence directives through consultation and attain a more mainstream presence (Chukwuma *et al.*, 2006).

Dean (2003:134), on the working of governance at meso and micro levels argues that 'New, multi-layered, poly-centric networks of 'governance' need to become 'cultural' because it must work through, shape and be shaped by the agency and energies of self-governing individuals and the communities (which may ultimately become visible)'. Were this idea to be fully activated it would open the way for the articulation of the Deaf collective with a view to their becoming visibly positioned in mainstream society, and as contributory citizens (see Chukwuma *et al.*, 2006). Turning to third sector umbrella advisory bodies, these might be said to operate more at a micro self-governance level.

Their awarded status as representative and advisory bodies enables their claim to holding some authority at a local and regional level. Their authority however might be restricted to drawing attention to issues of macro governance vis a vis the directions and requirements set by others at a more removed and powerful institutional level (Eriksson 2009; Wallace 2009). Elites within third sector Deaf organisations equally may operate at a level of micro self-governance, in terms of their organisation's systems of decision making, and in their approach to campaigning for local and regional recognition within the UK. It is of course something of a truism that in relation to any aspect of self-governance that 'the governing of the self is not wholly determined by forces of the self' (Sorenson and Triantafillou 2009: 2).

Thus governance-related actions are typically within systems and processes over which there may be contestation. Thus for example, in terms of general public sector policies, Deaf collective representative organisations may not currently be a likely constituency for close consultation by elite individuals from other powerful public institutions.

Issues of Identity and Language

Identity can shape how individuals and collectives become publicly seen and understood. This can be formed through reputation or an externally given label. Gergen (2000:34) discusses the impact of language in relation to identity, and observes that the hierarchy of languages is an indicating factor of social difference. A sense of imperialist and oralist colonial assumptions (see Ladd 2003) relating to the social construction of one's language position is indicative in the claim: 'that truth can be carried by language, and that some languages (and chiefly those which are in the language of scientific discovery) are closer to the truth than others' (Gergen 2000:27). A pivotal example of this in relation to the Deaf collective is that British Sign Language may be institutionally assumed by government to be a communication tool without independent status, structure or grammar (Lucas 2001; Coates and Sutton-Spence 2001). Whilst the British Government recognised BSL in 2003 (www.bda.org.uk 2012), the Welsh Government for example maintain that BSL is the language of Deaf people, *and* that Deaf people can be categorised within the social model of disability (WAG 2008). Deaf Studies academics would argue that one cannot collectively have both; Deaf people are assumed to be socially disabled because they cannot use the majority language, or communicate by majority means (Lane *et al*., 1996; Roots 1999). It would therefore seem that BSL as a minority language is assumed to be less important, as well as via Gergen (op cit) 'less close to the truth' than English, the majority spoken language (Lucas 2001).

Gergen (2000:42) explores the nature of identity in relation to social group profiles: 'It is not only a matter of public reputation, but *as these reputations become shared so do they come to be the taken-for-granted realities*. And it is these realities that inform public policies, educational practices, police actions and so on....' (my emphasis). It is these 'taken-for-granted realities' which have arguably shaped the way Deaf people are institutionally perceived. Gergen (2000: 43) explains that '...a mutually sustaining symmetry develops between self-knowledge and others' knowledge of you.' Thus Deaf people's societal position

could stem from being told as children and throughout their upbringing that they are 'hearing individuals with impairment' and so they internalise this medical view reinforced by the hearing medical and welfare professions (Ladd 2003).

A challenge to these ascribed identities appears to be intensely difficult. For example, formally organised and visible 'deaf' groups' working language is spoken English, hence they do not publicly represent the Deaf collective whose formal medium is their natural language of BSL (Maher 2002). The Deaf collective do not appear to *have* a political or administrative public reputation, instead, their reputation (and according to Gergen (2000) their 'taken-for-granted reality'), is of individuals with impairment and functioning need. BSL may be seen as a communication tool, where in terms of public recognition and treatment, an LEA (local education authority) in Wales will employ a hearing, learning support assistant with a minimum level of BSL knowledge who is employed to work with a Deaf child who is fluent in BSL, yet is limited to the learning ceiling of the language ability of the learning support assistant (see for example Vale of Glamorgan LEA policy 2011). This would seem to illustrate aptly the notion of oralist hearing colonisation as termed by Ladd (2003). Thus when Deaf children are permitted to learn through their natural language it is according to the limits set by a hearing educative system. The outcome could be that a child's language will be damaged, their conceptual development will cease to accelerate and as an already fluent signer, they will become frustrated.

Identity politics is discussed by Gergen (2000:43), where three different theoretical strands or stances are used to explore aspects of representation. The first strand is resistance:

> ...Now resistance is multiplied manifold. Native Americans reject the ways in which they are represented in museums – as savage and primitive... (and) numerous studies now explore the constructions of subaltern (or "subordinate") peoples within the common media of the day.

This example of Native Americans and the notion of 'subaltern peoples' is particularly pertinent, for example Ladd (2003) also describes Deaf people as 'subaltern', in being outside the class system due to their collective exclusion by society. Ladd describes how Deaf people over time have been depicted as having learning difficulties, being mute, and being almost savage and primitive. Gergen (2000) goes on to explain a second strand, that of self-representation. Gergen explains that this depends on how a collective represents itself, rather than this being what it actually is.

The marketing or promotion of an entity can be critical to the generation of a desired image; this is especially so for the Deaf collective which aims to shape public opinion and to engage with prominent authorities and investors in order to project an identity of competence, authenticity and the right to full citizenship. The third strand of representation is described by Gergen (2000) as political reconstruction. For this, political authorities are required to fully understand the Deaf collective as they understand themselves, and to demonstrate a durable commitment to facilitating the collective becoming mainstream across public policy. The Deaf collective would by definition become known as not suffering some impairment or disability but having a valid British language and a positive political identity until one is no longer needed (www.bda.org.uk 2012; Roots 1999).

De la Porte *et al.*, (2009:84) discuss the complex process of time and occupation whereby one secures one's adult identity, particularly in the world of work. In doing so they make particular reference to the profound influences from childhood and how these inform an early sense of status and position within society:

> In professional life, individuals may have a core identity–conferring job and various other secondary jobs that each have a partial identity – conferring function and identity. Other factors that may have an important influence on professional identities are earlier socialisation of family, school, religion, including political socialisation, understood here broadly as the core belief structure obtained from ideological perspectives on how to organise society.

Here, the identity producing aspects contributing to a Deaf person's professional life will likely be quite different from that of a hearing person's. For the majority of Deaf people who were brought up in a hearing world, many of their childhood memories may not be such positive ones. Their motivation with regard to how to change society may well be to challenge and tackle those negative aspects of their own histories so that these may be avoided for future generations of Deaf people (Lane *et al.*, 1996). This could involve for example ensuring equal language and ability status for Deaf people amongst hearing staff within a work setting, promoting the advocacy of the Deaf collective and seeking to challenge an institutional assumption of disability.

Conclusion

In Chapters 1 and 2 key concepts and normative assumptions surrounding 'deaf', 'Deaf', Deaf culture, Deafhood, the Deaf collective and ideas around the contemporary 'colonialism'

(Ladd 2003) of Deaf people were explored, together with an understanding of their social and economic location within a majority hearing society. Chapter 3 has focused particularly on this institutional ordering of Deaf people within policy structures and discourses in the public sector, particularly in Wales where much of the fieldwork took place. It has considered ways in which Deaf people have sought to promote a positive image and to thereby establish a mainstream position as contributing citizens of society. Institutional ordering however was shown as credibilising normative welfarist and oralist hearing values, so that 'd/Deaf' people are perceived generally as individuals with an individual and communal social disability. The chapter asked hypothetically, whether it was possible for mainstream public policy and society more widely to accept that Deaf people do not need to hear; the answer was not encouraging. It would be inordinately expensive and complex to transform the underlying and fundamental understanding about Deaf people in current welfare policy because then all other policy would have to change accordingly (see Fitzpatrick 2005). Similarly, to overturn the normative political and economic status quo in favour of a more differentiated set of inclusive responses to minority groups such as the Deaf collective, would assume a degree of flexibility and political will that is seemingly remote given the evidence to date (see Friedman 2002).

The social model of disability as an all-encompassing value was implemented in Welsh Government legislation (Patchett *et al*., 2000). The recently established Equality Policy Unit in Welsh Government (Chaney 2012) engages with known minority groups in public consultation, yet there seems no specific acknowledgement of the Deaf collective in their reports. Fitzpatrick (2005) asserts that welfare state public investment growth has ceased and funds are depleting (see http://www.guardian.co.uk /society/2012/jun /14/social-care-funding-cuts). There is no indication that if the Deaf collective were to be formally recognised by Government in the UK or Wales that investment on a national scale would follow. Here, Friedman (2002) asserts that economies will only grow through the incorporation of marginalised groups if political forces require it.

In this context the third sector exists to fill in 'gaps', that cannot be met by the state or market and to promote the interests of particular constituencies or community groups. Yet, a national third sector Deaf organisation may remain largely invisible where the national macro level does not recognise its relevance or potential. The Deaf collective argue that a welfare label

externally accorded to their members has meant Deaf individuals internalising a dependent mentality, and that multiple types of investment are needed to counter this exposure to a marginalising welfare discourse and history. In this sense, society's 'safety net' of statutory social services is possibly a barrier to the Deaf collective. An alternative is a state that challenges the status quo and looks to embrace newly profiled emerging minorities, and view these as viable contributors to the economy. The Deaf collective with its signed language and culture of mutual support is yet to be so recognised.

The chapter considered the question of the Deaf collective and social justice in relation to the third sector, which institutionally seeks to occupy the space between the state and the market. Examples were given of how the third sector umbrella organisation Wales Council for Voluntary Action (WCVA) issues guidance to the Welsh third sector. It encourages organisations to form partnerships, including cross-sector alliances in order to add value and build capacity. The WCVA (2011) advises the professionalising of administrative standards so that organisations are able to demonstrate accountability and effective self-monitoring as a means to legitimate their role and add confidence to any claim to public funding. But is this guidance sufficient to ensure that a non-obligatory third sector will arise and adequately fill the gaps that state or market cannot meet? Thus while the WCVA (2011) advise third sector bodies to tackle issues in a professional way, and for professionals from state and private sectors to be sympathetic in their negotiations with voluntary agencies, can the sector really secure effective political negotiation? The answer in relation to the Deaf must be equivocal because it appears there are barriers to the Deaf collective negotiating effectively on their behalf. The reasons are not entirely clear but may have something to do with language. Language in relation to identity is arguably pivotal. Languages have a hierarchy, particularly in the UK where the majority language is spoken and a minority signed language is relatively invisible. In the UK, Deaf people are considered to be both medically and socially disabled and for that reason it is assumed they *have to use* their signed language. This might suggest that sign language is still assumed to be little more than a default communication tool.

The chapter also examined key aspects of governance within the spheres of social policy and service delivery in order to provide a conceptual context for the study and its focus on elites in politics, government, and the third sector. The chapter considered the circumstances of the Deaf collective in relation to three types or levels of governance - macro, meso and micro. Welsh Government was seen to operate at a macro level in the shaping of ideology alongside

administration, whilst statutory social services operate at a meso level of decision making and guidance in implementation. Members of the civil service operate across meso and micro spheres of governance in regard to differing levels of hierarchical advisory and administrative position, whilst third sector umbrella bodies tend to be positioned at a micro level, working operatively with community bodies. It was shown that the ultimate ambition for progressive governance is promoting equal participation and equality of outcome. An example was given of the Welsh Government recognising diversity as a meaningful aspect of policy focus and ambition to achieve social justice. This commendable aim however has not, at the time of writing, involved the Deaf collective (www.wales.gov.uk/topics/equality 2012).

Having charted a range of key contexts, concepts and themes that have informed the direction of the enquiry, we now move to the study design itself in the chapter that follows. It will be seen that the complexity of the subject matter is matched by the need for a multi-layered approach to methodology and methods in order to capture an understanding of the social and collective world of the Deaf as well as key insights into the institutional worlds of those hearing welfare policy elites that seek to respond to this unique and rarely researched collective.

Chapter 4

Methodology and Methods

Introduction

In this chapter I shall discuss my research design from its methodological basis, through to the methods used, and the process of data collection, coding and analysis. My frames of reference are within the fundamental approach of structural narrative research and are both naturalist and constructivist. I focus on the poignant experiences of people's lives, utilising a broad and questioning inductivist framework exploring how data are produced according to meanings implied and inferred within interviewer and respondent interaction. I also consider the limitations to narrative analysis where these can be applied to my research. I discuss theories of interactionism and post-modernism which permeate this study into the minority and often excluded world of the Deaf collective and the equally under-researched world of welfare policy elites that claim some responsibility for institutional arrangements that seek to engage with this constituency.

The chapter will reveal in detail the methods deployed and related approaches to data analysis in order that subsequent researchers could follow and pursue these methods and approaches. My aim overall has been to approach the topic through qualitative methods to secure a systematic way of representing the social worlds of the respondents. The qualitative focus is epistemologically engaged in questioning socially constructed natures of realities, the relationships of researcher and researched and contextual constraints influencing research, all according to a set of balances and subjectivities. I have opted not to conduct an ethnographic study into the world of the Deaf where this might have been the anticipated method, partly as my research aim is not to capture intrinsic everyday social interaction. Instead I decided to focus on data at a more institutional level about strategic relationships between groups. Also I wished to avoid any unintended 'ethnocentrism' that might be perceived to flow from ethnography towards a minority which relatively few people know about. Instead, I have sought to explore issues of identity, the construction of needs, policy building and decision making that can affect public funding systems relevant to the Deaf Collective.

Research has involved two sets of interview phases; one was conducted in BSL with Deaf respondents who headed UK based organisations that sought to represent the interests of the

Deaf collective, while the other interview phase was conducted in English with hearing policy elites primarily located in government in Wales. Each required specific recording methods, using both visual and audio media. I proceeded to translate into English filmed BSL interviews with Deaf respondents, taking into consideration methodological issues over techniques of translation. Interviews were coded and analysed according to the methods associated with thematic and narrative analysis. Accordingly, it is towards the nature of narrative research that this chapter now turns.

Narrative Research

It can be established that narrative interviews are one of the most appropriate and useful method of qualitative research since 'interviews are necessitated when a researcher wishes to produce a work with textural depth as well as empirical strength ...where individual insights are required' (Lilleker 2003:208). Narrative research can uniquely invite exploration and challenge into established social identities and associated cultural values, and thus an interviewer gains both direct and reported experience of others' perceptions, actions and membership of a social system. Such impressions are secured by the invitation of complex descriptions of personal identity and external relations. These reveal insights into an individual's values, rules and practices. Classification and evaluation of the related data on the part of the researcher then contribute to its analysis. However Daiute and Lightfoot (2004:viii) state that 'narrative analysis can be artful and inspired, but narrative researchers rely on more than inspiration to find meaning in their subject matter'. Indeed the interview itself, the primary method of this doctoral study, is open to methodological direction in the way interviewer and respondent can jointly seek and construct depth of insight that will subsequently shape the analysis and the story that unfolds (Williams and May 1996). For example, Lieblich *et al*., (1998:13) list angles for analysis by the researcher focussing on form: these are 'the structure of the plot, the sequencing of events, its relation to the time axis, its complexity and coherence, the feelings evoked by the story, the style of the narrative, the choice of metaphors or words and so forth'.

A structural model of narrative can help to secure such generic aspects such as temporality, causation and human interest. Temporality clarifies the required rules of a story, that is, a plot sequence of beginning, middle and end. Theoretically, inherent in the plot is an established background of the status quo, a rise in drama demonstrating social or individual imbalance,

and a resolution resulting in a different ending (Cortazzi 1993). Narrative and accordingly causation and human interest, can be analysed for initial demonstration of orientation, and 'contents, structure, style of speech, affective characteristics, motives, attitudes, and beliefs of the narrator, or his or her cognitive level' (Lieblich *et al*., 1998:9). In this connection, both immediate cognitive and affective level and deeper structures can be analysed, exploring language used as well as the cultural values and practices that we inherently assume and which provide the 'rules' for narrative. Narrative here is considered 'an *autonomous* discipline… in the semantic organization of texts with its own rules and invariant patterns' (Cortazzi 1993:88). Limitations of this approach could include an overly narrow focus. Secondly narrative analysis could divert attention and move away from linguistic focus. Thirdly, any inaccuracy in the presentation or paraphrasing of narrative could imaginably prevent a more authentic analysis.

Allied to my approach to narrative research has been a fundamental naturalist orientation. This is adopted by researchers who wish to establish the social and individual identity of the researched, assisting their exploration of their lived experiences, highlighting themes of common interest, and bringing to the fore personal changes and self-development in significant aspects of their lives, careers or perceptions. It further involves reflecting on one's own input and interactions, and the meaning of these (Elliott 2006). The researcher here presents the researched with ontological questions of the 'what' kind, that is, questions about existence and identity from their own perspective. This approach was utilised in attempting to secure Deaf respondents' perspectives about their own lives and identities past and present. The invitation to respondents to discuss sensitive topics was inevitable. The flexible nature of narrative interviewing means that the researched can give rich and layered meanings to their answers, especially where stories are raw and being told for the first time.

Additionally, I also adopted a constructivist standpoint, whereby interviews need to be seen in terms of the interaction and mutual influence that the researched and researcher can have on one another; thus, 'these accounts cannot therefore be treated as an unproblematic window onto the social world' (Elliott 2006:20). Such a view has implications for narrative analysis. Gergen (2004) explores those aspects of the interview that may render narratives invalid in terms of reliability and validity. For example, it may be that, given the opportunity, interviewees wish to change their story where they become aware that their version has been overly skewed in the way the interview has constructed a particular unintended version or

slant, or that they have given an often over-rehearsed story, or where they may simply want to refocus on a different theme. Inevitably, interviews are a selective and unique construction and it is important to ensure that the respondent has an opportunity to reflect on their contribution. To summarise, Gergen (2004:280) states that:

> engaging in narrative research involves an exciting commitment to interdependent, contextualised, value-laden work; …(it) entails accepting that the subject matter of the field is a temporally and spatially sensitive cultural creation, produced in the limited space between teller and told. …The narrative comes into existence as a facet of relationship, not as a product of an individual.

Interactionism

Interactionism is the sociological research tradition which claims that 'meaning is constructed in the process of interaction' (Becker and McCall 1990:6). Social conditions are adapted according to individuals' awareness of the meanings of formed actions, where they are influenced by others' responses from previous actions (Becker and McCall 1990). Fine (2001:38) argues that 'norms and behavioural expectations should not be separated from the meaning systems of individuals who enact them or from interaction that occurs in local spaces in which they are enacted'. Norms are created from: social construction directed by situational contexts, influences from social actors, and understandings of behavioural norms; interaction enables continued individual and social functioning (Fine 2001). The implications of this stress on the normative is that a majority perception is likely to underpin the taken for granted world of interaction such that, for example, majority cultural hearing actors are likely to be unaware or uninterested in culturally different norms (Fine 2001; Reagan 2002; Grosjean 1996). Hence, cultural Deaf people typically are taught to exist as cultural hearing individuals who need to accept they have an impairment and need help from 'normal' hearing professionals.

In brief, individual interactions are directed by cultural approval and ideologies of what is normative, and of what is a threat to this, and in this way value systems are maintained (Maines 2001; Maines and Palenski 1986). Thus, Maines and Palenski (1986:576) observe:

> ...knowledge is not a cognitive or mentalistic phenomenon but always is a relation between the knower and the known. They cannot be collapsed into one another. Rather, they exist *relationally and social organisationally*, and refer to a set of practices which constitute the relations of what is 'known' about the world (italics original).

Thus, Deaf and hearing people are relationally often seen as essentially 'all the same', and it is widely held that teleologically the d/Deaf are people struggling to be hearing individuals due to biological-sensory impairment (see Grosjean 1996; Ladd 2003; Padden 1996). A compelling, medical influence which determines the philosophy behind the socialising system of treating and educating Deaf children as impaired is thereby accorded credibility and thus not questioned (Lane 1995). This position evidently detracts from an individual and social responsibility for questioning the validity and value of diverse identities. In summary, understanding the ways in which interactionism can reveal the normative and the routinised will assist us in understanding the taken for granted assumptions held about Deaf people by welfare policy elites. Similarly, appreciating the ways dominant perceptions help maintain the social construction of culturally shaped norms, makes it possible to grasp how the Deaf collective comes to see itself as marginalised within a more universal culturally given notion of need and identity (see Fine 2001; Hardesty 2001).

Post-Modernism

Another social science perspective that informs this study is post-modernism. Key post-modern thinkers question institutionalised and legitimised social underpinnings such as scientific knowledge and ideologies. Lyon (2000:7) comments '...however careful our observations, they depend on assumptions, …those assumptions are connected with world-views and with power positions'. Similarly, Vattimo asserts 'emancipation is …freedom with plurality, the erosion of the reality principle itself …the discovery of the finite historicity and contingency of our own identities and value systems' (in Lyon 2000:61), rather than endorsing somehow that we can only be 'knowing' of 'reality' via for example grand narratives. Post-modern thought goes much further than interactionism in that its challenge and explanation moves beyond an observation of legitimised social behaviour. A useful example can be seen in Young's (1995) application of Foucault's theory to assess how the social explanation of 'objectified' gender identity enforces what is normative. He draws upon Nicholson and Seidman (1995:190) who observe: 'in as much as sexual difference is classified only as man and woman, then gender always mirrors sex …(this is based on) the categories of gender construct(ing) sexual difference itself'. This may be analogous to the concept that *Deaf* (cultural construct) always mirrors *deaf* (medical construct), which is based on the culture-blind categories that reinforce deaf/hearing medical differences. Cultural Deaf Studies influenced by post-modernism question this biological aspect where it is used as a

defence for maintaining the power, position and status of the hearing (see Thoutenhoofd 2000). Ladd draws on post-modernism in using the concept of 'selfhood' through which a deaf person could come to question their normative identity as 'hearing-with-an-impairment' and their rejection of this identity and transition to a 'Deaf' one. In summary, a post-modern orientation allows us to question normative cultural values that underpin welfare policies and systems and has helped this study to explore how far cultural Deaf people's norms may coincide with or differ from these (McRobbie 1996).

Social Work Research

Much research into Deaf people can be seen as ethnocentric, assuming universal (spoken) language and (hearing) cultural norms, and validating professional 'help' supplied from and by the hearing (Hermans 2008). Some social work research on Deaf people may inadvertently favour hearing cultural values, for example where no recognition of different cultural identity is given or where there is a (traditional welfare) assumption that they need a social worker due to their 'impairment' (O'Brien and Penna 1998). Deaf people may be 'othered' in the sense that the researcher typically assumes the position in which her or his own 'self' is part of the norm, and the researched are thereby seen as outside this and are misrepresented (see Fine 1994).

The need for social science and social work research to question collusion, inappropriate de-contextualisation and inherent bias requires critical awareness of self and identity on the part of researchers (Denzin and Lincoln 2000). According to Fine (1994:70) research into the deaf world can be used:

> ...as a tool of domination… (We need to consider) a messy series of questions about methods, ethics and epistemologies as we rethink how researchers have spoken 'of' and 'for' Others while occluding ourselves and our own investments, burying the contradictions that percolate at the Self-Other hyphen.

Good social work research recognises the importance of challenging norms, recognising diversity, the need to be rigorous and reflexive in process, and the importance of demonstrating fair representation of the researched social world (Denzin and Lincoln 2000). Reflexive social work research enables one to challenge the prevailing evidence base where there may be conceptual weakness (see Butler 2003). Social work research enables ideological questioning of the social construction of need, and allied social understandings of

relevant individual and collective identities (McMillen *et al.,* 2005). Hence, the aim here is to assess the power and relevance of the established welfare framework and available alternatives, and to consider the socio-economic position of Deaf people, as a part of a highly focused qualitative enquiry. Law (2004) asserts the need for social responsibility in research: that is, a concern for social justice and respect for people's rights. The research relationship in qualitative interviews requires researcher sensitivity to diversity, anti-discriminatory practice, and recognition of structural injustices and normative systems. The researcher and informant ought also to feel they have had a mutually beneficial experience (Padgett 1998).

Political and Ethical Concerns

This study conforms to the ethical precepts required of social science research and set out in BASW (Banks 2001), BJSW (Dominelli and Holloway 2008) and the British Sociological Association Statement of Ethical Practice (2002) publications. I am aware that my understanding of issues is limited to my experience and data obtained, and does not claim to be some single 'true' interpretation of the data. Throughout the process of creating instruments for data collection and obtaining data, I have been aware that my social work research background contains subjectivities, values and theories that will influence how I 'see' the world (Banks 2001). Becker (1970:110) asserts that the researcher ought not to be sentimental but question the beliefs and perspectives that bear upon the research act '…we must use our techniques impartially enough that a belief to which we are especially sympathetic could be proved untrue'. Thus while I acknowledge the claims to parity and authentic identity by Deaf people I have sought to remain reflective and non-judgemental in my approach (Miller and Dingwall 1997). Hence, my aim has not been to criticise the Deaf and hearing elites that were interviewed but rather to learn about their assumptions, perspectives and institutional situations, in order to grasp more clearly how personal and professional social constructions of Deaf identity come about.

Gabriel (2000) questions how research projects are selected and to whom research is directed and this is particularly pertinent to interviews in qualitative studies wherein the research necessarily imposes editorial control when analysis is being done (www.britsoc.co.uk/ equality 2002). Therefore it is essential that the research design and analysis promotes commitment to questioning, disagreement, counter examples, interpreting and the identifying of hidden agendas (see Hollway and Jefferson 2000). Butler (2003:26) asserts that an ethical

guide can ensure good research, in 'the current scientist and managerialist context', so that those ethics become a part of the research process:

> Such a form of ethical awareness will have to consider the questions of what social work is for … (and this does not) imply that social work researchers should shy away from research that might undermine failing forms or structures of practice (Butler 2003:26).

Arguably however, ethical guidelines may not challenge or provide a form of scrutiny to tackle aspects of bias or values that may lie hidden within particular approaches. Thus in regard to the contemporary mode of 'evidence-based practice' we can note that 'service users have expressed concerns that the demand for evidence-based practice will restrict 'what counts' to professional or expert knowledge with a quantitative basis', for a scientific focus ensures a quantitatively shaped answer to what is evidence (Qureshi 2004:12). In turn, the common understanding of 'valid' knowledge thus informed by evidence may become reinforced and thereby not put in question (Dominelli and Holloway 2008).

Another significant ethical and political aspect which runs through the thesis is individuals' backgrounds and social shaping; that is, people's gender, ethnicity, ability, age, class, sexual orientation and culture (Thompson 2001). I consider that whilst these categories ought to be identified and explored initially when the researcher is referencing primary sources from respondents as a generic group, or secondary sources of reference material, respondent's social characteristics ought not to be considered when drawing patterns of knowledge and interaction. For example, arguably where writers are highlighted in mid text for their gender, particularly if their first name is given where they are a woman one is reminded that the default gender is likely to be 'the universal male' (see Elliott 2006). I consider that as a norm of referencing, a respondent or academic may not be unequally identified by their ability, class or sexual orientation, but *may* be identified by their gender – only where they are the sole writer of a text, and ethnicity – only where their name is given and is categorisable. One suggestion is that the point presented could be diluted, in an effort to demonstrate overall balance of social characteristics, especially of perceived minorities or those social groups with less power (Geertz 1994; Fine 1994; D'Cruz and Jones 2004). Lane (1996:1) writes 'language and power are so intimately related that (one) cannot (express) a single word… without communicating messages about group loyalty. (The difference between those with majority and minority status) cultures, explicitly and implicitly, is a struggle for power'. That

is, according to established 'knowns' of those considered to be rational, heterogeneous and universal, viz - the white, middle class, hearing, able man (see Cutler 2006). This reference to some characteristic of difference in a sense frames the identified as a token minority. In this way, to mention 'she argues…' in reference to an author, is similar to stating 'the *female* writer argues…'. Similarly, a Deaf person contributing to an article would not wish to be referred to as 'the *Deaf* academic…'. This is the case in Deaf Studies where academics are not highlighted as individually Deaf or hearing (see Ladd 2003). As Hardesty argues (2001:14), 'this conceptualisation of (minority social characteristic) diverts our gaze from human agency and social actors co-creating the meanings of (minority status) in our society. It ignores how (minority status) is situationally conditioned and created'.

I confirmed to respondents that both visually and orally recorded interviews would not be used for any purposes other than my research, and would be deleted after transcriptions were completed (BSA 2002). Ethical concerns for the first phase around the use of two languages and translation were a concern. Following interpretation and transcription of phase one interviews with Deaf respondents, I selected three interviewees and asked them to confirm the accuracy and intent of their responses within the interview transcriptions. This process caused some methodological and ethical concern insofar as I was asking Deaf respondents to assume the role of culturally hearing in requesting that they read these in written English (Banks 2001). All three confirmed that the transcripts were accurate portrayals. Given the small sample size and visible organisational roles of phase one and two interviewees it was important to ensure that participants were anonymised as far as possible (BSA 2002). Hence there is no reference to organisational names or to the respondents' gender, ethnicity, ability, age, or sexual orientation that might identify them.

The Samples

Purposeful sampling (DeCruz and Jones 2004) enabled the reaching of particular office holders in elite third sector Deaf collective circles, and hearing public sector institutions of: Welsh government, civil service, statutory adult social services and third sector advisory bodies. The first phase sample comprised leaders of Deaf-led third sector organisations in England and Wales. The initial identification of elite office holders of those bodies meant exercising my (then) position as internal staff member of a national Deaf organisation and seeking advice from contacts. Attempting to secure this information as an outsider would

surely have proved to be problematic (Goldstein 2002). Identifying the second phase sample meant researching publicly known office holders of public sector bodies, and inviting selected participants via public and formal channels. Key characteristics of the two samples are outlined in Appendix A.

In the first sample, fourteen Deaf chief executives and chairs of Deaf representative organisations were purposively selected in order to explore their institutional position and collective ambition for the future. Nearly all approached agreed to participate. The second sample was also purposively crafted from a target of fifteen welfare policy elites in Wales who were hearing and held, potentially, prominent decision making positions in relation to Deaf people. The second sample was approached to ascertain their own attitudes and those of their institution towards Deaf people and the Deaf collective agenda. The choice of a primarily Welsh cluster of hearing respondents was for pragmatic reasons of access and cost. The first phase of Deaf respondents comprised a sample of thirteen senior representatives out of a possible fourteen Deaf collective organisations of England and Wales. Whilst this sample was not representative of the wider Deaf collective in England and Wales which includes academics and campaigners, it could be seen as broadly illustrative of organisations which sign and act for the British Deaf collective (Goldstein 2002; van Manen 1990). In the first phase thirteen of the fourteen individuals who were approached accepted interview invitations. For the second phase, the sampling framework involved inviting fifteen targeted individuals for interview who were considered to hold leading professional roles in four public welfare service sectors that bear upon Deaf people: the Welsh Government, the civil service, third sector umbrella bodies and the local authority statutory social services. Some nine elites drawn from these sectors agreed to being interviewed. It is of course the case that the samples are small and not intended to provide a basis for generalisation.

To repeat, the accounts provided and their analyses are not intended to be generalisable. Rather the aim is to explore the narrative construction of meanings and assumptions held by these key respondents within and about the Deaf collective and their needs (Hammersley and Atkinson 2007). That said, the samples enable the production of transferable and authoritative data within the limits of the study design (see D'Cruz and Jones 2004). The first phase sample consisted of chief executives as well as chairs of UK based charitable, third sector organisations, controlled and run in the main by Deaf people. The second phase sample consisted of senior personnel from four spheres of the public sector, who have actual or

indirect links to those Deaf organisations, in terms of policy consultation and engagement, policy implementation, funding allocation, representation, negotiation or management.

The aim of creating both samples was to explore key ambitions of the British Deaf collective and to compare these with the attitudes of public service institutions and to compare their respective goals and cultural worlds. In accessing the Deaf participants I first considered that I should assume the role of outsider in trying to locate senior personnel of Deaf organisations – some of whom I knew, and most of whom I did not. Because I was representing Cardiff University in conducting formal research (an obvious long established cultural hearing institution), I wrote on Cardiff University letter headed paper requesting interviews with the chief executives and chairs of the fourteen Deaf led organisations in England and Wales and received no responses. Trying to gain access as an apparent outsider and possibly deploying a hearing majority approach, did not work. I subsequently emailed the same people in a more personal way, stressing a more insider status as someone with Deaf colleagues, and received some replies. I also attended national Deaf organisation gatherings and approached some of the same chief executives and chairs that I had previously contacted. Meeting them face to face enabled me to demonstrate that I was somewhat of an insider by signing BSL fluently. I also demonstrated some culturally relevant behaviour and knowledge. Some respondents assumed I was Deaf, when they discovered that I was not, no one minded or withdrew their cooperation (see Rossman and Rallis 1998).

Amongst the first phase of thirteen respondents, nine were men and four women. Eleven stated their ethnicity as white British, one as Asian British, and one as Black British. Twelve stated that they did not have a disability, whilst one felt that being Deaf did mean having a disability. I noted the current age of respondents, and the age they learned BSL. As might be expected, the three respondents who had Deaf parents, as opposed to the ten who did not, learnt BSL from birth. Of the other ten, the age of learning BSL ranged from three to thirty. Seven respondents were in their forties, three in their thirties, two in their fifties and one in their sixties. Eight out of thirteen respondents went to residential school where they were taught to 'hear' and speak, and where teaching was in the medium of English. The other five attended mainstream schools, with either an English oral class for Deaf children, or a mainstream class. In terms of geographical regions, two people were from Wales, three from central England, four from the north of England and four from the south of England. Class was not considered as a category, because there is significant academic debate in Deaf

Studies as to whether Deaf people are excluded from the class system of society (Ladd 2003; Lane 1984). The introduction to chapters five and six will remind readers again of the key features of the two samples.

The Interviews

My focus at the first interviews with Deaf respondents was to explore how they saw their own personal and professional biographies in relation to the agenda and ambitions of the Deaf collective. Questions linked to a second sequence of interviews with Deaf respondents concerned professional engagement, consultation, decision making, policy, implementation and directorship in relation to Deaf collective UK based organisations. These respondents control organisations of significant standing in local and regional Deaf collectives. Their leadership roles range from employed chief executives with the responsibility for direction and organisational vision, to democratically appointed, unpaid chairs with responsibility for overseeing the stated aims and ambitions of organisations' constitutions. All organisations have affiliated members who are a part of their Deaf local collective. Organisations range from representing the local collective in lobbying and engaging with local policy makers and funders in relation to community and outreach work, and joining in multi-organisational partnerships to campaign on specific policy issues, to providing services to the Deaf population, such as training, education and social activities, and to generating income through provision of an interpreter agency, training courses for mainstream bodies, partnership with statutory social services, and linking businesses with charitable status.

The second phase of nine respondents comprised seven men and two women. All stated their ethnicity as white British, and the age group ranged from those in their forties to some in their sixties. No respondents stated having disability, or sexual orientation other than heterosexual. All were hearing. These phase two respondents were more localised than phase one participants in that all were working as elites in Wales. The specific dividing characteristics of the second phase included which public sector sphere they represented and their institutional relationships with the Deaf collective and its agenda. Phase two respondents were selected from Welsh Government ministers, senior civil servants, senior umbrella third sector representatives, and statutory social service directors. Their individual organisations and activities included political direction and policy consultation, advisory and service delivery, statutory responsibilities and their interpretation, and independent and charitable

sector facilitation for the Welsh Government. The focus of interviews with these phase two respondents related to the institutional engagement and consultation, policy negotiation and directives, funding, policy application, and the varying relationships and roles of provider and client that bear upon the Deaf collective and its ambitions.

Researcher Identity and Status

As a researcher who could sign fluently it was often the case that I was assumed, in my initial encounters with phase one respondents and other Deaf people, to be a Deaf person. Part of establishing the identity of another is to search for culturally given clues to ascertain the nature of the stranger (Delamont 2004). This is also the case where there are social gatherings of Deaf people at, for example, a Deaf club. Upon meeting, one is likely to be greeted with the following questions: 'what (residential) school did you go to?', 'where are you from?' and 'are your parents Deaf?' (see Lane *et al*., 1996; Ladd 2003). These three clues if probed are deemed likely by Deaf people to yield adequate personal information about an unknown Deaf person – as to the extent of their membership of the Deaf collective (Branson and Miller 2002). Such information requests put to newcomers demonstrate an independent cultural existence, with historical and behavioural influences underlying the questions (Hammersley and Atkinson 2007). Such requests for cultural information demonstrate the national collective nature of Deaf people (Lane *et al*., 1996). These three Deaf cultural signifiers are explored briefly as they reveal something of the way identity and membership arise in Deaf encounters and this impacts upon the research identity too.

What school did you go to?

The pattern of Deaf education used to be that many D/deaf children were sent away to residential school, so that they essentially lived in continual close proximity (Ladd 2003). Most schools permitted the use of English only (Branson and Miller 2002). In my former social work role and in my research fieldwork I would often attend a Deaf club and would generally be assumed to be Deaf, especially when attending with a Deaf person. I would be asked the same immediate question in each place: "what school did you go to?" This initial search by the questioner can be conceptually grasped as based upon the notion of some joint cultural 'high context'. Mindess (2006:54) states that 'high context' is where there is a significant dependence on existing shared cultural knowledge: Deaf members did not use the word 'residential' when they asked which school I went to as their assumption was both that

any unknown adult Deaf person would likely have been to such a school, and also that they would at least know something of the newcomer from a school or type of school reference (Jacobs 1992). This is an immediate clue to whether the newcomer could be an insider or an outsider. Upon being asked, I began in the early days of my associations with Deaf people apologetically answering "well actually I'm hearing" – which would stop any further enquiries as there was no reason to continue with the conversation because it was immediately clear I was an 'outsider' (Mindess 2006). (Younger Deaf people began increasingly to go to local mainstream schools as residential schools for the deaf were closed down extensively by the 1990s (www.bda.org.uk 2008). This change in education provision may have somewhat changed the introductory conversation for a younger generation).

Where are you from?

In my later engagement with Deaf people both as social worker and a researcher, if asked 'what school are you from?' I would respond "oh a local school", assuming I was Deaf the follow-on question would often be "where are you from?". This question would help to locate me as 'known' in some sense by family name or membership of some known Deaf associations and thereby not an 'outsider' (see Branson and Miller 2002). Ladd (2003) suggests that meeting someone for the first time from further away implicitly confirms to Deaf members that their collective has geographical reach and significance, that there is a 'national' aspect to the collective.

Are your parents Deaf?

The third question asked of strangers by Deaf people is likely to be "are your parents Deaf?" (Ladd 2003). This is a further sifting question and seeks to establish if the individual is one of the few with Deaf parents (an enviable status), or if they had hearing parents, as do the majority of Deaf people, initiating empathy from most questioners (Branson and Miller 2002; Ladd 2003). It is considered good fortune if one's parents are Deaf in the Deaf collective. 'Deaf of Deaf' offspring are thought unlikely to have experienced some of the struggles for understanding and lack of affirming communication which Deaf children of hearing parents often have been troubled by (Padden and Humphries 2005). We return to this point in much

more detail in the chapter that follows. With this information about school, locality or parents, Deaf people do not consider that they need to ask for much more introductory information – they have established something of the membership status of the collective that the visitor enjoys (Ladd 2003; Lane 1984).

Complex power relations exist within the structuring of the researcher/researched relationship (Humphries 1994:187). Foster (1994) reflects on aspects of status in conducting research with Deaf people, and questions whether (i) a hearing researcher can select appropriate questions for study (ii) can appreciate Deaf people's experiences and (iii) accurately represent their observations and perceptions in analysis. Similarly, Young and Ackerman (2001:182) affirm that 'effects of historical identity attribution and cultural representativeness' will influence the research process with culturally different people. That is, the hearing researcher may by default enter the project from a hearing–dominant cultural perspective. Foster (1994) maintains that assumptions must be continually challenged through contact and interaction with Deaf informants, reinforcing a respect for, and understanding of, the perspectives of those being studied. Reflexivity involves the consideration of the researcher's impact on the study, social status according to gender, class, ethnicity, age, ability and culture, and value base (Padgett 1998). Here, reflexivity is an essential element of self-awareness and self-correction. Young and Ackerman (2001:187) state that 'for those working with oppressed and marginalised groups, questions about the recognition and legitimisation of knowledge that is produced are vital'. Morse (1994) describes a core element of qualitative data analysis as the researcher recognising their own knowledge base, and external socio-political influences. Young and Ackerman (2001) and Parasnis (1996) discuss the adequacy of conception and understanding that hearing researchers studying Deaf issues can attain.

I believe my integration and absorption into the Deaf collective first as a social worker and then interpreter able to sign fluently, then as a hearing researcher allowed me to gain an in depth understanding of the language and cultural issues. My interview approach was informed by a sophisticated level of Deaf awareness and sense of Deaf equality, together with ever present self-awareness of my own hearing cultural background, and of unavoidably representing a cultural majority. It was crucial that my research into Deaf issues was not based on any assumed needs or aims of Deaf people, particularly not having participants adopting a hearing cultural identity – or assuming any particular relevance to the matter of

hearing. Much previous research into Deaf issues conducted by hearing researchers has been disregarded by the Deaf world for this reason (Lane *et al*., 1996).

Elite Interviews

Lilleker (2003:207) describes elites as 'those with close proximity to power or policymaking'. Elite interviews are about attaining individuals' policy related institutional perspectives according to their understanding, their linked biographical experiences and their personal opinions (Kincaid and Bright 1957). The aim of elite interviews as a research tool in this study was for purposes of exploration of their institutional and where relevant personal worldviews and associated narratives:

> Members of the elite serve as sources of information on specific areas of knowledge that would otherwise be inaccessible. Correspondingly ...the comparative analysis of different interviews seeks to provide an objective reconstruction of the facts, problems, decision-making processes, networks and other aspects described by the individual interviewees (Littig 2009:101).

Engaging with elites can prove difficult, especially where they have become somewhat removed from public access. Requested interviews proposed by a researcher may not be prioritised over other routine or pressing demands. During interviews, the researcher needs to be flexible enough to allow a respondent space to reflect and divert whilst covering core topics. A respondent may only invest their time in an interview if they are confident of the researcher's knowledge of the policy area concerned. The respondent could categorise the interviewer's status as supporter, as having neutral interest or as critic of their policy perspective. Dexter (1970:84) writes: 'in preparing ...an interview design... it is safer to suggest asking about the moderately general than the particular (in situations where one is) trying to discover'. I was aware that the elites I sought to access could have been conscious of my position as representing an academic research-led institution, and could have seen me as either a useful tool or as critical judge (Cortazzi 1993).

In summary, I wished to interview chief executives and chairs of Deaf controlled collective organisations, as well as relevant hearing elites such as senior political and civil servant policy-makers and social service senior officers and leaders of voluntary sector umbrella groups. I wanted to explore their respective understandings of the ways in which Deaf people are seen and understood and are constructed in policy and practice. I wanted to gain knowledge of Deaf led collective representatives about their organisational vision for aims,

survival and growth. Similarly, I wanted to capture the parallel purpose of elite decision and policy makers. My intention was to invite respondents to answer questions according to their own interpretations and understandings, in order to achieve my purpose of establishing *their* 'truth' about the social worlds they inhabited (Kincaid and Bright 1957).

Insider - Outsider Issues

Here, I will first deal with my status relating to phase one respondents, the chief executives and chairs of organisations representing a Deaf collective agenda. I have been actively involved with the Deaf collective in my own region on a regular basis for the last ten years; this has included having colleagues, friends and a partner who are all Deaf, as well as my making regular visits to Deaf clubs and events in the regional area. Throughout this period I have co-developed projects both internal to a particular Deaf organisation and in partnership with others. My immersion in the culture to be researched (Silverman 2001) however, did not mean that I was necessarily perceived by Deaf people to be culturally Deaf (Delamont 2004; Miller and Glassner 2004). A pertinent example of my insider – outsider status occurred when I approached one chief executive who knew of me and therefore knew that I was not Deaf. This fact was enormously significant to this person – s/he informed me that I unavoidably represented the hearing oppressive world, and that my completing doctoral research about Deaf people as a hearing person amounted to 'stealing' a PhD from the Deaf world while doing little to promote the status of the Deaf collective, which would not have been the case had I been a Deaf student. Indeed, this person stated that s/he too wanted to be in the position to do a PhD and went on to express their refusal to participate on the assumption this would collude in research conducted by members of the hearing oppressive society which typically constructs and spreads a paternalistic, limiting conceptualisation of Deaf people. I was reminded that I could not after all be an insider. While I understood and empathised with the view that this person presented, the experience illustrated to me once more the significance of my study. I was taking on the uncomfortable responsibility of representing a minority who may well want to conduct and represent themselves within academic research were they ever in a position to do so – and most were not.

Another example of my insider-outsider identity relates to an experience I had during my initial interviews with Deaf elites. It starkly illustrates the cultural contrast that relates to the metaphorical notion of doors and windows, where reliance of signed or spoken modality

affects where communication is possible. For example, 'the attributes of doors and windows are often tied to communication permeability, which is connected to language modality, and thereby to culture' (Bahan 2004:143). Windows enable visual permeability, and doors auditory. Hearing people are excluded from communicating through closed windows, whereas Deaf people are excluded from communicating through closed doors. Bahan (2004:144) discusses contrasting examples where deaf and hearing people are prevented from or can generate communication: for example, a Deaf person can get the attention of their partner sitting in a car outside a supermarket and can converse through two walls of glass about what they would like for dinner that evening. Deaf people conversely are prevented from communicating where reliance is through a closed door, which might present no difficulties for a hearing person.

This was brought home to me uncompromisingly when I had to rapidly think myself into a cultural Deaf household, and 'be' an insider. One chief executive / chair I visited at their home to interview kindly offered a meal as part of the arrangement. Before the meal I went upstairs to their bathroom anticipating that I would be about a minute or so. On leaving the bathroom it immediately became apparent that the door was truly stuck. After struggling to open the door for some minutes I considered my escape options. My first impulse was to bang or shout through the door to seek attention and ask for help. I knew however that this oral-audio method would not work. The second (and feasible option, apart from an uncertain wait for rescue) was to climb out of the bathroom first floor window, down a drainpipe of an outside wall, and then walk around the house to a front window where I could visually get my host's attention and explain the situation and re-enter. It took a few minutes to carry out. I explained through the downstairs front window why I was outside, wet from the weather and wearing no shoes. A colleague subsequently commented to me "Deaf people will meticulously try all visual means of getting the attention of their target; it is the Deaf way" (personal communication d: 2009). Indeed as Bahan (2004: 144) observes:

> A large number of 'Deaf' narratives, especially narratives of personal experiences, have recurrent themes of protagonists being caught, shut in or locked out behind closed doors… the ultimate solution is almost always found through a window of some sort. Windows are permeable; protagonists wave through windows, …and climb up to windows to communicate. As conveyors of light, windows are conveyors of communication.

In approaching potential respondents for my phase two fieldwork with hearing elites, I had two replies offering me interviews with personnel working at middle management or lower operational levels. I decided to decline because my interest was in the holders of more senior and strategic policy responsibilities. I made this clear in my replies, and no further responses were forthcoming from these sources. This suggested that I was not an insider in terms of holding sufficient senior status myself to engage their interest. Four other potential respondents failed to acknowledge my request for interview, despite reminders. I can only speculate as to why this may be the case. For the most part I may have been perceived by hearing elites as a doctoral student with some substantive expertise in d/Deaf issues and policy but ultimately dependent upon their patronage and goodwill in obtaining access and where knowledge transfer, in their view, was likely to be from them to me (Miller and Glassner 2004).

The Involvement of Two Languages

The language of my academic doctoral thesis is English, in keeping with the requirements of Cardiff University academic institutional standards (Cardiff University 2011); my phase two interviews were similarly held in English and therefore did not require translation. My first phase interviews however required translation, because they were conducted in a different British language. The dominant institutionalised UK language is clearly English, and it is important to acknowledge the cultural influence behind this norm (Young and Ackerman 1998). The research process of phase one demonstrates some 'commitment to BSL as (one of the two) languages of thought for the project and (one of the two) languages in which knowledge is constructed' (Young and Ackerman 2001:185). BSL is an independent language, just as is English. BSL has naturally evolved over centuries, and has its own grammar and lexicon (Sutton-Spence and Woll 1999). BSL is neither signed pidgin English, nor a communication tool to support English, nor mime or gesture (Sutton-Spence and Woll 1999). An English sentence can contrast notably with BSL structure. Whilst the former can vary enormously, essentially a BSL sentence has the order of: subject, verb, object (SVO) (Sutton-Spence and Woll 1999). It has to some degree the logical structure also found in Welsh (www.cymdeithas.org/deddfiaith 2008).

In conducting my phase one interviews I could have opted to use an English /British Sign Language interpreter. This would have meant that I could take in data through listening to an

interpreter's spoken English voice-over whilst taking notes and using an auditory recorder, and not having or needing eye contact with respondents. I feel however that it is crucial to interview respondents directly in their natural language, and without the input of a third party. There are several reasons for this preference. I wished to develop a direct relationship between myself and the respondent, both allowing me to gain a depth of understanding of respondent presentation and knowledge, and affording a subtle shared link, where I can gain certain nuances of behaviour, attitude, expression and sense (Sutton-Spence and Woll 1999). This would in a sense validate the worth of my study with a view to ultimate research credibility, and at the same time retain authentic cultural value. I was able to ask questions in culturally appropriate ways, understand answers with Deaf cultural meanings, and ask follow-on questions and steer the direction of interviews according to the flow of a conversation led in a culturally sensitive manner. This arguably would not have occurred if I had asked the questions in a different (cultural) language to a respondent and used a third party. I did not want to rely on hearing led methods of obtaining data, and thus inadvertently render my research study culturally blinkered or biased and arguably 'imperialist' in method (Ladd 2003). As Lane observes:

> Language and power are so intimately related that an interpreter cannot translate a single word, cannot even appear on the scene, without communicating messages about group loyalty. Much of what the interpreter mediates between two cultures, explicitly and implicitly, is a struggle for power (Lane 1996:1).

Another reason for conducting interviews directly relates to the presence of an interpreter as a third party and its impact. If I chose to involve the presence of a third party, this would mean having to trust and depend on another person for conveying expressed information accurately, and also having to pick up any subtle behavioural inferences and senses of tone in which information is transmitted. Not only would I have to trust their technical ability, but I would also to a significant extent be passing over control of the process (Turner 2005). An interpreter - who would not be fully aware of the basis and purpose of my research - may misinterpret or miss subtle information, or make general errors; avoidable incidents such as these may occur at any point in or throughout the interview. As Metzger (1999:11) observes, 'interpretations include omissions, interruptions of the input, errors, delaying - queuing, systematic omissions - filtering, and reduction in preciseness of output - approximation'.

The inadvertent control of an interpreter means that conversation participants can become confused by what each other is apparently contributing or receiving through missing cultural cues. Monitoring in an interpreting situation can partially counter this, although interpreter presence cannot be made accountable unless there is also present an interpreting auditor, which would normally be extremely difficult to arrange. By their involvement, an interpreter will influence any interaction: 'Interpreters are not merely impartial intermediaries facilitating dyadic interaction. Instead, interpretations function as participants within the discourse, regulating turns, and altering contributions' (Metzger 1999:23). Fortunately I am in the position of not needing to be dependent on an interpreter – although if I were not fluent in BSL I would not presume to conduct research with Deaf people (Lane *et al*., 1996; Pokorny1996).

Interview Recording

Altogether my respondents had two languages between them. This was clearly a consideration in deciding how to record as well as how to conduct interviews with individual respondents. As discussed, the first phase respondents signed British Sign Language; accordingly I recorded interviews visually, using a digital film camera. The second phase respondents spoke English, so for these I conducted interviews in English, and recorded interviews aurally, using a digital audio recorder. Lomax and Casey (1998) discuss the status of data generated on film in qualitative research, resulting in its more recent usage for experimental research methods rather than as a weighty qualitative research tool. Pro-film researchers argue that film use is a reliable source in creating an accurate recording of the original event (assuming one's research is ethnographical). A specific aim is to record natural environments and social interaction, and to record visual and vocal behaviour and naturalistic activity (Heath 2006). In contrast, my research does not include the observation of social environments or behaviour of Deaf people's actions and activities, but consists in interviews alone, and attempts to capture respondents' perspectives. The film method – like the aural alternative with spoken language, allows accurate recall for transcription via a different cultural system. Filming the interviews – instead of my attempting additional or alternative note-taking - arguably enabled my full interaction with respondents. Note-taking would have demonstrated an inflexible lack of Deaf behavioural understanding causing suspension of eye contact. This would consequently have distracted the interview flow and created false conditions of disrupted conversation, as well as demonstrating rudeness and a lack of

consideration of Deaf people typical of hearing culture and its participants, and in particular an assumption that Deaf people can 'fit into' hearing research processes (Mindess 1996). Deaf people tend to be at ease with filming, which is both a recording mechanism and an obvious resource for disseminating information (personal communication e: 2009). Whilst there is a lack of literature regarding the validity of film recorded interviewing, and indeed of conducting film research in Deaf Studies, this can hardly be a reason to neglect this method. Similarly, for my phase two interviews, I used an aural recording system, which I subsequently replayed in order to transcribe interviews conducted in English.

The Translation of One Language into Another

Transcribing the phase two interviews was relatively straightforward. In contrast, phase one interviews had to be translated in order to be transcribed. This was not straightforward; the presence of two languages inevitably means dealing with two distinct linguistic structures, as well as determining the methodological route of translation, and implementing this. '...a translation is a receptor language text that interpretively resembles the original' (Gutt 2005:377). One should first identify the differing linguistic properties of each language in relation to one another, in order to understand the resulting dilemmas for translation. The two main issues are equivalence and non-equivalence, and also cultural difference between the two languages (Baker 2006; Blum-Kulka 2005). Choice of translation depends on common terms, specific meaning and cultural and local availability, as well as the individual translator's focus in translating (Isham 1996; Venuti 2005).

Translation difficulties arise where the target language (English) could have: more distinctions in meaning than the source language, no specific synonym or hyponym, differences in expressive meaning or in form, or more or less focus on position or interpersonal view (Baker 2006). 'We do not usually realise how semantically complex a word is until we have to translate it into a language which does not have an equivalent for it' (Baker 2006:22). Many examples of this occurred in translating all the phase one interviews. An example of this, demonstrating difference of language and culture is where in BSL there is no need for the gender specific English labels 'he/she' or 'his/her'; in BSL these labels are gender neutral, that is, the signs are 'that person' or 'their'. During an interview I ascertained that one respondent went to see a doctor; the respondent then subsequently referred to the doctor using this efficient label positioning (Kyle and Woll 1983). Throughout the story I did

not ascertain whether the doctor was a man or a woman - this was considered irrelevant to the respondent, according to the rules of their language. Whilst I was interested to know the gender, I considered that such insistence on clarification would be like ethnocentric interference, implying that one needs to know gender, according to the patterns of English as if it were the universal language. In terms of culture, I considered it interesting that the gender of the described doctor was known, but not given (Baker 2006; Blum-Kulka 2005).

A crucial distinction influencing translation method is one's decision of whether to adopt a literal route, or an authentic route - 'The goal of literal translation is to pursue equivalency with regard to the form, rather than the context of the text' (Metzger 1999:4). This means that cultural and behavioural means of articulation of the source language may be demonstrated superficially by default, so that the intended meaning may inevitably not be clear because of contrasting cultural influences in the target language. The received translated message may rather reflect the mode in which the contribution is given. The resulting translation may thereby give a rather superficial meaning, with traces of the means of expression of the source language, and a resulting appearance here of the BSL contributor having used signed-supported-English, that is, like a contributor not having full command of their own grammar, and thus their language. This method arguably involves risks of ethnocentrism; it may support 'outdated assumptions that signed languages are primitive non-linguistic systems' (Metzger 1999:21), where cultural difference may be misunderstood from translated text. Where translation from source to target language (as in this case) is from a relatively unknown minority language to an institutionally established majority language, confusions may lead to illusory defective perceptions of 'self' and 'Other' (see pages 72 and 74).

Authentic translation in contrast involves no display of source language culture, or of any pattern or structure of the source language. Using this method, one still experiences problems in finding equivalent meaning, just as in finding equivalent form. The focus of such translation enables demonstration of the exact level appropriate to the target language, here English. 'It is a translation that is produced in an accessible register of the target language, using as many or few words as possible to convey the same sense as the source text' (Metzger 1999:7). Demonstration of the culture of the source language becomes irrelevant. Instead, this route takes into account the integral nature of social, political and cultural aspects of both the producer and the receiver of the text. Meaning does not merely 'reflect intent of the originator, meaning is also influenced by the intent of the recipient of the text' (Metzger

1999:12). I adopted a method for translation based on authentic translation theory. Examples to illustrate the reason for this are particularly cases where respondents shared jokes, powerful declarations or emotional experiences. My aim was for the point to be clear in English, taking into account the different cultural bases of both languages, and the likelihood of the point being missed from a literal translation where an outsider (whether the reading audience is hearing or Deaf) is understanding through a structurally and culturally different language (Metzger 1999).

An illustrative example is where one respondent signed a funny yet extremely poignant story about their old school, and the appalling status it was viewed to have by some of the respondent's adult Deaf peers. The collective joked about the name of the school in using a made up sign-supported-English name, instead of spelling the name of the school in BSL (taken from the English name). Sign-supported-English is a non-language where signs have historically been taken from BSL by hearing educators to educate both hearing people with learning disabilities and Deaf people - in the grammatical order of English (Sutton-Spence and Woll 1999). In schools in which signing has been permitted, SSE signs have been taught to Deaf children, where the basis of a sign is an English meaning, used in a meaningless context for BSL. BSL to an extent has been significantly damaged through this process (Tervoort 1983). Hence, the joke referred to above is a play on the fundamental basis of the school's education system, of forcing an oral approach – that is, forcing the Deaf children to 'hear' and 'speak', and not allowing them to: communicate in BSL, learn through the medium of BSL, or indeed *learn* BSL, or, to be culturally different (Tervoort 1983). I presented the joke in such a way that a hearing person reading the translation could partially understand this for themselves, even though I did not add explanation of what the respondent had not signed. The respondent did not go on to expand on the joke's significance, possibly because they assumed this was obvious. Unfortunately when one reads the translation it does not appear as amusing as it does being signed in BSL, according to the culturally attached and immediate nature of a joke (Bahan 2006). The respondent and I had a shared background and political knowledge of the irony of this given label, and a shared understanding of why it was a play on signs for a few reasons:

> Respondent: ...They tease me about having gone to Mary Hare. Their sign for it is so rude! – It's *hair* as in *armpit hair*!
>
> Researcher and Respondent: (both laugh)

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Respondent: It's a hearing joke that *hearing educators* wouldn't understand! The name really is only *spelt* - there's no *sign* for it. You know, so it is reverse high jacking of English, making an SSE sign; Mary Hare forces a hearing identity, and Deaf people correspondingly make up a hearing joke playing on their obsession!

A second example of a reason to select an authentic translation route was to clearly convey another respondent's anecdote illustrating a significant point. According to the visual and spatial nature of captive description in BSL, a literal, accurate translation arguably would not have enabled the reader to be clear about what had actually occurred in the anecdotal description. The authentic translation attempts to maintain meticulous equivalence of sense, whilst allowing the reader to understand the point of what it is they are reading, according to the knowledge of one's own cultural norm. A literal, accurate translation with equivalence of form would arguably mean less to the reader, so in the example below, the reader could gain a grasp of an act of violence, rather than of a political point being made (Bahan 2006). The reader of an authentic translation in some areas may remain oblivious to some concepts which are discussed because these are culturally unique to the speaker's life. When the anecdote was reported to me, as with the joke, an immediate shared understanding of language and background history enabled me to appreciate the full significance of the point, since the respondent and I were face to face, whereas a reader with superficial knowledge, or, due to their reading the anecdote in an English version might not gain a similar depth of understanding:

Researcher: What do you feel about cochlear implants?

Respondent: I went to a world congress a couple of years ago, and as an opening gesture, the President grasped a hearing-aid and smashed it on the lectern with a hammer!

Researcher: WOW!

Respondent: Yes, exactly. It was the most powerful symbolic statement I have ever seen. A cochlear implant is used for the same fundamental purpose. *Having* a cochlear implant makes one disabled. It was a metaphor making us realise that one *can* reject the 'hearing' identity forced on us.

Resultant phase one transcriptions will appear to be in my style of written English. I could not compare a translation of the same interview composed by another translator, given the confidential nature of data. As with writing, translation is a creative process – the presentation of resembled meaning by default requires a subjective style; several translators of one source language text would present the target language text differently, even if they selected the

same theoretical translation method (Metzger 1999; Marschark *et al*., 2005). Just as BSL can be translated differently, English can be presented differently. I attempted to translate all material in as 'neutral' a way as possible to maintain precision in meaning, although points covered in the above discussion played a large part in influencing the process.

Approaches to Analysis: Methodological Aspects

Reflexive analysis, influenced by interactionism, and deconstructionist perspectives influenced by post-modernism assisted the conceptual process. Reflexive analysis involves researcher consideration of 'dynamic social interactions wherein multiple dialogues are conducted between multiple selves' (Collins 1998:1). The researcher needs to understand that they influence a part of this social reality. The interview is interactional, and thereby 'structured' in that its existence is created by artificial means, notably by relatively fixed roles and inherent rules. Meaning is a recognition of and negotiation between 'multiple selves', where the researcher ought to acknowledge their position of engagement, rather than attempt to be detached. The selves of both researched and researcher are demonstrated in both parties' use of language and performed roles; these reflect inferred and implied power – both in relationship and individual experiences. For example, hearing elite interviewees hold significant authority, whilst also being significantly influenced by both statutory and internal systems, other sources, senior colleagues, as well as established general perceptions which have influenced policy making. Reflection results in the recognition of a single self, pulled in different directions of vulnerability and strength. The interviewer is dependent upon an interviewee's participation, even though it is possibly a matter of one-sided gain; the researcher can only be continually aware of this, whilst focusing on the cultural process which influences what the interviewee reports.

A question posed by an interviewer will by its nature be leading; therefore interviewer encouragement via use of personal opinion must not be allowed to damage the generation of knowledge (Collins 1998). The reflexive interviewer is interested in the *way* that information is conveyed. Two parties, through a particular relationship, create interviews. Meaning is therefore relative to the individual situation, where stories are generated through negotiation in interaction (Elliott 2006). Within this, deconstructionist analysis is about questioning a dominant ideology in the accounts provided by respondents. The dominant ideology in this instance, held by both samples of respondents, could be that of hearing cultural norms,

maintaining the way that Deaf people are identified and treated. This 'knowledge' may prevent consideration of an alternative – Deaf cultural values - and thereby recognition of the lives of Deaf people, as well as preventing some reflection on how a different collective can fit in with the fundamental values of the welfare system when that collective does not believe its members to have disability, 'needs' or 'risks'. A deconstructionist looks for manifestations of power and authority, and their limits. This is clearly pertinent to data provided by hearing elites, and to a focus on cultural norms (Feldman 1994). A deconstructionist approach questions the validity and weight of meaning in language, and particularly of conflicting ideologies which highlight an uncertainty of meaning, and the limitations with respect to any 'certainty' claimed by a dominant ideology:

> Deconstruction forces (the analyst) to confront the ideology of the culture, to look through holes in it, and to see how it differs from what it purports to be. It is the art of announcing that the emperor has no clothes (Feldman 1994:62).

Analysing the Interviews: Issues of Method and Bias

The data produced consisted of three sets of semi-structured interviews, conducted with two phases of respondents – Deaf and hearing elites. The first two sets of interviews were conducted with the thirteen Deaf respondents of phase one. The third set of interviews was conducted with the nine hearing respondents of phase two. The two sets of interviews with phase one respondents had a focus of 'first-order' narratives (Collins 1998). That is, the first interviews, lasting for approximately an hour, comprised searching questions about their personal backgrounds and views on questions about social and individual existence and identity from their own perspective. The second interviews focused on the individual and their perspectives of their professional identities, experiences and the organisational settings in which they worked. In contrast, phase two interviews with hearing policy elites were of a 'second-order' focus, where individuals were invited to give a 'collective story' about their institutional world (see Elliott 2006). Here, questions were particularly focused on relevant policies and funding decisions in a way that probed 'for information and to give respondents maximum flexibility in structuring their responses' (Aberbach and Rockman 2002:673). Phase two interviews were individually tailored to the particular respondents' fields in terms of policy responsibility, and were based on relevant literature and legislative frameworks. Common themes across interview schedules were constructed, although questions allowed for particular individual standpoints or expertise to shape the direction of answers.

I transcribed all interviews verbatim, both English oral interviews and BSL signed interviews, the latter being committed to paper immediately following translation into English. I did not wish to focus on any type of discourse analysis notation; rather, I wished to concentrate on subject content and meaning in the light of relevant cultural and political values. I therefore disregarded *how* answers were presented in terms of pauses, repeats and timing, instead I sought to note emotions and mood (Rubin and Rubin 1995). Discourse analysis of an interview which had been translated from one culture's language to another would be complex and the material possibly mis-analysed with regard to notational significance in the target language transcript (Metzger 1999). Hence I transcribed all data before engaging in coding and more detailed analysis in order to prevent presumptions around patterns and premature indications of possible classifications (Rossman and Rallis 1998). In doing so I followed Seidman's advice to '…come to the transcripts (inductively) with an open attitude, seeking what emerges as important and of interest from the text' (Seidman 1998: 100).

Interview schedules differed in that questions sometimes snowballed in relation to an individual respondent's chosen direction. In any one interview, questions were prone to be repeated in order to allow a fully informative answer from a respondent, whether the second answer confirmed their position, or whether the second answer clarified, expanded on or even apparently contradicted their view. Following first the obvious divisions of question categories, my analysis focussed on thematic classifications relating to events, relationships, settings, meanings, emotions, experience, or action. Themes gradually condensed as I became more familiar with the data. More useful and meaningful themes became prominent as narrative types emerged and were compared across transcripts (Rubin and Rubin 1995; Rossman and Rallis 199). The position of individuals as social actors in a range of contexts, overlaps and layers became increasingly clear, and I began to understand how smaller categories slotted into more fundamental themes and narratives, which in turn have informed the three findings chapters that follow. Rather than use an analytical software package, I colour coded categories in the course of manually segregating and distinguishing themes. I used a colour highlighting computer facility, and cut out and selected sections enabling clear core analytical categories. This enabled me to cross reference core categories with highlighted aspects remaining in the data. This approach allowed careful management and methodical analysis, where themes gradually evolved through my studying the data from

cutting, pasting, and producing various stage category maps, whilst making preliminary linking of key selections to literature and theory as appropriate.

Silverman (2001) asserts the importance of research being reliable and conclusions being valid. However my research methods of data collection and analysis involve interpretation and therefore selectivity. Hartman (1994:467) discusses the nature of bias: 'The presence of bias is difficult to determine. Yet its occurrence as a threat to the validity of social work knowledge has always been recognised, as has been the importance of its identification and control'. The effective research study requires ethnic and cultural sensitivity to avoid stereotyping and the misperception of informants (Hartman 1994). In terms of a hearing perspective and the potential for bias in grasping the meanings intended by Deaf people (see Foster 1994) there is much challenge. A hearing researcher, however much immersed in the Deaf world, cannot have instantly accessible understanding of the daily experiences of a Deaf person (Roots 1999; Lane *et al*., 1996; Young and Ackerman 2001) because their respective personal experiences are profoundly different, and cannot be simply anticipated or prepared for. Hence it was important to seek appropriate support for my interpretations from what is inevitably a slender research literature on the Deaf experience. Credibility and authenticity for my analysis required that social realities I depicted have been represented fairly and furnished with independent support where available in other theoretical and empirical sources, in which case research such as this can to some extent be transferable (rather than generalisable) and replicable, thus demonstrating some reliability (D'Cruz and Jones 2004).

Repetition between one respondent and another enabled me to judge the appropriate level, type and use of questions presented, so generating some basic validity (Brinberg and McGrath 1985). Repetition also enabled me to judge consistency in assessing the ways respondents chose to answer questions, as well as the answers that they gave, so enabling a degree of reliability (Seidman 1998; Berry 2002). Lilleker (2003) explains that individuals' perceptions will contrast with each other, as well as diverge from 'hard fact'. It is perceptions, understanding and 'knowledge' that I am most interested in, whilst 'entering into an interview with as good a command of the facts as one (could) have' (Lilleker 2003: 212). What soon appeared evident was that respondents - ranging throughout each phase – often varied notably in their responses to the same topic. This strengthened the data gathering process (and my confidence) in that conflicting data enabled me to subtly challenge the answers given, both during interviews and in subsequent reflection. Bloor (1997: 38) writes on triangulation that:

'findings may be judged valid when different and contrasting methods of data collection yield identical findings on the same research subjects, a case of replication within the same setting'. Phase two interviews promptly following phase one arguably allowed the triangulation of data, particularly where overlapping areas produced congruent answers, albeit often from polarised ends of the spectrum. Phase two as well as producing data of intrinsic value, served to assist in validating within and between both sample sources. Some significant phase two data contrast directly with phase one data and to a varying extent help validate one another from often opposed perspectives (Brinberg and McGrath 1985). A pertinent example is where a member of the Deaf elite signed "hearing people don't accept that we exist as a collective", and a member of the hearing elite said "Deaf people are hearing impaired, not some political body". The two statements help validate the attribution of domain assumptions held across much of the two samples and as a device triangulation offers the 're-examination of findings' that Bloor advocates (1997: 38). To repeat, my area of focus is relatively under-researched; I therefore wished to secure as detailed and extensive a picture as possible from both sets of data, particularly as to where these elites share or diverge in their views about the relevance of the Deaf collective (Aberbach and Rockman 2007). Bloor (1997: 38) highlights a more qualitative research principle however:

> …nevertheless, ...(data) are merely relevant to, rather than constitutive of, validation: all data are shaped by the circumstances of their production, and different data produced by different research procedures cannot be treated as equivalent for the purposes of corroboration.

One has to consider the unique property of a semi-structured interview; the data produced is a product of the researcher as well as the researched. This means that each different research mode is unique; it cannot replicate original data already secured since a neutral system cannot be implemented. Hollway and Jefferson (2000) however assert that according to more positivist social science principles, one must aim for 'objective' neutrality where possible in order to contribute to the process of validation. Bloor (1997: 49) accepts that different research modes contribute value and strength to one's research, so that the opportunity is produced for further analysis, enabling validity, and 'reflexive elaboration'.

During the process of studying one's data from first highlighting items of noteworthy interest through to producing a polished, finished and sophisticated analysis, one can experience an

on-going limitation. 'Researcher anxiety' occurs when the researcher loses the confidence they had in their research design, implementation, and transcription stages:

> ...you lose confidence in your ability to sort out what is important, you wonder if you are making it all up, and you feel considerable doubt about what you are doing. You feel worried that you are falling into the trap of self-delusion ...(which can be) the bane of those who analyse qualitative data (Seidman 1998: 100).

This issue was certainly present for me. I often felt that since my doctoral study was conducted for the potential use of two contrasting cultural worlds for which every aspect seemed to be complex and at very least compellingly interesting, to elicit and summarise complex themes seemed somehow absurdly reductive. I initially did not know where to start. I also felt that I could become consumed with the unfathomable nature of complexity, to the extent that I was losing sight of what straightforward responses are like, since I could have been 'over-interpreting' the data. Also in some instances I was conscious that the data produced was 'covering new ground', so that I felt increasingly uncomfortable in being its guardian. But as I became familiar with the data, I slowly felt more competent about reducing and condensing data themes into overarching fundamental divisions, through taking significant time to learn, value and tackle the data calmly and appropriately (Seidman 1998).

Conclusion

By the nature of the process, through partly representing a marginalized collective, the narrative researcher partakes in the unjust social system of privilege, being able to represent the powerless and 'invisible'. Whilst there is the possibility of one-sided gain by the researcher, one may collude with institutionalised social structures in order to publicise and reveal the existence of such under-privileged groups. This can be apparent as a structurally generated situational opening *and* constraint; enabling research to occur, yet involving an inherent artificial relationship based upon a pre-shaped privileged position for the researcher (Becker 1970). The researcher must question their own complicity, motivation and partiality for research in order to remain credible. Qualitative research can misrepresent 'knowledge' of socially constructed reality, and relationship with and meanings of the researched and of contextual constraints. Misrepresented 'best quality' evidence could be used to reinforce legitimated social work practice. Analytic rigour of research means in-depth, fundamental challenge of the standing of research, having regard to all factors which a study is claimed to be representative of, that is, particular social work methodology and method (Bryman 2004).

Ethical consideration may not be a defence against institutionalised culturist values; particularly in evidence-based practice; it may not mitigate a tendency towards 'technical rationality …(of such practice where there may be) an inability (of researchers to recognise) a more sophisticated awareness of the realities of service users' lives (Butler 2003:22).

In current social work research with deaf people, whether a quantitative or qualitative approach is selected, acknowledgement of Deaf individuals according to a cultural hearing identity arguably causes limitations of social work research knowledge. My use of dual-angle narrative research had the aim of using first-order and subsequently second-order approaches for both naturalist and constructivist interviews where contrasting perspectives became apparent. Both routes assist each other in gaining research insights, strengths and rigour, and potentially securing conflicting knowledge and norms. Through dual-angle social work research I have become aware of assumed ideological norms, normative policies and expectations of need, as well as practical obligations and budget restraints which have led to my gaining thorough insights into respondents' positions across the two samples.

This is an inductive focus where a conceptual framework directed my data collection and analysis and formed a clear process for my research. Narrative analysis, interactionism and post-modernism are commentaries, representations and rejections of mainstream society, which itself can be seen to be led by cultural hearing norms. These social science perspectives can be utilized beneficially in the field of research of the Deaf collective: for as Vatimo (in Lyon 2000:61) states 'our understanding of reality (is) composed of multiple images, interpretations and reconstructions'. This post-modern viewpoint may be present in cultural studies, where multiple constructions allow one's recognition and questioning of cultural majority dissemination. Interactionism is useful in questioning 'ascribed status' and examining the 'identity process' for both individual and collective experiences. Atkinson and Housley (2003:165) emphasise the centrality of language as a system, and its function for meaning, creating. '…ideological factors (are) embedded in the linguistic constructions of various products'.

It is with these methodological perspectives and caveats in mind that I now take forward my selective presentation and interpretation of the data obtained as specified above. Three findings chapters now follow, the first two of which are about the world as understood by

elite Deaf respondents and the third provides a contrasting institutional view from hearing elites.

Chapter 5

"...people were communicating with their mouths like goldfish!" What it is to be Deaf: perspectives of Deaf collective elites

Introduction

The chapter title stems from a respondent reflecting on their experience as a child aged six, the moment of their watershed realisation that their cocoon of Deaf social surroundings was not the only way to live, and that there was a parallel world – where 'others' behaved very differently. This was the extraordinary discovery of a Deaf child of Deaf parents. It may be difficult for those living in a hearing world that is taken for granted to fully grasp this discovery, because from the perspective of the 'normal' hearing person, Deaf people's experiences are typically cast as impairment, vulnerability and struggle. This eye-opening statement may therefore be in conflict with a more institutionalised view of Deaf people's human development as sub-optimal. By contrast, those respondents who had hearing parents appeared to face this deep-rooted institutionalised view earlier on, so that their opportunity to recognise a Deaf language and identity, and Deaf social surroundings, was not likely to be available to them at that critical juncture in their development. It is possible that these respondents (who grew up apart from Deaf culture and whose parents were not Deaf) are the ones who were exposed most to a societal label of being impaired and thereby cast as disabled, and who experienced isolation by being 'othered' by and within their everyday social surroundings.

This chapter will discuss these very contexts – of the growing up and personal life experiences of phase I respondents (that is, respondents who were chief executives and/or chairs of the Deaf controlled third sector organisations for England and Wales). The chief executives and chairs of Deaf organisations are defined here as elite representatives of the world of Deaf people. Some knowledge of their personal backgrounds will assist an understanding of the positions of their organisations, and their social business aims and vision that would likely have some impact upon the British Deaf collective. What is significant about respondents' perceptions and reported experiences is that however negative and down-trodden their memories were, we know that they all went on to succeed to a level of relatively senior employment, and to holding leadership positions in representing their section of their

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collective. The change between these initial and later memories, extending to their holding elite and professional status, is pivotal. How did these respondents manage to generate opportunities and capacities to be in a position to become a role model for others? To repeat, the focus is *not* to investigate the experiences of service users – as traditional social work research may have done - as the question of access to welfare resources that Deaf people can secure is not the topic of this study. The focus instead explores the position of Deaf elites, to ascertain some impression of the Deaf experience at the stage of their upbringing and background. The main themes which were soon apparent from the data of these first interviews were: 'childhood - learning to be 'different'', 'school experience - learning to be 'disabled'', 'becoming Deaf - issues of identity and transition', and 'learning to be Deaf - exclusion and discovery of collective challenge'. Four other sub-themes that arose from the analysis were: 'culture in language', 'disability', 'cochlear implants', and 'the Human Fertilisation and Embryology Act 2008'.

In this chapter, analytical categories overlap and converge, so that where respondents are given individual numbers under particular categories, these numbers change as individuals either remain in or move group, in accordance with the relevant category. These labels are intended to allow anonymity on the part of respondents, where, as members of a tight-knit community, information may render individuals identifiable, whilst at the same time demonstrating that a valid portrayal of data is retained. The first category on childhood and parent type is divided with respondents labelled 1 - 13, where 1 – 3 had Deaf parents, and 4 – 13 did not. The second category on school type has a different number allocation; of those with Deaf parents and who attended residential school (1 – 3), respondents as children who went to residential school but who had hearing parents (4 – 8), and respondents as children who went to mainstream school and who had hearing parents (9 – 13). The third category of age at which they learned BSL is again different; it is divided into groups of those with Deaf parents (1 – 3), those who learned BSL at school age (4 – 6), and those who learned BSL later on (7 – 13). The 'Learning to be Deaf' category is divided by parent type, with Deaf parents (1 – 3), and non-Deaf parents (4 – 13). Finally, In the 'opinions as indicators' sections, respondents are numbered in order of interviews completed in date order.

Childhood: Learning to be 'Different'

This section looks at issues of language, confidence and identity according to whether or not respondents' parents were Deaf and belonged to the Deaf community, thereby receiving the Deaf language and Deaf identity. Where parents were hearing, Deaf people's upbringing appeared to be different in that the language which they depended upon was a hearing language, and they signed with a hearing identity. It will be seen that parental and community influences profoundly affected respondents' understandings of their positions in the world, ranging from an enduring positive outlook and the sense of a productive childhood, to, by contrast, believing they would somehow not survive long in the world once released from the security of school. A key variable was whether respondents' parents were themselves Deaf or hearing. Out of thirteen respondents, three had Deaf parents and their childhood seemed clearly different from those with hearing parents. Respondents with Deaf parents described an awareness of difference between themselves and what is termed here 'normal Deaf' (those with hearing parents), indicating that they were aware that a 'normal' environment for Deaf children could have limited opportunities for positive experiences. For example, respondents with Deaf parents observed:

> ...my life was parallel to a hearing upbringing, it was normal and happy (respondent 2).

> I found life easy – my parents taught me about the world, and they prepared me well for school (respondent 1).

> ...our family language is BSL so I was fluent in written English and reading newspapers I guess at the age of 7 (respondent 3).

The three with Deaf parents appeared to take for granted having a core language which enabled them to go on to learn their second language, English. Jones (2006:59) comments, 'there is clear evidence to show that an initial preference for the 'home tongue' gives children the cognitive thinking skills with which to think and from which they will be confident to tackle a second and third language.' However there was one notable upset for all three at primary school age: "I remember the shock of learning that the world wasn't Deaf – *what* a disappointment!" (respondent 3). And "it was a depressing realisation when I saw that people were communicating with their mouths like goldfish!" (respondent 1). This respondent's world felt turned upside down when s/he realised that they were not after all to be a part of the mainstream of society; they had felt 'normal' up until that point.

The following statement could be seen as encapsulating the essence of minority Deaf life chances: "I was one of the lucky few; I have generations of Deaf family" (respondent 2). These minority Deaf people enjoy a cultural capital (Ryan *et al*., 2008) – that of early natural (signed) language fluency, via interaction with parents and cumulative gaining of knowledge, leading to formal skills and (later) qualifications. Social capital becomes increasingly accessible where one has membership in the collective – indeed individuals can access their network freely (see Portes 1985). The form of capital may be political, historical and other knowledge rather than wealth, where the Deaf collective have established 'bounded solidarity and trust at the core of the group's ...advance' (Portes 1998:15). This is in contrast to a hearing 'colonisation of the mind' which seeks to put in place a more individualised agenda for success and identity (Ladd 2006a:9). Rogers, Coyne and Bale (2007:45) outline research into the success of available use of a natural language which 'illustrated that Deaf families who use sign language had higher mean self-esteem scores than those (Deaf children) who had hearing parents'.

Childhood recollections of respondents with hearing parents appeared notably different. This group of respondents typically went away to residential schools at different age points. No respondents with hearing parents had signed conversations at home. All had to rely on communication in the family spoken language, and felt they had to appear to act like others in the family. Four respondents described their former sense of identity thus:

> I learnt to *look like* a hearing person, I learnt passable speech and I learnt to lip-read quite well, ...but I went through many an occasion not knowing what had been discussed at all (respondent 5).

> I followed my siblings around without knowing what was going on ...I lived in a fog until I went away (respondent 6).

> I felt like a hearing non-person; I looked like a member of my family but I was a vacant member, I was released when I went [away] to school (respondent 8).

> I went to [residential] school aged three, so that's where my identity comes from. My parents never saw me sign (respondent 12).

These comments contrast markedly with the above respondents with Deaf parents who described sharing a relatively comfortable and unbroken parent-child bond. Respondents with hearing parents described giving an *appearance* of fitting in, but of actually feeling apart and

alone. Respondents who attended a local mainstream school described a sense of isolation in their childhood lasting up until late teenage life at home.

> I grew up as a lonely hearing child who couldn't bond with anyone, or anyone with me. I didn't know there were other Deaf people until I was aged eleven... that period lasted a lifetime (respondent 10).

> ...decisions were made about me that I didn't know of. I didn't have choices (respondent 11).

The following respondents described memorable events and understandings which for them have remained pivotal:

> I dreaded family occasions. The whole family would come over and I would freeze for hours.... I knew I would never fit in (respondent 13).

> Sundays were bad enough, but Christmas day was the worst. That was the loneliest I had ever been (respondent 4).

Mindess (2006:82) likewise notes that 'Deaf children's isolation may be extreme if relatives do not sign well or at all. Children may miss out on everything from dinner table gossip to a feeling of being truly understood and accepted by their family.'

One respondent stated, "people assumed I had a learning disability - I couldn't do anything about their awkwardness and pity towards me" (respondent 9). The following treatment suggests that the hearing assumption of being 'normal' may not include a Deaf person, and that being *Deaf* is somehow 'below-normal' (Mallinson 2004). "In public my family expected me to try to look 'normal'" (respondent 7). The family's possible embarrassment suggests perhaps a sense of guilt for producing a 'dysfunctional cog' in the social system. Hearing cultural norms appear to shape what is functional and acceptable. The difference of being Deaf may not be considered acceptable. "I did not know that there were Deaf adults. I thought I'd die when I finished primary school. I was stunned when I saw another Deaf person.... what a revelation!" (respondent 5). Such sentiments were not exceptional in this group. It seems incredible but perhaps not impossible that respondents as children were not informed by the agencies holding responsibility for them (eg education, health and social services) that other Deaf people existed as adults contributing to society. Such information could have generated significant enhancement in self-worth. This may have been due to a societal and professional assumption that Deaf people are impaired and thereby socially

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disabled, rather than viewing them as part of an acknowledged and valued alternative group (Lane *et al*., 1996; Branson and Miller 2002). Respondents with Deaf parents seemed to invoke a polarised (and disappointing) recognition that they were not valued by the community and had no sense of membership that would value them as Deaf. Burns *et al*., suggest (2001:197) '(those) Deaf children (of hearing parents) rarely have exposure to adult Deaf or native signing role models. They are not taught their native language, either naturally or formally unlike their hearing peers.' That is, they may not see themselves as having positive potential or cultural difference, let alone have fluent command of any language, and yet they gradually secure these aspects themselves (Jacobs 1992).

Two respondents had different childhood environments from the others insofar as their families had minority ethnic identities. They were brought up with dual hearing cultures and languages:

> I didn't belong to my family's Asian culture – not in the way they did - or to a white hearing community. (My family use) English, Urdu and Punjabi. I can do basic conversation in all three (respondent 10).

> My family spoke more Arabic at home than English. ...so I learnt to lip read bits of two languages, but couldn't really express myself or learn anything in depth (respondent 13).

Language ability here appears intricately linked with a cultural absorption and sense of commonality. A lack of family language confidence therefore seems to shape a lack of belonging to one's family norms. This example serves to indicate the parallel experience of Deaf children surrounded by their hearing family culture and language, and their own segregated sense (Padden and Humphries 2006).

School Experience: Learning to be 'Disabled'

In this section respondent perceptions of the outside world obtained first through school will be addressed. Poignant moments were recollected when interviewees spoke of new found awarenesses of clues for survival strategies learned from peers at school. Respondents reported that some schools allowed BSL to be used informally in the playground, whilst others forbade it. Teachers were hearing. BSL was never used in formal education. Occasionally children were taught a version of single signs, signed in English order, used to support the learning of English (Rodda 1979). Eight respondents went to residential schools

for Deaf children, five of whom went to the same school, even though they came from all over England and Wales. As we shall see, data about the experiences of respondents at residential school who had Deaf parents contrasted markedly with views from those with hearing parents. Respondents with Deaf parents appeared to have enjoyed a significant advantage through their acquired fluency of a core (sign) language and a more developed understanding of the world, as well as having a good standard of written English, having been taught by parents. This appears to have given them a cumulative head start for further study and may have given some heightened status amongst other deaf peers at school:

> School was easy for me... Other children looked up to me because I knew everything... I was fluent in English and knew about the world (respondent 3).

> My mother would go over all my term's work with me in the holidays so I would go back understanding everything! I knew then I could help my friends who didn't have Deaf parents because they would just be lost. It was a powerful institution – how could you argue with it? (respondent 1).

Mindess (2006:77) discusses a similar situation in America: 'often the few children from Deaf families who had already learned ASL (American Sign Language) at home acted as language models for the other students.' Rogers, Coyne and Bale (2007:46), drawing on an Irish context, concur: 'the change in policy (in Ireland in 1946) from sign to oralism brought with it a notion that deafness was an abnormal condition. ...this method of teaching underscores deficiencies rather than maximising the strengths of Deaf children.' Thus it was not surprising to note how some respondents with Deaf parents found the residential school experience contradictory and uncomfortable:

> School 'taught' us how to be hearing people! [laughs] how ironic – I was the wrong way round for the school!... I knew it was bizarre but I had to go through the system (respondent 1).

A further five respondents with hearing parents went to residential school. Their experiences seemed quite different from those with Deaf parents. Their success seemed to vary according to the degree of command of a core language that they acquired:

> I could sign in my school with my friends – I later went to a different one where it was strictly oral, but it [BSL] was in me by then. It was my BSL that gave me that head start (respondent 8).

the teachers would write on the board and turn their backs to us – and then we would try to explain it to each other in what BSL we had between us! We were taught English parrot fashion so it never meant anything (respondent 6).

Pinker (1994:416) reinforces the point made above: 'explicit pedagogy – learning by being told is one kind of general purpose learning, but most would agree it is the least important.' Despite a lack of oral ability to articulate feelings at school one respondent stated: "my friends and I supported each other through looks and some secret gestures" (respondent 4). Mindess makes a similar point about life in a residential school (2006:77) '...despite the policy of oralism, a sense of bonding developed among the children in the residential schools through the use of the forbidden signs with each other, behind the teacher's back.' Those who had the opportunity to learn their natural language of signing appeared to benefit greatly, whereas those without it appeared to be notably disadvantaged:

> I realised other children were communicating with one another using their hands.... I watched carefully and took in everything, humour, impersonations, description, and knowledge (respondent 7).

> I went to school, and BSL was absolutely not allowed. I used spoken Pidgin English. I left school with no BSL whatsoever, I was extremely isolated and it was very hard (respondent 4).

Branson and Miller (2002) demonstrate the negative results of such education practices for adult life and we return to this theme shortly. In contrast, one respondent recalled a positive residential school experience: "I benefitted from the school oral system because I could speak quite well and teachers liked me. I knew my peers signed in the playground, but I never knew any [signs] so this segregated us" (respondent 5). This respondent saw knowledge of their core language - English - as positive because this fitted the institutional structure of what was deemed an 'ideal' deaf student, whilst acknowledging that they were in consequence cut off from deaf peers. Burns *et al.*, (2001:195) offer one explanation for this, 'many Deaf people have adopted the negative attitudes of hearing society and downgraded themselves. They may be anxious to improve their skills in spoken language, believing it necessary for social success.'

Five respondents had quite different experiences at local day schools through their continuing daily relationships with their families and of residing at home. Their educational focus on 'speech' and 'hearing' remained the same as in most residential schools (Rodda 1979). Again

there was a demonstrable connection which children felt towards each other, without having adequate means of communication; it was their position and experiences which they had in common:

> I went to mainstream schools ...I met other Deaf children later on who also couldn't sign, but we had a definite connection between us (respondent 12).

> ...school was ok, but I wasn't even taught English properly. My deaf friends and I made up signs together – we didn't know about BSL. We all needed each other (respondent 10).

Mindess (2006:78) argues that '...the need for Deaf culture may be even stronger than in previous generations because with (the attendance at mainstream schools) the opportunities for enculturation are now either gone or delayed for many Deaf people.' On this point, three respondents stated:

> Schools focused on speech therapy. ...I struggled to get qualifications (respondent 9).

> …there were five of us Deaf children, and the teacher would shout at us – it was a shouting system! (respondent 11).

> I didn't learn anything at school. My parents taught me in their home language. We drew pictures of countries, planets etc. I didn't get any qualifications whilst at school (respondent 13).

Respondents' experiences of education here appear uniform and recurrent – of education generally being the teaching of 'speech', and 'hearing' English as carrying more weight than academic study. Such an approach is seen by Branson and Miller (2002) as an institutionally created learning disability.

Becoming Deaf: Issues of Identity and Transition

This section focuses on discoveries by respondents of their own cultural Deaf identity. Also examined are that minority of respondents whose self-awareness was reported as not changing nor needing to because of a purported pre-existing inner confidence and sense of identity. Those whose identities changed at different points in their life described the events leading to the dawning of a new understanding. By contrast, it is notable that all three respondents with Deaf parents specifically stated their not experiencing any sort of identity transition surrounding their being Deaf, as they had been brought up and socialised as

cultural Deaf individuals, signing BSL. This position has remained for the three. The first respondent starkly reported:

> I've always had Deaf culture before hearing culture; I've never had hearing friends or wanted them (respondent 3).

> ...well BSL is my native language, I have always chosen to have Deaf friends, and where I could Deaf colleagues. It is just easier and relaxing. I know I'm lucky…… (respondent 1).

> …...my parents have always confidently reinforced the value of my culture and language (respondent 2).

> my school did its best to take all of that away from me. But being Deaf is at my core (respondent 1).

Whether taking their situation for granted or reflectively viewing themselves as fortunate, their views are similar – they have stayed firmly in the Deaf world. They know that had they been born to hearing parents, their life experience, knowledge and social position might have been very different. Burns *et al*., (2001:198) explain that the adoption and use of BSL is the engagement of the Deaf social identity, and that the earlier this opportunity comes the more meaningful its effect on one's life chances: 'Use of natural sign language is the primary identifying criterion for membership of the Deaf community'.

There was some variation in the descriptions given by those respondents with hearing parents when describing their transition to a Deaf identity. Influential factors tended to be experiences at school and access to the Deaf community thereafter.

> I can remember not really communicating with my parents, and then at an early age I gained a Deaf identity from school and I have not looked back (respondent 5).

> I was fluent in BSL and comfortable enough to feel culturally Deaf at the age of seven. Later on I went to Deaf clubs on my own – just to soak it all in (respondent 6).

> I was 17 and I met an American Deaf person. It dawned on me that BSL was a proper language, because I didn't understand him [using ASL]. I realised that it was valid to enjoy Deaf culture and BSL, which was actually natural to me, whereas English wasn't (respondent 9).

The above respondent had had some knowledge of BSL, and yet had not then been convinced about its legitimacy. It was a pivotal moment when the above respondent gave him or herself

permission to use this 'authentic language' and the rich culture it allowed access to. A further respondent explains their period of transition:

> My family were profoundly hearing! I married my spouse who was from my school – and we spoke English to each other. Then after having deaf children and us still using English, I had to search for answers about my identity.... We moved to [a town with a large population of Deaf people] and within weeks my children had learnt a huge amount of BSL, way more than me! But soon I was having rich, meaningful conversations with people. I also had in-depth conversations with my children – it was a learning curve in many ways. But my spouse didn't really learn it; we no longer had anything in common (respondent 13).

The above respondent's self-perception evolved through a profound transition of self that stemmed from a shift away from the cultural majority language system to a belief in a fundamentally opposite worldview, leading to the abandonment of a former way of life and the embrace of a new future (see also Lane *et al*., 1996). Many Deaf people may internalise an institutionally held belief that being a hearing person is 'better' than being a Deaf person, and that English is 'better' than BSL. It is a significant watershed to those who discover through a personal journey that for them, this is not the case:

> I learnt BSL from age 30. I previously believed I was 'good enough' to be hearing, but I was missing something and was subconsciously pulled back to the Deaf community (respondent 13).

Burns *et al*., (2001:195) explain that, 'those who use sign language have been particularly oppressed because their language was so alien to speakers of spoken language, and their varying degrees of hearing levels seemed to justify viewing them as deficient.' This would appear to obtain similarly from the opposite view – that of a Deaf person who has been influenced by hearing educators to hold that the way forward is fitting in as a culturally hearing person, and to use the majority spoken language. This respondent may have missed information, knowledge and understanding on a daily basis, but this would have become normal for them. Mindess (2006:80) compares this to the difficulties that we as hearing people have when we '…do not even notice how much information we pick up without trying until we have an extended stay in a country where we do not speak the language.'

Five respondents who attended mainstream schools expressed pivotal incidents which influenced their evolving self-perception and future direction. "I was fluent in BSL by age 21 and suddenly confident, life became *available* to me. I went through a vertical learning

process" (respondent 10). The idea that BSL had to be seen to be a real language with status and legitimacy before a respondent had confidence in its use emerges from interviews. Perceptions may have varied, from observation of the language in application by a community, to undertaking some academic linguistic study of BSL once an adult. The magnitude of influence that hearing educators have had when little attention is given to BSL and while priority to speaking and hearing English is given is considerable (Vale of Glamorgan LEA policy 2011; Branson and Miller 2002). Respondents stated that at the stage of non-belief in BSL, they were aware of their lack of ability in English:

> I wasn't able to let go of my old life even though it was a struggle because I didn't recognise that BSL was a true language. I was age 29 when I realised (respondent 9).

> I didn't grasp that it was a proper language until I got to my late teens. I had started going to the Deaf club but my parents were very suspicious of these 'different' people, and me losing my English – the English that I had (respondent 8).

There was no obvious difference in this evolving self-perception between those with hearing parents who had either been away at residential school, or who had gone to mainstream day school. Upon learning BSL, the following two respondents recognised a feeling of belonging to a culture, where they had not previously felt closely linked to their minority ethnic home cultures:

> I learnt BSL from nothing at 15. I learnt at the same time that Deaf people have a parallel culture, it was like the African culture my family had (respondent 12).

> I went to university and met Deaf friends and learnt from them. I increasingly realised what a waste my life had been. I was confident of my culture – it was Deaf identity and not so much Asian (respondent 10).

In becoming confident about the purpose of BSL, respondents may have become less concerned about the language and identity of parents, and other outside parties. Respondents no longer seemed to comment about what others thought once they felt confident in being culturally Deaf (Sutton-Spence 2005).

Learning to be Deaf: Exclusion and Discovery of Collective Challenge

This section examines respondents' descriptions of institutions and systems which were not open to them, *because* they were Deaf, although this situation seems not to have been recognised by these same agencies. The effects were that interviewees felt they could not

freely contribute to social and economic life as equals. The multiple adversities experienced by some interviewees appeared to enable them to challenge and secure changes to the institutional recognition of a Deaf collective identity. This section gives some brief indication as to the direction in which respondents lead their organisations in promoting Deaf interests and is explored in more detail in Chapter 6. First, we turn to a world beyond the influences of school and parents, and it will be seen for these respondents that in becoming adults they continued to experience exclusion. For one respondent, exclusion was soon evident as a young adult:

> I have 'O' levels and 'A' levels, but I hit a ceiling when I couldn't go to university because of the system. ...similarly I can only be a CEO of a Deaf organisation, not of a mainstream one (respondent 1).

Turner (2007:51) reports that 'historical records consistently show hearing people remaining in powerful positions relative to Deaf people's lives. This situation (stems from the) family life, where the vast majority ...are born to hearing parents, (and from) the formative years of schooling.' Burns *et al*., (2001:190) write that 'in situations where two languages are in contact, the majority language is usually attributed positive qualities, while the non-dominant minority language is often viewed negatively.' In line with this, respondents stated:

> ...our exclusion is too big to measure – ensuring individual access on a daily basis is tiring (respondent 7).

> Our families couldn't include us. ...and on a grander scale, society can't engage with us; the default situation is that Deaf people are not allowed to use their brain, have an education, have a career, or hold status. The extent of the exclusion is all encompassing (respondent 8).

> ...the system excludes Deaf people openly without justification – because it is seen that Deaf people fit into social welfare as struggling hearing individuals – which we are not (respondent 6).

Jones (2006:62) explains that if BSL were recognised as a British functional language then what passes for normality would be different: '(a) shift in emphasis ...would frame (signed language) within the normal domain of language and not so strangely different from spoken languages. ...The more encompassing the definition of 'normal' is the less falls outside it.' A shift in societal default situation could therefore have an impact on the social exclusion of Deaf people. Two respondents' answers were more philosophical:

> We are surrounded by a majority who is different to us: we are automatically 'invalid' because the majority need to hear, and so assume we do (respondent 9).

> We have to access a system of a majority of which we are not a part. Because we are the minority, we cannot access financial or media investment. We have to work out solutions to influence systems where these are mutually beneficial both to our collective, and to hearing institutions (respondent 2).

Turner (2007:50) summarises the position thus: 'Deaf people's experiences can be characterised as 'institutional audism'. Jones (2006:62) asserts a sustained historical institutionalisation; '...the roots of neo-classical economics, bio-medics and the law structure serve to exclude Deaf discourses and limit Deaf agency'.

When asked what inspired them to be ambitious in their career as a CEO or chair of a Deaf organisation, respondents often invoked a sense of identity and struggle. One interviewee (who had partly held onto their hearing identity because they had sought to fit into management posts in established hearing institutions), expressed a level of ambition for Deaf community acceptance, in order to resolve a sense of inner personal conflict: "...well I worked hard to learn a high level of English, and went into management. I was subconsciously drawn into the Deaf community for personal benefit in the guise of my career..." (respondent 7). The answer is revealing in that the respondent states they 'worked hard to learn a high level of English', perhaps implying that they felt as if they had learnt a difficult foreign language. In this regard, Burns *et al*., (2001:197) observe in the US 'typically, there is a tension between the two languages (English and ASL): on the one hand, the spoken majority language is needed for social and economic survival or advancement; on the other hand, Deaf people continue to use natural sign language because it plays a most important function in their lives.'

Other respondents, those with hearing parents, who reported growing up initially with some sort of hearing identity and who later learnt BSL, subsequently gained confident membership of their collective, and displayed much ambition to forward the cause of the Deaf collective. One respondent stated:

> My aim is to push the Deaf community into achieving for themselves – but importantly within the mainstream. ...The notion of 'normal' will be modernised, and we will *be* normal. ...There is a large amount of apathy amongst a minority

community who is ignorant of the institutional mistreatment of them. They need to see proof of this treatment first (respondent 4).

Some respondents of hearing parents, who attended either residential or day schools, identified a sense of personal responsibility to assist their collective:

I am an individual member of a collective who is discriminated against. *I* am in the position to represent us and to change things for future generations (respondent 5).

I finally understood the inequality we faced and needed to challenge ...I work hard with passion and have strong determination (respondent 8).

I cannot allow other Deaf generations to suffer what I've been through. We need to push ourselves and transform the way we are seen (respondent 12).

Similarly, other respondents referred to past (and on-going) adversity as the stimulus for their ambitions in life:

I've always been ambitious – my unfair treatment in employment because I was Deaf motivated me even further! (respondent 5).

I have been through severe institutional exclusion and eventually I realised it. I want to facilitate for this and the next generation of Deaf people to become inter-dependent within society, so that society equally depends on us (respondent 13).

One respondent with Deaf parents felt a rather altruistic collective responsibility without having personally experienced adversity as others had:

...there shouldn't be any more Deaf people to live regressive lives... I have a very clear purpose to enable the next generations of Deaf people to progress to senior levels and to themselves become prominent role models (respondent 1).

This sense of civic activism and identity politics both explicit and implicit in the above data extracts seemed motivated by a shared sense of marginalisation and the acute feelings of grievance this gave rise to, and is a theme that will be returned to in later chapters.

Opinions as Cultural Indicators:

Culture in Language

As discussed in Chapter Two, sociolinguists have debated the nature and extent of culture as an aspect of language, as have sociolinguists in the field of BSL language research (Sutton-Spence 2005). Deaf Studies academics assert that if culture is established in language this

should accordingly lead to full recognition of BSL as an authentic language, where an identified condition of language is the presence of a cultural dimension (Woll *et al*., 2001). It follows that British Deaf culture may then be understood as present in the UK. BSL has formerly been, and to an extent is still, seen as a tool to assist Deaf people communicating in or learning spoken English (BDN 2010). The impression may be formed by hearing educators and policy makers, that BSL is not an individually meaningful, rich and inter-subjectively created language, let alone having independent grammar and structure. It is not recognised that Deaf culture is saturated in use of the BSL language and assists group identity in the sense of Burns *et al*., (2001:198):

> …all languages can serve a bonding or solidarity function; they can act as a symbol of group identity. Knowledge of a language involves a personal sense of unity with, and a set of attitudes toward the community that uses (that) language. Language and identity are intimately linked.

Respondents were asked if they believed that BSL language has or generates a definable culture. A typical response was:

> ...yes of course it does – my friends and I share wave-length and understanding before we even start a conversation (respondent 1).

This link between cultural identity and language implicated above was not accessible to the following respondent:

> I have a very personal answer to that (question). I don't get Deaf jokes! To me, the language has a secret code – I use the language but haven't cracked the code yet! I believe I haven't let go of my hearing identity, and the secret code is the cultural depth to the language (respondent 5).

This respondent indicates a more complex link between culture and language, in that a certain degree of knowledge of BSL does not automatically enable one to understand a culturally specific joke. To follow such humour, it may be necessary to be submerged, as the following interviewee was, in the language, nuance and inter-subjectivity of Deaf collective culture in order to share and construct meaning:

> ...there are openings in BSL for local slang, telling stories, using humour – that's all cultural... I compare Deaf behaviour to African behaviour – I didn't know this when trying to be African. Once you behave Deaf and live the language, you become a member (respondent 13).

This comment implies some process of acquisition of language and identity in order to engage in culturally competent interaction. The following respondents express this thus:

> ...slowly myself and my family started to feel like strangers towards each other. I had new life injected in me – I understood the Deaf way and I felt more attached to Deaf people (respondent 10).

> ...it's not just that the language is different, because of my transition to Deaf culture I now understand Deaf humour. The same joke in English wouldn't be funny to hearing people. And it's a really beautiful language – delicate signing is so moving (respondent 2).

Sutton-Spence (2005:14) discusses the expression of BSL as a linguistic aspect, and the range of culturally expressed hand movements and style, ranging from the flat expression of a learner, to the intricate and delicate dancing movement of a BSL poet:

> Sign language poetry is the 'ultimate' form of aesthetic signing, in which the form of language used is as important as – or even more important than the message. Like so much poetry in any language, sign language poetry is a means of expressing ideas unusually succinctly, through means of heightened 'art' language.

Burns *et al*., (2001:197) also assert that '...natural sign language is sometimes considered to be an art form by its users.' Hence it was not surprising to note that one respondent felt that: "being with hearing people – even those who have learnt to sign requires more effort!" (respondent 4). This respondent indicates that hearing people may have been taught 'BSL' in relation to English, which may make their language more like a signed pidgin English. Here, they are likely to 'think' in English whilst attempting to communicate in BSL, and sign more in the order of English so that correct BSL structure and signs are absent. This may also apply to Deaf people learning BSL, as their previous language may be 'spoken pidgin English' (personal communication f: 2011): One respondent with Deaf parents, whose first language is BSL, commented, "I've watched many Deaf people learn BSL and as they have become more fluent they have become more culturally Deaf. I think it's that they get away from a kind of two-dimensional English, and hearing culture" (respondent 7).

The absorption of Deaf culture, and of understanding cultural levels in the BSL language, may take time, explaining the difference between first language Deaf people, and a Deaf person who has maintained use of English and a hearing identity. Smith and Sutton-Spence (2007:19) discuss clues to gaining insight into the culture present in the BSL language,

'folklore in language generally functions in one or more of four ways: firstly to express the culture of the group, secondly to justify group behaviour to outsiders, thirdly to educate group members about the values and norms of the group and fourthly to maintain those expected ways of behaving'. This explanation contributes to the view that BSL is a valid linguistic system and that by extension the articulators of this language could correspondingly be valid in their own right. Culture expressed through language in a lived context could be a part of the cultural way of being in the Deaf collective:

> Before I had BSL, life was flat, as well as difficult. Now I can express my own personality in the way I use BSL – that is, we're all different, but once you can express yourself I think it's true – we share a wavelength (respondent 6).

Another respondent explores this further:

> BSL is culturally different to ASL. American Deaf people have signed to me that we [British Deaf] are really conservative! I think that's funny because we're not at all! But isn't that interesting? (respondent 1).

A different nationality Deaf person's observation of British Deaf people as collectively showing a single cultural trait (of conservatism) does seem intriguing, demonstrating an outside view of an inside 'shared cultural wavelength' of Deaf BSL signers (Sutton-Spence 2005).

Disability

As discussed in Chapter Two, Deaf people are defined by statute as disabled and categorised under welfare legislation and policy accordingly. The traditional assumption held by policy and law makers is that 'sensorily impaired' groups are so called, due to their loss of a physiological sense, required for functioning in society. For Deaf Studies academics, a label of impaired, and thus disabled, may mean an unwarranted societal refusal to accept any collective identity for Deaf people (Lane *et al*., 1996). Deaf Studies academics may refute the label of, say 'sensory impairment', and thereby any assumption of commonality with cultural hearing individuals with visual impairment or hearing loss - those who rely on English, and who from their perspective do experience individual loss and disability. Particular Deaf individuals have been reported as refusing to accept the label of disability, and thereby not claiming disability benefit. The issue of whether Deaf people are disabled or not appears to be one of the prominent factors for the potential recognition of Deaf people as a collective

and valid British cultural and linguistic minority. Some would argue that Deaf people cannot both reject their status as disabled, and continue to claim disability benefits or receive specific support: 'Deaf people who refuse to label themselves disabled surrender their access to services for disabled people' (Elliot 2007: s88).

Six respondents signed they had never received 'sensory' services and asserted that the availability of such services and disability benefits to Deaf people is unhelpful, and prevents Deaf autonomy and collective recognition:

> We are *not disabled*. We have a language different to English, and we can communicate when hearing people can't, as well as vice versa. The label of disability and the linked 'benefits' prevent us from gaining recognition. It is unhelpful, and it is not our label (respondent 9).

Sparrow (2005:138) concurs, '...society thinks of human variation in terms of deviation from some imagined perfection... (while) in certain environments Deaf people have *greater* ability to act, and it will be hearing people who are "disabled".' The following three respondents signed accordingly:

> I don't believe most of the Deaf collective feel disabled. I know society believes us to be disabled, but society hasn't asked us! (respondent 2).

> ...it is a disability for adults who struggle to hear and to communicate. I was like that before I went to school. We *don't* have impairment because we have a functional collective where we all know each other. What is disabled about that? (respondent 3).

> ...Deaf people are not disabled. I learned this when studying Martha's Vineyard. The *whole community* had a common signed language and a strong cultural core (respondent 8).

Levy (2002:134) reiterates that, 'treating (being) Deaf as a medical condition is inappropriate since it is not a disability; that so treating it sends a message to the Deaf that they are of lesser worth; and the treatment ...is impermissible because Deaf culture is intrinsically valuable.' Some respondents drew parallels between themselves and minority ethnic groups: "It is not that I function *despite* my 'impairment' – I don't *have* impairment; I have two full languages plus qualifications. Why would I want to be hearing? You see, British Asian people are not 'disabled', even if they can't speak English" (respondent 11). The next respondent answered similarly: "I am not disabled, and neither is our collective. If one cannot sign – and relies on hearing, it is they who have disability. Public bodies don't realise we are the same as

an ethnic minority" (respondent 7). The following respondent explained on a basis of personal understanding of being in a dual minority, and the apparent illogical status of Deaf as different to African: "We are isolated and excluded because we are different. But so are my family, who are African – but they are not accused of being disabled!" (respondent 13). Sparrow (2005:139) argues '...for much of the history of Western culture the "normal" person was white, male and propertied. (Others) were thought to be inferior examples of the human form... Medical science was a central discourse in the theorisation of difference.'

Elliot (2007:s89) writes of historically fixed, medically influenced labels attributing social status to Deaf people: 'The assumptions that are made about ...being Deaf take no account of the ambivalence individuals feel towards these categories. Current legislation continues to regard Deaf people as 'impaired' and being Deaf as a 'condition' requiring treatment.' Respondents appeared aware of the societal view of their 'medical' identity:

> Disabled? No! According to a medical view I am, and according to the social model of disability. But that's rubbish; I can do everything. I just don't fit in to hearing systems as a well behaved 'normal' person. Deaf does not mean disabled (respondent 12).

Another respondent articulated a somewhat more impatient (their emphasis in italics below) summation of the experience of Deaf people as a collective, where the perception was that the label of disability serves to restrict their freedom:

> *Of course* Deaf people are not disabled. Yes they are *told* they are, by social services and government, and it is *infuriating*! Once Deaf people reject that idea, they can be free functioning individuals with expectations (respondent 4).

Two respondents discussed the event of BSL becoming officially recognised as 'a language in its own right' in 2003 when it was first announced by the then Secretary of State for the Department of Work and Pensions, and the *Minister for Disabled People* (BDN 2003:6) (my emphasis). One respondent referred to this occasion with profound disillusionment:

> I wish they hadn't bothered. The Government tacitly *reinforced* that we have a disability with our 'own little primitive language', as if we have learning difficulties. Then they invested a token amount into training and employing *hearing* people to learn BSL and become interpreters – what about investment in real live Deaf people? We were so horribly patronised that day (respondent 3).

Another respondent saw the situation in a related light; "...that day the Government rendered our language as an 'apparatus to help us to get by': we are seen as 'disabled individuals'" (respondent 6). Respondents here felt condescending treatment was almost worse than societal neglect (Turner 2003).

An opposing and untypical view was offered by one respondent who went to residential school and stated that s/he did *have* an impairment: "Well – I actually feel impaired, but I know many Deaf people don't believe they are. Many pupils left my school feeling this disability but gradually changed their views in the adult world" (respondent 5). This view is distinctive in that it differs from all other phase one respondents. The respondent who identified as an individual with impairment was well aware of the stance of others in eschewing their categorisation as disabled and claiming a more authentic and shared sense of identity.

Cochlear Implants

Cochlear implants (see Chapter 2) and the issue of their fundamental purpose is strongly questioned by the Deaf Studies community, since consultation has not occurred systematically with Deaf people as to whether they want their collective to be 'cured' (see Branson and Miller 2002). All respondents had definite opinions as to the nature of the underlying understanding by society of themselves, in the medical attempt to 'resolve their deafness'. Some responses reflected a personal abhorrence at the idea of themselves having a cochlear implant, particularly where feelings of strong confidence in their established identity were made known. Some demonstrated a more relaxed view as to the choice of other members to choose a cochlear implant for themselves and whether thereby those others opted to change their cultural identity or not. Respondents however were all against children being selected to have the operation, because it would inevitably be someone else's decision: "I don't believe in them. But some Deaf people have them. That has to be up to them, they're the ones who are persuaded more easily" (respondent 12). This is also observed by Jones (2006:53) who observes that people who opt for the operation become understood in terms of the medical intervention: 'Deaf people become the sum of their 'assistive' devices.' As one respondent observed:

I wouldn't want one. I'm definitely against giving them to children – they should make their own decision. Enforcing a cochlear implant means enforcing the child's cultural hearing disability (respondent 6).

Another stated:

My parents were advised that I should have one. But of course they ignored that. Other Deaf people who choose to have them as adults, that's up to them. I'm against children having them, because it's never their decision (respondent 4).

Jones (2006:54) observes: 'some see this as child abuse because it inflicts extensive brain surgery on a normal child for the benefit of hearing people.' Although being against children having cochlear implants, the above respondents do not appear to question the underlying implication by way of 'choice', that is, a cochlear implant is offered by audiologists as a medical 'cure' whereby an individual can become a 'normal' hearing person (Levy 2002; Doe 2007). As noted earlier, one respondent gave their views on cochlear implants more forcefully:

I went to a world (Deaf) congress a couple of years ago, and as an opening mark, the President got a hearing-aid and smashed it on the lectern with a hammer! ….It was the most powerful symbolic statement I have ever seen. *Having* a cochlear implant makes one disabled. It was a metaphor making us realise that one *can* reject the 'hearing' identity forced on us (respondent 11).

The following respondent goes further, and questions the institutionally established nature of cochlear implants, in relation to an apparent unquestioned government investment in audiological advances:

They should never have been invested in. The money that goes towards cochlear implant production would be better invested in employment training and opportunities for Deaf people as a Government programme. Cochlear implants are destructive and confuse some Deaf people into thinking their identity can become a cultural hearing one; instead they become isolated and not part of either world (respondent 6).

In this context, Jones (2006:54) asserts the priorities of both medical influence and of profitable business: 'The advent of brain surgery... has seen the creation of a highly lucrative business in research, design and manufacture and in surgical expertise in micro-surgery'. Respondents mentioned what in their view were the real life consequences of people having cochlear implants and the following seemed to represent a broadly shared perspective:

Cochlear implants are destructive in that they delay the membership of individuals' natural culture. Once those individuals are able to reject their cochlear implant, they come back to being Deaf and are bitter about their 'hearing' experiences (respondent 1).

Jones (2006:55) supports this point: 'there are emerging accounts of the successfulness of such aids to hearing, but also those of Deaf people who feel they cannot belong to the Deaf or hearing worlds because they are misfits in both.' The very limited hand of assistance via this technology was deemed inadequate by respondents - "Research on cochlear implants shows they are 'successful', but in medical terms a cochlear implant has twenty-two tones of sound, and a hearing person has thousands. So *how could* a cochlear implant give 'hearing'?!" (respondent 2). One respondent articulated the dilemma s/he was presented with, when offered a cochlear implant:-

The doctor said 'well done you qualify for a cochlear implant. You've got a week to decide!' - I didn't know about the Deaf community then. My deaf child was four, s/he said to me "if you become hearing, you won't want me because I'm deaf." Wow, *that* made me turn it down (respondent 3).

Another respondent reported personal knowledge of someone who had a cochlear implant aged fourteen, who struggled for several years "...s/he learned to cope with it, but s/he didn't actually feel like a hearing person. Finally s/he went to university and met Deaf people, and realised s/he had a Deaf identity which couldn't be taken away from her/him. S/he was twenty" (respondent 9). A respondent's childhood friend experienced this: "...doctors pressured her/his parents and no-one realised the consequences. After the cochlear implant s/he was very insecure, self-conscious, and less confident with us, as well as with hearing people. After four years, s/he turned it off" (respondent 10). These people learnt to reject implants and to adopt a different cultural identity from the intended normal functioning behaviour that a medical procedure was presumed to initiate (see Sparrow 2005).

Lane *et al.*, (1996) and Doe (2007) write that cochlear implants cannot damage the evolution of a Deaf collective, as generations of hearing control have already attempted to prevent Deaf existence:- 'The Deaf community has survived far worse than the medical intervention of cochlear implants and will continue to do so' (Doe 2007:14). A similar point was made by one respondent in discussing a peer who opted to have a cochlear implant themselves: "As you know, one adult chose to have the implant, and their allocated sign name is now

'cochlear implant'! [Both laugh]" (respondent 2). This suggests that some stigma may be attached to an adult choosing this option and may act as a powerful cultural protection for the majority Deaf (Smith and Sutton-Spence 2007). Respondents similarly noted:

> I feel sorry for adults who 'choose' them. They are confused Deaf people with a prolonged 'hearing' identity. And there is such a stigma relating to this, they are looked down on so obviously (respondent 13).

> ...we support those who have them, because the community can shun them. They go through depression and prolonged isolation as 'hearing' before they can learn how to be themselves, and come back (respondent 7).

One respondent who identified as possessing an impairment and disability through being deaf, answered differently to all others: "I think it is up to individuals if they want to have one. I would support anyone who made that decision" (respondent 5). Such a view would not be likely to emanate from those who were passionate defenders of their own Deaf membership or who would not in some way fear for fellow Deaf 'entering' into the hearing world. Sparrow (2005:141) explains that this may be due to one's lack of 'contact with cultural role models ...enabling cultural transmission of Deaf culture.'

The Human Fertilisation and Embryology (HFE) Act 2008

The Bill for the HFE Act was being debated at the same time that a Deaf couple were in the media spotlight for announcing that they had wanted their (Deaf) child to be Deaf, and indeed wanted another one (BBC Radio Four and BBC Radio Two programmes, web-archives 2008; King 2009). The media reaction to them appeared somewhat negative from a Deaf perspective. One response to this may have been a late addition to the HFE Bill in 2008. In the House of Lords, Baroness Deech proposed an amendment that embryos susceptible to deafness should be destroyed once detected: 'I hope that your Lordships will be pleased that the deliberate choice of an embryo that is, for example, likely to be deaf will be prevented by Clause 14.' (Hansard 672-675:2007). The response illustrated the speaker's assumption of a universal view of being deaf as a damaging deformity (King 2009). Deaf Studies academics have argued that this clause in an Act is an indicator of the UK societal intention to eradicate the occurrence of flawed citizens, with an aim of producing a 'pure' functional-according-to-the-majority population, a return to eugenics for some (see Proctor 2002).

Several respondents were ignorant of the existence of the Bill and only one national consultation session on the proposed legislation had been conducted inviting a Deaf audience to participate in April 2008 (Wales Gene Park 2008). After discussing the Bill with respondents their reactions revealed a shared concern over the messages that the legislation would send more widely:

> Well I'm against it then. It means Britain is going backwards. It's depressing – that's why I don't bother with politics. No one is interested in Deaf people (respondent 12).

> ...it reminds me of the old taxonomy theory justifying slavery, where the justification of subnormal was based on 'colour'. What is the justification for this clause? We are 'subnormal' based on our 'biological' position, and therefore should not be allowed to continue to exist. It is sickening (respondent 4).

The belief in natural difference and natural biological variation, determining natural inequality, based on a scientific and cultural imagination, was used to 'prove' racial inferiority in the past (see Morning 2006; Thompson 2008), and from the standpoints of these deaf perspectives could conceivably be applied now to justify cultural difference, and by implication inferiority.

> It worries me enormously. It is the Deaf collective having a rug pulled from under them. It means the government are saying theoretically it is illegal for us to exist, or at very least, pointless (respondent 6).

The above respondent went on to assert that the Deaf as a collective and as users of a language are not acknowledged as legitimate and indeed are viewed as invalid (see Emery *et al.,* 2010). Another respondent raised the issue of the Deaf collective's lack of consultation in relation to the Bill, where the one national consultation session was viewed as tokenistic and effectively too late to make a difference; the event in question was said to have accommodated an audience of only a hundred people, and was not Government sponsored or supported (King 2009):

> We are not even valid enough for genuine consultation! It is public confirmation that we should not exist: it is personal prejudice influencing legislation, so rather precariously, human rights in Britain have regressed (respondent 2).

Emery (2009:31) comments on the citizenship of British Deaf people: 'Deaf citizens are marginalised in society largely due to a citizenship that assumes an idealised individual as a speaking and hearing citizen, with a social policy constructed and made in the image of

hearing culture.' The respondent cited below summarises how Deaf people are understood in hearing cultural terms as having 'severe deformity' (Fox 2009; Human Fertilisation and Embryology Authority 2008) and thereby as potentially damaging the 'pure' population at large (Emery 2009). The respondent argued that hearing cultural values –

> ...influence their actual belief of us as suffering, deformed invalids. That's why the Census doesn't even acknowledge us as citizens who have a different British culture, and the second British language…..Our chief executive group have informed the Government that we are utterly opposed to this clause in the Bill, because it means in their eyes we should not have been born. What next? I know for example that Deaf people cannot emigrate to Australia. That is disastrous for our human rights. How will we ever be accepted as equal human beings if this is the way forward? We understand this clause has been inserted by a couple of ignorant and prejudiced Lords, and imagine if this Bill becomes an Act (respondent 3).

Another observed of the Bill:

> ...remember, we don't actually *have* a 'deformity', and to Deaf people, giving birth to a Deaf baby would be a wonderful miracle... the testing of an embryo in this context is the Government reminding us of the worth they award us (respondent 7).

Jones (2006:67) writes about the modern day development of research into deaf genes, affecting the core human right of existence; 'the 'right to life' of a potentially deaf child is now compromised due to the so-called advances in genetic engineering'. There is for some a parallel to the ideas of racial and ethnic hygiene in 1933 Germany, since the Bill aims to prevent Deaf reproduction (see Proctor 2002:35). Respondents likewise made this connection:

> Well it's an attempt at eugenics isn't it? Under Hitler, there was sterilization, in order to prevent the 'impure' producing. But the Government can't stop Deaf people being born! It is just so *tiring* that our collective and language is not seen (respondent 11).

> I am sickened by the Act. What is also extremely scary, is research into a 'Deaf gene'. Then what? Eradicate us all? It's like announcing that a 'female gene' discovery means they can eradicate all girls (respondent 9).

> ...the aim will be for society to create 'perfect' babies – we are seen as contaminating that aim. The initiative is clearly modern eugenics (respondent 8).

Being Deaf in 1933 Germany was considered to be a 'genetic disorder' (Proctor 2002, Muhs 2002), just as it similarly may be considered in 2008 Britain according to Emery *et al*.,

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(2010). In summary, most respondents drew parallels with either the hierarchical classification of human beings or with medicalised cleansing, and discussed the worrying implications of this for their sense of identity and social worth, and their citizenship and human rights.

Conclusion

Respondents' perceptions and experiences appear highly significant when one can see the wide range of backgrounds of Deaf people; that Deaf people do not have a single experience of being 'impaired', but varying influences cause notably different understandings and perceptions in young people as they are growing up. The minority of Deaf people with Deaf parents (n=3) grew up confidently in terms of their language and cognitive potential, and communicative social bonds – in parallel in large part to the majority of the hearing population, and with no understanding of impairment as relating to themselves. This compares with the majority of Deaf respondents (n=10) who had a cultural hearing upbringing, according to the culture and language of their parents – with a hearing identity and using spoken language. These Deaf respondents grew up having internalised an identity of impairment and invalidity. The next classification was in terms of school type. Five of the group of ten with a hearing identity upbringing attended a residential school with d/Deaf children. Some benefitted in being able to undergo a culture transition and become Deaf in learning BSL from their peers and developing confidence in feeling Deaf. Two respondents who attended residential school however did not develop such an identity until later on, and both regretted this into adulthood. Five respondents attended mainstream day schools with hearing children, and a unit for hearing impaired children. These were the respondents who learned BSL in adulthood, and who may have struggled the most in terms of their adverse early surroundings and isolation, having lived the longest as culturally hearing impaired individuals.

All respondents came through their childhood, school and youthful experiences, and eventually accepted the roles of elites of the Deaf collective. It is indeed interesting to explore where these professionals came from, socially, culturally, and politically, what inspired them to achieve, and what their continuing motivation is in holding their roles. What is also significant is how these elites remember the events that shaped their world, and what they

chose to articulate during interviews. Now that we have considered respondents' personal backgrounds and views on salient issues, the ground is prepared for an exploration in the next chapter of these respondents' visions and achievements in their third sector organisations that seek to represent the interests and agenda of the Deaf collective.

Chapter 6

"We don't want *funding*, we want *investment,* and we *don't* want to become hearing": Deaf organisations' structures, philosophy and direction

Introduction

This chapter addresses the second round interviews conducted with Phase I respondents. Previous analytical categories of parentage, school type and age of learning BSL became less relevant to the interpretation of the data once Deaf elites focused on their professional role and purpose. In the discussion that follows I use the terms 'respondent' and 'agency' interchangeably whilst recognising the methodological challenges this represents to an adequate understanding of both. Analytical categories dividing the thirteen organisations for this chapter do not overlap or converge as did the categories in the previous chapter. In this chapter data are instead grouped into three core organisational clusters: group A, those organisations that maintained 'self sufficiency' towards a Deaf agenda in terms of their funding and finance (n=7); group B, those which took on conditional funding with social services departments as service level agreements (SLAs), (n=4); group C, those which included among their clients service users with hearing impairment, and thereby embodied a medical deaf orientation to their activities (n=2). Deaf agency vignettes (below) clearly display organisational defining features. Throughout the chapter I refer to individual respondents by group letter and individual number. I have focussed on all organisations in turn, exploring their value orientation, vision and discourse, policy and funding systems.

The chapter explores the practical and discursive contexts of these third sector 'social businesses', that is, their politically and culturally rooted principles, as well as respondents' views on conflicting social and economic environmental influences. I have considered

organisational issues of vision, core values, organisational provision, business philosophy and income, political mobilisation and professionalised level. The literature I draw upon relates to the sociology of organisations, social policy relating to the third sector, and the identities of organisations and their position in relation to public sector governance and funding. I refer particularly to organisational culture and leadership where these aspects became prominent in the narratives of respondents. Respondent background cannot be taken to predict their role and attitude as organisational leaders. Rather, the value orientation of the organisation now seems to take prominence in the way that being Deaf is constructed and deployed as both knowledge and practice within any particular agency.

The title quotation signed by a respondent typifies many of the views held by participants about the fundamental aims of their organisation. This respondent explained a shared sense of frustration at the way the Deaf collective fails to be recognised by funding and policy making bodies. The distinction alluded to is that 'funding' represents fixed term donations to allow impaired people to help run disability projects, whilst 'investment' implies a preferred understanding of Deaf collective people as citizens of their country who experience enforced barriers, as indeed they see themselves. Hence, "...we *don't* want to become hearing..." implies a rejection of a medical and social disability view that Deaf people wish to be 'cured', *or* that they are seen as a disability community experiencing struggles as culturally hearing individuals. These assumptions are in general dismissed by respondents; their view appears to be that a different British cultural identity is valid, and that their culture and language ought to be protected and promoted – hence the existence of these third sector organisations, and their core philosophy.

Summary of organisational properties and characteristics

	Group A Organisations of 'self-sufficiency'	Group B Organisations with SLAs	Group C Organisations with deaf service users
Vision	Achieve political and policy authority, re-education of Deaf people	Achieve Deaf independence and empowerment	Achieve influential public profile, Deaf independence

Values	Enhance the collective sense, develop shared responsibilities	'Narrow the direction and expand forwards'	'Not to be oppressed by those in power'
Provision	Forums, teaching, employment, advocacy	Advocacy, outreach, social events, social service	Advocacy, outreach, community skills swap, support work
Business philosophy and income	Unconditional grants, contracts, private income, fail on many grants	Community care funds, other grants, fail on many grants	Conditional 'disability' grants, fail on many grants
Professionalisation [No aspects group specific]			

Deaf agency vignettes

Group A: Organisations of financial 'self-sufficiency'

A1

This agency was co-established by the respondent. There are no paid staff, only volunteers. Income is in grant form which is problematic and they are not currently in receipt of funding. The agency facilitates forums upon which to negotiate with local policy makers. They maintain clear political ambitions.

A2

This agency receives local and national grants outside of disability categories, and submits bids to tender for their provision of services. Many of their applications are turned down. Their aims are to educate the Deaf collective in political awareness, and local public hearing bodies about the Deaf collective. They have research links with two Universities in England.

A3

This agency is in receipt of public grants relating to equality and diversity. They find this system difficult. They also secure income from teaching BSL to staff in public (hearing)

bodies. They have links with international Deaf bodies and Gallaudet University. They provide advocacy and outreach services.

A4

A4 submit bids to tender to provide services such as teaching, outreach and youth projects. Many bids fail, as well as funding applications. They are currently financially stable but fight to survive rather than push their own campaigns. They aim for the Deaf collective to be recognised as a business community.

A5

This agency represents Deaf minority ethnic women. The organisation was set up by the respondent and peers. The committee run the organisation and it is staffed by voluntary workers. Their aim is to empower and educate members of their organisation. They have financial partnerships with a neighbouring Deaf led organisation, but still struggle to secure income.

A6

A6 set up his/her own organisation. This agency facilitates local members to set up their own businesses with loans, and funds from the organisation, and trains them in business knowledge and employment skills to manage their own non-profit making ventures, which are linked to the main organisation. The agency also successfully tenders to carry out services for the local authority. It has community development projects within the regional collective. It has political links with international Deaf bodies and project links with local minority ethnic partners.

A7

A7 represents a minority ethnic group. They set up their own organisation. They struggle to secure public grants. One staff member is employed. Their aim is to promote the position of minority ethnic Deaf people in their region. They have political views but cannot afford to focus their time on campaigns or on educating hearing bodies.

Group B: Organisations with Service Level Agreements

B1

This respondent was employed by a hearing and Deaf committee. They have a legacy of hearing church control. This organisation has a statutory social services service level agreement (SLA). The organisation claims 'disability' status in receiving funds, although still struggles to secure income. The Deaf collective side of the organisation runs advocacy and outreach projects. The respondent has political aims of achieving full Deaf employment and is a member of the chief executive lobbying group.

B2

This agency has an SLA with their local authority, as well as deaf service users, having also merged with an organisation with a medical deaf focus. The organisation does not struggle financially. Their projects are designed for both cultural Deaf and cultural hearing deaf people together. There is a liaison and counselling service. The respondent is not involved in political campaigns, but is a member of the chief executive lobbying group.

B3

This organisation has an SLA, as well as deaf service users, it also merged with an organisation with a medical deaf focus. Projects are kept separate in relation to adults in distinguishing the two cultural and language groups, whereas both Deaf and deaf children are invited to join the same projects. The agency promotes political values of Deaf independence whilst receiving community care and disability related funds. Many funding applications are rejected. The respondent is a member of the chief executive lobbying group.

B4

B4 has an SLA and so receives community care funds, and carries out the role of social services for D/deaf people. They seek this income so as to survive financially. They also organise traditional social events for the regional Deaf collective, as well as advocacy, outreach services and forums. The respondent holds a political view of Deaf people as non-disabled, but believes that political action is typically ineffective.

Group C: Organisations with deaf service users

C1

The agency of C1 has a financial agreement with a medically deaf focussed organisation in order to survive financially. The respondent inherited this position of funding and identity. Projects are largely organised separately according to language and culture, so that Deaf collective members can continue to hold their projects of outreach, advocacy and social events. The respondent is a member of the chief executive lobbying group.

C2

C2 also arranged partnership with a medically deaf focussed organisation, so that they have deaf service users, and receive funding with the condition of 'meeting disability needs'. The organisation still struggles to survive. This organisation set up a community voluntary skills swap project, a Timebank, where Deaf, hearing and deaf people can be members. The respondent is a member of the chief executive lobbying group.

Organisations and Vision

An organisational vision can be seen as the purpose of an organisation, described by Silverman (1981:126) in the words, 'an organisation itself (being) the outcome of the interaction of motivated people attempting to resolve their own problems'. Having a vision means for an organisation to have an ultimate aim of challenging established social meanings, towards a fundamental good for the organisational community (Silverman 1981). This section will set out how the three different organisational groupings claim a distinctive set of ambitions for both the agency and a wider collective that they assert some authority to sign for.

The first organisational type (group A), who are financially 'independent', secure funding where possible from public grants and trusts for third sector organisations, or from 'profit' through generated income, and their members and participants are Deaf alone. The shared vision of these seven agencies is to promote the status of the Deaf collective, through

autonomous power networks: '(Such) settings may be most appropriately thought of as a social landscape in which collective actors – i.e. organisations - struggle to increase their control by manipulating their material and ideological resources' (Reed 1992:175). Thus Respondent A2 signed:

> we want the Deaf collective to expect independence. Deaf people are proud of their culture but not so much of their worth. This is as a result historically of institutions' view that Deaf people are inferior and able to achieve nothing.

The respondent went on to add: 'our responsibility is to secure worthwhile employment as a norm for the Deaf... to the extent that Deaf people serve the economy of the nation and our citizens'. Respondent A7 however, presented a different position by way of a statement of financial struggle and issues of risk to survival:

> our vision remains for the Deaf collective to achieve an acceptable position in society, however currently we cannot pursue this actively as our funding has fluctuated, and currently we do not have an active funding source.

This respondent's unique position illustrated their purposeful decision to maintain values of group A whilst not being able to function proactively; in their view they would not compromise to solve their funding conditions.

Group B with four respondents appeared to share the same ideal vision as those in group A, whilst having different functional arrangements in terms of funding and provision, resulting in their aims to achieve their vision likely to be somewhat delayed. Respondents from group B explained to differing extents why their vision may not be achieved in the foreseeable term. Respondent B1 explained:

> Our vision is to develop collective strength and empowerment, to be a part of society on our terms. However we are partly funded by local government community care money, and we also have to apply for partnership money which covers medical deaf issues.

This respondent invoked an obvious conflict between the maintenance of such a vision in contrast with the implication of conditions attached to such funding. Webb (2006:170) questions whether the self-identity of an organisational community 'is as universally fragile and precious as sometimes implied'. One's organisation may be able to tolerate some level of concession whilst upholding one's fundamental purpose in mind, although how effective the organisation can then be in promoting their ideal vision is uncertain (Webb 2006). Such an

organisation however may only be viewed publicly as 'legitimate' or even 'visible' where they are seen to reinforce established social systems. '...within the problematic of control, 'organisations' are redefined as power containers supporting institutionalised structures of dominations and regulation': that is, institutional legitimacy may be 'awarded' only where they are understood according to the social order. A shift in the dynamics of control however invites a perspective of 'the analysis of change and transformation in organisational forms' incorporating the politics of organisation (Reed 1992:186). This shift from established to open perspective can allow a fundamental purpose of 'concern with structural constraint and human agency within one conceptual framework' (Reed 1992:187). Under these conditions, collective Deaf organisations can maintain independent autonomy where unconditional resources permit, and attempt to develop mainstream profile. Where funding is conditional, organisations seek to maintain their ultimate vision, and continue to survive for the immediate-term.

The third group C (two respondents) again expressed a similar vision for the Deaf collective, whilst recognising that the service users who participated with their organisation and received their provision – both Deaf signers, *and* medically deaf people, do not enable either organisation to claim some singular representation of cultural Deaf people. Thus respondent C1 signed:

> our aim is for the regional collective to be in control of their lives. ...(s/he also stated) we are dependent upon the rent of other organisations. Our disabled deaf clients can receive support from our tenant organisations.

This respondent did not want to focus on their medically deaf services users, but rather to focus on Deaf participants, in accordance with the focus of the interview. Reed (1992) explains the problematic position of these social agencies; their desire to achieve their purpose conflicting in some sense with their need to survive: 'The contradictions between generalised mandates and everyday routines, and the uncertainties they produce, must be squared in some way' (Reed 1992:174).

The stated vision of respondent A6 was for Deaf people themselves to challenge their institutionally internalised understanding of their position, and their previous inability to question:

Deaf people's upbringing is to depend on welfare and belief in their dysfunction. We want to kick start their expectations and aspiration.

A similar comment came from respondent A4:

Our vision is for Deaf people to be normal, and live in the mainstream. ...shake them into action!

Both suggested desires to encourage the Deaf collective to think differently, and to challenge what they had previously been led to believe about their own identity and prospects. These respondents asserted their ultimate vision of society adapting to Deaf people, whereby their deep-rooted exclusion would inevitably diminish, to the extent that Deaf people would no longer be labelled or seen as minority members of society (Chukwuma *et al*., 2006; Deaf business representatives contributing to the 2006 Gallaudet University Conference on Deaf Independence). Respondent A3 expressed a similar view:

We work for a sea change where Deaf people have self-belief, *and* the institutional view that controls Deaf people's treatment has changed. There will ultimately be no need for this organisation and I can be a bank manager instead!

This view is reinforced by Ogunjirin (2006:63), who observes that businesses which employ a local Deaf collective will initiate high expectation and skill: 'they will access telecommunications technologies and come up with viable solutions to achieve improved education, services and job opportunities'. The following respondents stated similar views. Respondent A4 signed:

The vision is for members to be integrated citizens, with cultural membership as a celebration, not as a necessity,

and respondent A7 signed:

the vision is of our collective freely engaging in society, and where individuals do not have to experience isolation and anxiety.

Such views find similarity with the work of Choudhury, senior officer of a third sector Deaf organisation, writing in Deaf Worlds (1999:6): 'it is to assist (our clients) to realise their potential to lead fulfilling lives.'

Respondent A7 signed that their primary consideration was financial security before any realisation of vision:

>We can't afford a collective vision – we struggle to carry out our operational goals – that is what we have to focus on.

The ideal of 'vision' does not exist alone; instead conditions may be attached with external dependence. An ideal vision needs to be an achievable target of long-term use, so that tangible conditions mark measurable progress and direction. Voluntarism allows the way for the challenge of structures; this open perspective however does not help organisations to maintain autonomy where there is financial and conditional dependence. Reed (1992:187) writes:

>the theory of structuration is invoked and employed by ...organisation theorists in their attempt to develop explanatory logics encompassing both the enabling and empowering aspects of 'structure', as well as its constraining or limiting influence ...the way in which organisationally specific practices of coordination and control are based on institutionalised structures of power and domination operative in the wider society.

Group B were four respondents (two of whom also had deaf [English speaking] service users) whose agencies received conditional funding and where organisations' visions may have been put forward in accordance with these conditions. This aspect further illustrates a complex formulation of an organisation's fundamental purpose being shaped at creation stage, where there were prospects of change and challenge, which could bring serious instability; hence a preferred effect is permanence, where constancy, rather than political activism allows smooth organisational processes and external partnering structures. Organisational studies therefore allow for a 'pervasive intellectual pluralism' which can consider the range of 'inherent partiality and limitations of preferred choices' of fundamental organisational vision (Reed 1992:188).

Two of the four in this group (respondents B1 and B3) described their individual situations as less than ideal, but unavoidable because of the need to secure continuity of resources. They instead expressed an ideal vision for the Deaf collective which would see Deaf people no longer as service users, or eligible under welfare and disability legislation. Respondents B2 and B3 had service users who were deaf (English speaking users), in addition to their Deaf participants. Respondent B2 described their vision in terms of a contractual expedient, and having consideration for deaf clients who require a medical focus. This respondent expressed their slightly contrasting vision for deaf people (English speaking users) as well as for Deaf people without referring to any cohesive group, referring rather to individuals' needs:

> We aim for independence for all – I would like both types of Deaf and deaf needs to
> be supported.

This last view may have coincided with that respondent's own personal positioning, as both deaf person and Deaf person, where they remained a member of both cultural worlds. This respondent differed in some way from the other respondents, in that their personal identity expressed was one of disability, even though they were aware that the Deaf collective in general does not identify with the label of impairment. Respondent B4, with a social services financial contract but with Deaf members alone, answered:

> Deaf people can lead the lives they choose – whether they work or not. There is no
> need for exhausting campaigning, it never works. Our organisation is at the city's core
> for Deaf people to organise a good social life.

This respondent's answer demonstrated a different angle from all others; there did not seem to be an implied intention for organisation guidance as to influencing Deaf individuals or the collective. This would seem uniquely apolitical compared to others across the three groups.

A further group working with medically deaf people (English speaking users) as service users but *without* a contractual link to conditional funding included two respondents. Respondent C1 stated:

> the perfect ideal would be that we would not need this organisation if all Deaf people
> had full integration opportunities. At the least we would want to campaign for our
> own profile. *But we can't aim for that sort of level here, it's not workable* (my
> emphasis).

The respondent displayed a perspective at odds with their ideal mission, and some pessimism about securing the resources to achieve a vision of a Deaf mainstreamed society. Whilst they did not have a conditional contract providing secure funding, they received funding to support medically deaf people, which may still signify that they did not have a singular and purposive political identity. Both organisational studies approaches of 'system' and 'action' take the view 'that organisations ...are the product of the self-interested actions of their members' (Silverman 1981:39), according to their understanding of who holds the relevant power. A systems theory approach where 'society makes person' as opposed to an action theory approach where 'person makes society' (Silverman 1981:40) takes this possibility into

consideration; the vision of the above organisation appears to be shaped by the view that 'the system' considerably limits the vision that one can undertake.

This section demonstrates the complex difficulty in an organisation creating their purpose, and so vision. Organisational theory allows for organisations which wish to sustain the historical pattern of reinforcing the status quo, as well as those that adopt a purpose of challenging policies and practices, in order to be recognised differently in the long-term. The theory also allows for those who believe they cannot publish and promote a vision that they cannot afford, or who cannot risk political instability as opposed to equilibrium. The thirteen organisations diverge into three groups in terms of their approach to their organisational purpose. The seven respondents of group A stated visions of long-term institutional change, through values of education and empowerment, where the collective are enabled to create this change themselves. The seven appeared to vary in terms of their focus on 'survival'. Whilst one respondent stated they cannot afford a vision because they are not prepared to compromise on principles, another stated that they are twenty years ahead of other organisations because they do not negotiate 'permission' for citizenship recognition, but rather, they establish themselves as 'normal'. Groups B and C varied in their assertions of (a) ideal Deaf political systemic achievements and (b) less ambitious visions of survival in an environment where they are not politically prominent.

Organisational Values

An organisation creates values to define the ways in which its organisational structures and policy are directed. Values stem from one's organisational identity, which is influential in maintaining a long-term grounded position. A review of values is useful therefore in assessing an organisation's lasting identity and position, as well as for understanding its fundamental basis behind operational structure and policy (Webb 2006). Values contribute to an organisation working towards achieving their professed vision. Webb (2006:188) describes how one's identity shapes one's values. The identity fixing process is challenged through an: 'obligation to confront existential dilemmas and to come to some accommodation in relation to them (which can provide) a means of gaining perspective on one's circumstances'. In turn, established values will continue the cause of an organisation at an operational level of policy. Having secured an identity with a particular project for example, the related values will shape

the operational working within the system (Webb 2006). An example of fundamental and operational values - in a post-modern working structure where the culture is more open are:

> network structures, informal divisions of labour, high-trust work relations, participative decision-making processes and advanced information technology. The organisational values which are as a result of the socio-economic, political and cultural development of modern societies ...contribute to strong cultures, ...within solidaristic communities (Reed 1992:228).

The first seven respondents (group A) all had a cultural Deaf focus, in their political, social, economic and language position shaping their projects and services. There appeared a common core within these organisations; of educative values, and concern for their participants to gain skills and knowledge. Three out of four of group B promoted these common values, whilst the fourth of the second group defended the rights of culturally hearing deaf people to equal consideration to Deaf people. The final view was shared by the two respondents of group C who expressed frustration at the limiting parameters which influenced the shaping of their values, whilst also holding similar values to groups A and B, of educative and empowerment values for their Deaf participants.

Of the seven respondents in group A, respondent 6 stated clear organisational core values of Deaf people achieving independence through gaining employment skills:

> The board of my organisation is strongly Deaf led. Our aim is to proactively increase the employability of regional members. ...this is written in our organisational constitution – it clearly directs how we drive forward.

Reed (2006:229) describes the post-modern organisational emphasis with values of: 'expression and involvement, within which autonomy, participation and disagreement are openly encouraged. ...They facilitate the personal development of individuals within collectives ...ranging from staff to (members).' The following approach by Chukwuma *et al.,* (2006), is also to initiate education through work experience, so that one's confident identity can change through new personal understanding; 'our responsibilities are to find jobs for Deaf people. Our system works very well. It has the advantage of serving the economy of our nation and our citizens. Our factories are schools for the training of Deaf people' (Chukwuma *et al.,* 2006:70). Respondent A2 claimed an educative value:

> we aim to change Deaf people's mindset – they can do anything through a new confidence and through their own negotiation.

The approach of respondent A3 included a wider focus, to educate public institutions, as well as the shared self view of the Deaf collective itself:

> our core values are to work on Deaf people gaining equality, based on the collective's *and* society's recognition of our validity. We slowly educate institutions so that they forget their defensive assumption of us.

Ladd (2006:246) reminds the reader of the assertion written two hundred years ago by European Deaf scholars that 'all people are fundamentally equal, and those more fortunate are obliged to fight for the others to have the same opportunities'. The following view from respondent A4 reflected this:

> we educate people about acting on behalf of themselves, in an organised way. We also educate that it is not *Deaf* people who have needs, but that it is the economic need of society for cultures to cooperate and merge on an equal basis.

Ladd (2006:246) invokes another historical claim of European Deaf scholars, 'sign languages are a gift offered to hearing people, so that if they joined with Deaf people and learned them, the quality of their lives would be improved'. This notion suggests that where Deaf and hearing people are integrated to the extent that hearing people understand the Deaf language of common denomination, the economy would be more productive in terms of capacity, knowledge and growth (Cole 1998; Jenkins 2006).

Respondent A6 similarly advocated finding community niches and exploiting market needs, whilst operating a not-for-profit organisation:

> obvious community businesses were needed, such as a cafe, a hairdressers, a crèche; that's where the demand was, and that's why we are successful.

This parallels Chukwuma *et al.,*'s (2006:71) preparatory investigations for their for-profit Deaf businesses, 'we study the market and try to find our niche. We go to larger firms and ask them if they have work for us. We could find a niche for products that we can supply to the government.' Two respondents in group A adopted a more narrow focus than that of community wide empowerment, but still with an educative orientation. Respondent A7 signed:

> We support minority ethnic Deaf people in this area. Our aim is to educate them in areas of self-belief and practical skills. We teach BSL to enable them to gain command of a whole language, and we introduce the collective sense.

And respondent A5 signed:

We support Asian Deaf women. Our core values are reducing hidden isolation and invisibility, and to increase Deaf collective strength for our women.

On examining group B respondents (with conditional funding contracts to deliver support to Deaf service users), all four included the following key aspects when answering about organisational core values. The core value of respondent B3 was:

...the development and progression of Deaf people. I want us to narrow our direction and expand in forward ways, like develop education and employer partners, and so towards redistribution.... I know we can appear as both a cultural and a disability organisation – but that's the situation - we inherited it. My aim is for us to go back to being a political organisation.

In the same way, respondent B1 explained what they perceived as their difficult legacy of having been under the directorship of a vicar, and church control, which historically created a situation of hearing control and a focus on 'Deaf as disability' (Lee 2004; Ladd 2003):

We want local employers to understand the benefit of employing Deaf people. We still have the historical link with statutory social services. *But this will change* (respondent B1).

Respondent B3, with both Deaf and deaf participants, as well as being in receipt of a conditional funding contract, discussed their organisational values:

R We facilitate groups to run themselves. The collective is not formally educated – this is our way of enabling their political autonomy through the development of skills, confidence and responsibility.

I You didn't include your deaf service users in your values, do you feel your organisation's identity is confused?

R Well yes... we've been able to carry on with our principal aims although admittedly we cannot unfairly prioritise signers.

One respondent (B2) had a notably different view about medically deaf (i.e., cultural hearing people) from the three other respondents. There also appeared to be a different level of strategic aim for achievement. In addition there may have been a different understanding of the political aims of Deaf people:

We want Deaf and hard of hearing (deaf) people to be independent, and to achieve what they want through our support. This is obviously different for both groups as they have a different language to each other and different values. But both groups need visual or vibrating alerting devices, and social services pay for this, so really, Deaf people use social services.

The above respondent did not seem to question what money funds social services, or why a system is in place so that equipment is 'needed', or if indeed Deaf people do use alerting devices (which is denied by some respondents, see Chapter 5 page 124). This answer appears to have been different to the view of all other respondents, in assuming that (cultural) Deaf and (medically) deaf people have a similar need of support, and that they can be treated together as one group. Out of the two remaining respondents of four, group B, both respondents represent organisations that have a social services conditional funding contract, and without cultural hearing, medically deaf service users. The first (B4) explained:

> social services contract out to organisations like us – they don't mind us doing Deaf led work... but I do have to attend regular social services meetings, I don't see the relevance of these to me, I don't contribute to discussion outside of our contract.

This respondent's organisational values appeared to seek more short term gains than other respondents. Respondent B4 is aware that they are given permission to carry out some of their work, on a conditional basis. Such statutory monetary agreements impose a label of 'severe deformity' and so disability on all deaf people, where only a medical focus is considered – of which the respondent was aware.

Respondent C2 signed a poignant description of the organisational position, where their ideal values appeared to contrast with their current status quo. The organisation appeared to attempt to continue with ideal values whilst segregating groups internally:

> Our core values are to not be oppressed by those in power, and for Deaf people to gain recognition of self-power and status.... We are however stuck because we had to merge with an organisation for disabled deaf people. But we have continued with our focus on Deaf people – the internal projects are entirely separate.

Values are the operational aims of organisations, allowing the shaping of policy. The thirteen agencies' values ranged from the promotion of cultural Deaf status, particularly in relation to education, empowerment and employment skill to quite different values. Some focused on the promotion of minority Deaf groups, of minority ethnic and women's groups. The general aim of most respondents was to maintain a political focus. There appeared a contrasting value orientation for those who have both Deaf and deaf participants or service users; some aimed to focus more on the political Deaf movement, whilst one diverged in assuming the needs of deaf and Deaf people simultaneously.

Organisational Provision

The aim of this section is to explore the span of service provision offered by the range of organisations represented in the sample. It is interesting to identify differences in provision due to organisation type, and this pattern will be explored. Different types of provision allowed income generation as well as the development of employment skill, education and experience: – these included running private businesses, advocacy, education, teacher training and the teaching of Deaf citizenship and British Sign Language. Silverman (1981:18) describes 'an environment-output typology (that) has been used and applied to 'integrative' organisations... Organisations are distinguishe(d) by whether they are most important for their productive, maintenance, adaptive or managerial-political functions'. That is, the three different organisational types studied in this research may vary in their main functions. All thirteen produced an output of provision, whether to generate income, or to develop a profile of mainstream community action or business. Silverman (1981:18) discusses organisational output differences according to 'who benefits'; these are ' 'mutual-benefit associations' - where the prime beneficiary is the membership, 'business concerns' - owners, 'service organisations' – clients, and 'commonweal associations' – the general public'. An organisation's reasoned definition of particular goals will indicate a primary beneficiary. Collective political development appeared to be a basis for twelve out of thirteen organisations' models of provision – models of development contributed in differing ways across the twelve towards the advancement of Deaf citizenship and participation. The Federation for Deaf People (1998:12) asserts that political organisations do not represent a *community*, as this word implies passive grouping; rather, they work for their *collective*: 'a 'Deaf community' is all fine but of minimal relevance unless it actually influences policies in society. Deaf people (are working hard to) participate fully and influence policies'.

Out of group A's seven respondents who were financially independent and have only Deaf members rather than having additional deaf service users, five have established advocacy based projects. These organisations explained how they view the input of statutory welfare services as controversial, as a conflicting purpose to their own presence. Respondent A1 for example rejected the notion of their organisation as representing culturally hearing people with impairment, and affirmed a model which facilitated an environment of group self-initiated activity:

> The welfare system assumes we are service users *of* society; we fit in as hearing impaired people, and structural changes *do not* have to be made. But we ignore this

whole assumption, we initiate collective advocacy – we give ourselves negotiating power.

The following respondent (A4) rejected the legal/ welfare definition of Deaf people as individuals with impairment, at risk to their independence and in need (SSIW 2004), and in reaction employed Deaf professionals to empower fellow Deaf people in different activities:

> Our advocacy is fundamentally different to social work. We refute the definition of us in welfare legislation. An advocate enables others to act for themselves, by teaching and facilitating.... Deaf people are not reliant on hearing people.

Respondent A2 explained how group self-facilitation allowed authoritative empowerment, which in their view was very much the opposite of what they perceived to be the core function of statutory social work, whereby Deaf people are seen only as individuals (and not an authentic collective) and are assessed for *their own* needs as 'disabled':

> Cultural Deaf participants are not service users. It is mutual collective learning and cooperation. We teach groups political and economic issues, and enable committees to represent themselves in negotiations with public and private sectors to change *their* systems. We do not visit individuals and assess them.

The Federation of Deaf People (FDP) (2000:12) states '...the 'teaching people to fish' principle is adopted in collective organisations with an emphasis on advancement and establishing the human rights of its members.' This observation appears to summarise many respondents' comments. One statement of particular interest was from respondent A5, who heads a body growing organically whereby provision initiated in a volunteer informal setting had gradually become formalised. They described their dual isolation in having minority ethnic status, as well as being Deaf:

> The idea has evolved. We all experienced isolation from both sides, from our own community, as well as the hearing community. This organisation grew from voluntary support I and my colleagues gave to our peers; we wanted individuals to be educated sufficiently.

Amongst group B of four respondents whose organisations have a conditional funding contract with statutory social services there are some notable contrasts and insights. The following two respondents from group B offered similar answers to those of group A, whereby both respondents B1 and B4 signed about projects which did not relate to their conditional funding. Respondent B1 explained their various strands of provision, including advocacy. This may have been significant where they wanted the focus of their organisation

to be recognised as contributing to the cultural collective, rather than to adopt an outside view and to assume a link to the medical definition of deaf people, and consequent services:

> We facilitate self-run support groups; we have an outreach service and some advocacy, and have regional campaign partnerships. We have minority ethnic outreach work, as well as outreach for older members who have been cut off.

Respondent B4 similarly reported projects involving participants as a part of the collective, rather than including provision funded by social services. They also employed advocacy:

> Advocacy comes under our community service. We lobby public bodies to negotiate policy changes. We have regular forums which educate members how to represent themselves; we then take a back seat.

Both respondents' answers may have implied a narrower focus than the entire provision of the above two organisations, either according to the preferred focus of the organisation, or for the purpose of this interview.

The remaining two respondents of the group of four mentioned their services with both Deaf people and 'disabled' deaf people, the first with a focus on education and individual empowerment for both groups, where the service is integrated. Respondent B3 stated:

> We teach sports for young Deaf and hard of hearing people, and through this we integrate their identity issues in amongst that. We also have provided adult Deaf groups with buildings with which to organise their own collective lives.

Deaf adults here were recognised as having an independent cultural collective, whilst young Deaf people were not regarded as having a separate identity to young 'hard of hearing' (deaf) people. This apparent differential approach is an interesting notion and raises the point about when a young person becomes an adult member with a singular cultural Deaf identity. This point was not answered directly by the respondent, where like the above two respondents, this respondent either preferred to focus on the Deaf members, or, there was an assumption of hard of hearing adults' 'normal' blending into the local mainstream community at some stage. Finally, respondent B2 mentioned both Deaf and deaf people purposively as core to the organisation:

> Deaf people don't have to take up our social service if they don't want it – I suppose hard of hearing (deaf) people use it more. We also have Deaf and hard of hearing groups for public body liaison for modernising, and also a counselling service which caters for each language.

Deaf and deaf people here were seen in some sense as more of a composite group, where differences were acknowledged but where a medical label seemed to be a primary focus over cultural identity. Silverman (1981:20) highlights an ambiguity with agency service beneficiaries where priorities may conflict: 'The concern is therefore with efficiency; analysis centres on the degree of 'fit' between organisational requirements and environmental characteristics'.

The exploration of group C provision illustrated interesting issues, different to other agency interpretations of the Deaf collective; here they are seen as a core part of the mainstream community, and thus engaging with people with a hearing cultural identity. This reflects a different ideology through a workable project, enabling an equivalent to an economic monetary system and offering instead a voluntary skills swap project, initiated by Deaf people. This respondent discussed the movement of Deaf people as central, wanting also to include hearing society (and deaf people), and explained visionary community business aims for Deaf people in doing so:

> A significant area is our community 'Time Bank'. We provide required professional skills or services for each other, earning ourselves tokens to pay for other reciprocal services. Deaf people are at the core of this social business – it has become a mini society, open to anyone. This means that *Deaf are in the mainstream* (my emphasis).

The Deaf people central to the Time Bank project became as the respondent suggests, 'normal' mainstream citizens *as* cultural hearing people became reciprocal members (www.timebanking.org 2008). Business advocate Collins (2007:16) agrees that people in terms of services exchanged can replace a monetary system; 'the number-one resource for a great social sector organisation is having enough of the right people willing to commit themselves to mission. ...Time and talent can often compensate for lack of money, and money cannot ever compensate for lack of the right people.' The above organisation (respondent C2) had much in common with another more financially secure and independent organisation (respondent A6) which fits into the first classification of seven, and the provision of which was not influenced by outside partners, funders or conditions. The organisation's model of provision became evident in the course of the interview in terms of its core operational values:

> I Does your organisation have advocacy?

R   That's an outdated idea – that's just an extension of social work. What we have done is set up many Deaf run private businesses. The aim is to professionalise Deaf people as business operators, and to attract mainstream custom. *Deaf people are now normal and in mainstream business* (my emphasis).

Whilst the organisational types of these two agencies were entirely different, both demonstrated their independence in terms of their non-reliance on funders. The first organisation did not need funding because they functioned without a monetary system but instead with cooperative principles, and the second because they functioned on private income of charitable profit. The above two statements are almost identical to each other, for in both Deaf people are claimed to become normalised as part of the mainstream environment. In both, Deaf people were at the core of the enterprise, for Deaf people were skilled providers, no longer seen as 'Deaf' but as 'contributor', and their service being a part of the mainstream. Agboola (2006:75) a Deaf business representative contributing to the Gallaudet University conference on Deaf independence, discusses another cooperative, which appears to be an example comparable to the above two, and which involves paid employment: 'a business cooperative may comprise from two to as many as fifteen or more members, each in specific roles from management to employee. A cooperative may be ideally affiliated with a Deaf association, rather than with a charitable organisation'. This preference of affiliation is discussed in the section on business philosophy and income, later in this chapter.

In clear contrast, a respondent with a social services contract with Deaf participants and without deaf service users (B4), answered,

we provide support to Deaf people to help them to live their lives. A Deaf person working with another Deaf person is a good role model. We also have our community events.

This organisation appeared to have an expectation of their provision contrasting to the above, and one which appeared more in parallel with individual services lead by welfare principles. The aim for provision here may have been to help Deaf people to exist with a bicultural identity, where they could function in the hearing world. Silverman (1981: 20) provides an explanation of agency provision with goals of promoting the norms of society, for example where Deaf people with a bicultural identity can rely on their functioning as a cultural hearing (impaired) person in order to operate in the mainstream: 'the objective factors outside

the organisation can determine the behaviour of its participants (and are) concerned with the problem of the system'.

Business Philosophy and Income

It was important to explore issues of business philosophy and income because these aspects of organisations indicate a fundamental agency approach, and generally indicate whether they are based in a systems or action mode according to organisational social ordering (Silverman 1981:40). That is whether institutional bodies largely shape organisational directions, or conversely, whether organisations attempt to develop their profile and to influence institutional bodies. Webb (2006:6) describes how:

> agency and meaningful selfhood are not eliminated through organisations, but are progressively reconstituted in terms of different priorities and values, notably those of individualism, choice and voluntarism, but also those of personal accountability and responsibility.

Business philosophy is the shaping and thinking behind how organisations decide to operate as their particular agency, according to the level of autonomy that they can establish. Their income significantly shapes who they are able to set themselves up as, and the direction and goals which can become achievable (Webb 2006). Respondents discussed economic aspects of their organisations, and explained their perceptions of required underlying knowledge, as well as methods for learning and remaining in control of financial administration. Respondents explained having varying levels of experience, economic and business skill, which may have significantly affected organisational strategic decisions as to targeted funding, income generation and direction of projects. The literature on (for-profit) entrepreneurship supports the aims and motives of some respondents, whilst for others their community voluntary orientation diverges from running as a business. Business advocate, Collins (2007), affirms that this indeed divides organisations seeking a surplus to operate as a social business, from those which are more of a cooperative or have evolved organically.

Group A of seven respondents who were financially 'independent' diverged in different directions, whereby three successfully made a surplus which could fund other parts of the organisation, whilst others struggled to source all projects with reliance on public funding. Respondent A6 discussed how their businesses had been set up either through their own money, or from a loan:

> The businesses have the same status as charity shops – they can make a profit, which goes back into the organisation. We have either invested in setting up, or used a business start up scheme with a loan: we have provided advice and then withdrawn.

The same respondent discussed their other income, which included receipt of public funding, and independent income generation:

> We have local authority funding relating to equality and diversity. ...We do not claim, '*you must fund us because we're poor Deaf people*'. We also have income from our interpreter agency and BSL teaching services – which we invest in our community development.

Six respondents of seven from group A received grants or bid for project contracts from public funding sources. This involved risk elements of time usage versus application worth; many applications were turned down after a lengthy application process, resulting in no secured funds or contracts. Respondents reported that some grants were only available under 'disability' categories; a decision was made as to whether an organisation was prepared to receive a 'disability fund'. During interview, the following respondent (A4) considered the reasons for their struggle:

> I Do you struggle financially?
>
> R We are currently stable but always have to deal with survival instead of being able to deal with campaigns.
>
> I Is your organisation's philosophy understood by funders?
>
> R We have to apply for available public funding, and expect many failed applications. We would never apply as a 'disability' or 'special needs' group, so much funding is closed off to us. It is frustrating to have to *explain your existence* every time, but more frustrating that we are not moving forward – there is no government recognition of us, funding structures are so rigid – it is difficult to negotiate any changes.

This next respondent (A3) also signed of the frustration of not being understood as a cultural and political group - who have been discriminated against by institutional restraints:

> We've changed our focus from voluntary to social business. I think this is the way forward. The Government can't seem to convert from the social model of disability influence; *we are not related to that.*

Webb (2006:7) writes that external environmental, legal, cultural and public policy influences, as well as internal pressures, set out the path for a changeable philosophy, in which 'organisational elites may set out to prescribe legitimate identities and to shape

common beliefs and desires, but history shows that consent to such prescriptions remains partial and prone to reversal'.

One respondent (A7) stated that they avoided compromising on their principles in order to achieve their aims but that this has contributed to their financial struggle. They were limited in their reliance on grants. Respondent A5 in a similar financially challenged position reported,

> Government money we did qualify for has been reallocated to the 2012 Olympic fund. How ironic, we struggle and are on its doorstep.

Soukup (2006:6) comments on the weak situation of organisational reliance on public funds: 'Service organisations have relied on state grants to support human services. But we cannot expect to rely solely on the government to meet all of our needs.' Collins (2007:25) concurs that grant giving is a weak system, where grant allocators fail to value the worth of third sector organisations; social sector funding often favours limited and small scale projects:

> Restricted giving misses a fundamental point: to make the greatest impact on society requires first and foremost a great organisation, not a single great programme. ...(one's organisational) brand reputation is built upon tangible results and emotional share of heart.

The following respondent A6 indicated a contrary view of what constitutes plausible investment:

> Well, clearly we would wish for government understanding of the collective. It ought to be statutorily commissioned. Instead we are pushed into the third sector as a *charity!* Our collective ought to be invested in as a benefit to the economy.

Ladd (2006 b:246) quotes the fifth Deafhood principle of Deaf entrepreneurs of two hundred years ago; 'BSL is valuable to the economy, because communication through universal language will enable contribution from both hearing and Deaf'. The Federation for Deaf People (FDP) (2000:4) support this idea and similarly state 'being Deaf must be seen as a political issue and not a cause for charity and benevolence. It needs to be seen as an issue of rights and responsibilities. Therefore, it must be tackled through politics and political action and not through begging.'

One respondent (A2) believed government investment ought to reciprocate with a Deaf collective advisory agency:

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> We help policy makers to readjust society's systems to allow our economic contribution, through our education and employment. We should be recognised as an interim social business government advisory agency, with payment to us.

A deep-rooted summary (respondent A3) is:

> ...our treatment is a repeat of Black people's, financially controlled by white people trying to 'help' them to become culturally white. All we want is to become full citizens; we don't want *funding*, we want *investment,* and we *don't* want to become hearing!

Ogunjirin (2006:63) writes that investment could be attained from sources other than the government: 'one needs to work on the possibility of providing funds to Deaf businesses or to work as investment partners in setting up Deaf businesses to counter the imbalance of the lives of Deaf people'. Ogunjirin (2006) writes that Deaf people could improve their life quality through business investment, whether governmental or private.

Four organisations had service level agreements (SLAs) with statutory social services (i.e. group B). This meant a legal obligation to fund the provision of some statutory social work service to Deaf people (see Clements 2000; Neath Port Talbot 2012). Collins (2007:24) states:

> In place of the "fair-price exchange" of the free-market model, those who fund the social sectors can bring an assumption of "fair exchange" that is highly dysfunctional: if we give you money, we are entitled to tell you how to use that money, since it was public funding.

For three of these organisations, respondents stated that they were compromising their principles in order to survive; for the fourth, there was no such stated compromise; rather, this logical financial security enabled the carrying out of their mission. Respondent B1 reported:

> ...we employ hearing support workers to support those deaf who do not sign, which does not assist our profile. Finance and surviving has determined that.... Half our grant applications fail, and we even apply under 'disability grants' – which of course Deaf people are not.

Respondent B2 similarly stated:

> We're partly funded by community care money. This unfortunately covers medical deaf people and issues.... We're not disabled, and yet we're forced to claim to be.

Respondents stated that the consequences of this 'moral burden', whilst securing their financial position, meant having an organisational split in terms of having two different culture and language groups as participants, and:

> of course we have to negotiate with social services and inform them of our plans, which takes away our autonomy (respondent B3).

Respondent B4 whose organisation felt positive about their SLA explained the economic sense behind this rationale:

> We have to fit in with the climate. It's better to exist than to disappear without compromising your principles. If funding came flooding in, we could terminate our contact with social services.

The point made by Silverman (1981:20) (applied earlier), further highlights an internal conflict with an agency's business philosophy and income, and an ambiguity with agency service beneficiaries where priorities may conflict: 'The concern is therefore with efficiency; analysis centres on the degree of 'fit' between organisational (preferences) and environmental (conditions)'.

Group A of seven respondents out of thirteen are financially 'independent' in the sense that they are not beholden to periodic statutory conditional contracts. Six of these seven, however, receive conditional public grants that presuppose eligibility aspects. Organisations need also to generate their own income either by successfully operating in procurement, or by selling services privately to the public or private sectors. One organisation operates as a commercial business, making a surplus with which to invest back into more traditional third sector projects. The next group (B) consists of the four respondents who have a statutory social services SLA, where they receive secure, periodic funding for particular projects which both parties negotiate as to the type of social service to Deaf people that will be delivered. Two of these four organisations *also* have additional culturally hearing, medically deaf service users, in order to attract funding to cover the range of medical and social disability D/deaf issues, in order to fit in to the way society perceives Deaf and deaf people as a unitary type. Respondents from these four organisations however do not necessarily agree with the constitutions which shape these organisations' paths.

Political Mobilisation

Political mobilisation is the desire and action of a collective, represented by organisations to campaign to government bodies about their presence, identity and requirements. Out of the thirteen researched organisations, eleven indicated a political influence inspiring their purpose, to empower their fellow cultural collective to become mainstream citizens. An important question to raise is therefore, how far are Deaf-led third sector organisations able or willing to politically mobilise in a national sense? Also, does this depend on their level of autonomy? To participate in political action, agencies need 'specific organisational forms and procedures for gaining support from the organisational environment, (that is) competition with other organisations, bargaining, co-optation and coalition', Silverman (1981: 18). Silverman supports the idea of politically motivated organisations adopting an action approach, in asserting that their organisational community's presence can educate society: 'an organisation itself is the outcome of the interaction of motivated people attempting to resolve their own problems' (Silverman 1981:126).

There is a noticeable variety of responses in relation to organisations' involvement in identity politics. Deaf commentator and academic Breivik (1999: 21) asserts that Deaf bodies hold a general understanding that their identity explicitly is of a political nature: 'Within the Deaf collective there is an agreement on the general aspects of promoting a cultural identity politics.' This understanding however ranges from local through to international involvement, whilst two respondents (B2 and B4) stated a lack of involvement with any politics. Group A who were more 'independent' as a whole appeared to campaign politically about their organisational mission to achieve mainstream cultural and language recognition, and citizenship, whilst *not* being members of the chief executive lobbying group. Of group B of four, three respondents' organisations are members of the chief executives lobbying group; one was a member of this, yet reported having no significant political ambitions. The two respondents unattached to political motivation demonstrated opposite standpoints to one another.

Only two respondents of thirteen (A6 and A3) referred to aims involving international developments. Soukup states (2006:8) 'there are attempts to branch out on a global basis for the advancement of knowledge ...(there is) value in working with other businesses, partners and universities.' The first respondent signed,

we have made links to Gallaudet University to assist our national campaigns. I believe American society to be more advanced than the UK in terms of human rights.

Dunne similarly writes (1999:13) 'one of the important actions was joining the World Federation of the Deaf, and gathering vital information on Deaf people and their achievements in other countries.' Breivik (1999:22) critically discusses an 'ambiguity' within Deaf identity politics – as to whether a bicultural and bilingual way of life is preferred, or whether the: 'more militant politically correct consciousness promoters – the more purist monocultural approach' is pursued.

Respondent A4 accepted that integrated life was bicultural and bilingual, but in asserting this, the Deaf collective must be recognised for their merits – of a consciousness promoting shrewd business community. This second respondent (A6) refused to campaign with others because of a belief that these were not sufficiently advanced in their outlook and mission:

> We are not politically mobilised with Deaf partners because they are all twenty years behind us. We have an Asian group partner and others, who we set up campaigns with. We also have links with European university departments doing Deaf research.

Some bodies have concentrated on national political development through partnerships. A senior manager in an Irish Deaf organisation, Stanley (1999:40), writes 'the IDS (Irish Deaf Society) embarked on a major organisational transformation. They formed a national council as an umbrella body to share the philosophy and priorities of the Irish Deaf collective. This led to a series of spectacular achievements...' Respondent A4 signed;

> yes, we campaign nationally with our regional partners to Government. Welfare law does not recognise who we are – a national collective with political identity, and who are not disabled! We keep to sectional themes and propose issues.

Soukup (2006:6) describes businesses with a political dimension:

> Businesses that are willing to share the same political mission lead to partnerships whereby businesses and human service models can work together. By using the philosophy of working with businesses to address social and economic responsibilities, we are able to establish our own direction.

Three of four of group B respondents explained their membership of a national body. Reed (1992:229) asserted that such organisations: 'are seen to rely on much more 'emotional' cultures in the sense that they facilitate the personal development of individuals within collectives based on trust, and the relatively high level of risk taking which this involves'. As a senior manager, Stanley (1999:41), states 'only nationally, through Irish Deaf people, the

collective having partnership, and through democratic empowerment, can (monopoly) be achieved.' This assertion can perhaps be applied to the UK. Five respondents stated that their organisations are a member of the political Deaf lobbying body of regional chief executives. Some may feel more committed to this body than others: One respondent (C1) focused on political negotiations to contribute to a united national force:

> We have political and cultural connections with fellow regional organisations similar to us, I am in the chief executives lobbying group and we organise events cooperatively.

And:

> I am a member of this national partnership. We channel our political issues through this – we campaign for changes of law (respondent C2).

Agboola (2006) discusses lobbying governments for the modernising of laws, and the validity of forming cooperative associations. Two respondents portrayed a lesser belief in the group's capacity;

> I think this is worth participating in. Presenting a united front shows that we are part of a political collective. Although I think it will be a long time before they actually accept what we are pushing for (respondent B1).

And:

> we are a member organisation of the national Deaf organisations partnership. Us chief executives meet to agree political principles and the way forward. But we all have our own strict agendas - we have to avoid being closed down! (respondent C2).

Three respondents from group A concentrated their political energy on local lobbying and academic projects: "We definitely have political strength. It is worth lobbying local government, but central government is a waste of time" (respondent A1). Another respondent (A2) reported,

> We have links with (two English Universities) and we participate in managing research projects. There are other regional Deaf organisations we are partners with, but they fear us being too radical!

Some respondents foresaw problems with Deaf generic political campaigns:

> It's difficult because our visions are so different from other groups – we are so group specific. But we have a regional partner who we can campaign with on Deaf existence issues (respondent A5).

Respondent B1 signed of their perceived inadequate partnership position where their autonomy was limited:

> We're a member of a consortium of Deaf organisations, who campaign on our behalf – I represent my organisation on that campaigns board. But we do have to consider medical deaf issues, which is the drawback.

Two respondents notably reported seemingly opposite apolitical views to all others, based on their conceptions of the status quo. One was from group A, and the other from group B: Respondent A7 signed:

> I mean, I know how important politics is in the long term for our recognition and investment in us, but we are too busy trying to survive – we have to prioritise our reactive demands.

In this section of the interviews, the final respondent (B4) stated a contrasting view to all other organisations given that s/he believed their organisation was a member of the Deaf collective but that they refused to campaign, believing others were "wasting their time":

> R I am not political, and I am not interested in political mobilisation. I don't see why we should try to prove ourselves to a government who refuse to believe we exist.
>
> I Do you think you may be unusual in having this view as a chief executive of a Deaf controlled organisation?
>
> R I might be, but we survive. That is what organisations should be concerned about. We have to look after our own interests. I know who the political ones are and they can continue wasting their time.

Group A maintained a varied interest in political mobilisation. No respondents from A were members of the chief executive lobbying group. Two respondents identified with a dual identity which they believe may not have been represented by mainstream Deaf bodies. Three respondents stated having political links with other bodies and two believed the national chief executives group not to be activist enough. Three out of the four of group B were active members of the UK chief executives group. All acknowledged the culture and language differences between Deaf and deaf people, and two did not mention their medically deaf service users when explaining their organisational provision. All stated that this position continued from a legacy of either hearing control or of previous partnership with social services. The final two agencies out of thirteen (group C) had medically deaf service users and agreements with deaf organisations. The second asserted strongly political views, whilst the first demonstrated views which were more apolitical.

Professionalised Level

Professionalisation means the improvement of the collective knowledge and skill set of the organisation (WCVA 2011). Reed (1992) explains that increasingly, professionalisation is combined with bureaucratisation and that the two are often judged to have a flexible connection. Bureaucratisation is seen as beneficial in regulating and securing an advanced, controlled mode of administration. Together the two establish an 'organisational rationalisation', that is 'a long-term trend towards ...abstract, codified, and integrated systems of surveillance and control' (Reed 1992:207). A particular level of analysis of interest here, relating to such professionalisation, contributing towards the promotion of organisational rationalisation is in regard 'to the overall impact of changing professional powers and ideologies on the structures of domination and control which determine the distribution of allocative and authoritative resources within modern societies' (Reed 1992:208). The aim of professionalisation here is to secure the mastery of a knowledge, an identity and a skill set, whereby an organisation can persuasively influence government bodies as an authoritative advisory association. Agencies discussed attempting to secure such a status with influential authorities affecting their communities, ranging from local to national.

It is more difficult to classify organisations in this context, partly as each respondent commented on different aspects of professionalisation such as: structure, accountability, communication, working methods, third sector organisational knowledge, evaluation and staff training. A brief selection of respondents' statements is now presented. Nor did the views of respondents here appear to slot neatly into the three organisational classifications of this chapter. For example, differences did not appear evident as shaped by whether or not they had a statutory SLA, or indeed had deaf service users. Respondents across the three groupings stated similar objectives of needing to satisfy performance indicators, and of having limited educational and training opportunities with which to upgrade staff to higher levels. The general aims of all organisations were to have successful projects and an accountable organisation run by qualified and trained staff.

Chukwuma *et al.,* (2006:69) state that employing one's community requires knowledge and initiative in every relevant aspect: 'To be able to create money and jobs to give to other Deaf people, you have to know the economy. You have to know how to organise jobs and manage them. You need to know overriding civil policies, and (inter)national politics and work within

the framework.' Respondents discussed their organisational structure and accountability where organisations varied in size and complexity: "We have two tiers of management, and a board of trustees. Our formal structure and constitution directs our way forward"; "we are accountable to the Board of trustees; there is myself and then my staff under me" and "as chair, I guide the implementation of our stated priorities and principles. We minute all committee meetings, and staff record all work." The next respondent focused on a language issue, contributing to the communication flow and accountability of operational working:

> We have a formal hierarchy; we have managers of different projects and operational staff, myself and the Board. We have a few hearing staff, they use interpreters.

The last point is interesting in that it was the *hearing staff* that were presumed to need interpreters. The following Deaf person became a senior manager in a mainstream business in the US, and reports a similar perspective:

> When I first joined (the) export business I was often sidelined from participating in meetings... because of lack of communication. To overcome this, *I decided to teach ASL to my office staff so that we could communicate*. I also taught them the importance of an interpreter for use in meetings or in making calls (my emphasis) (Kejriwal 2006:64).

It is interesting here that even though American Sign Language (ASL) is the minority working language of the company referred to above, the individual Deaf manager adopts the view that hearing staff need to be able to communicate with their manager, in their manager's language. An opposite audist view would after all see the *Deaf person* in need of an interpreter to access the 'universal' language (Sainsbury 1986; Harris 1997). Staff are also educated that it is not the *manager* who needs an interpreter, but all staff including external partners.

One respondent focused on the importance of knowledge of competition, marketing, and the creation of products as mainstream providers. '(A business should) look at its competition... stay abreast of what is new, and adapt. ...Keep an open mind and be creative with its plans, and stay one step ahead' (Chukwuma *et al.,* 2006:71). This respondent similarly believed:

> Marketing is essential in selling Deaf politics training. Marketing is about making them want it, and from *us*, rather than from anyone else – make them have an urgent need to gain that knowledge, i.e. their custom base will increase, and their profile will improve.

The above respondent focused on marketing strategies which included being fully knowledgeable of the strength of the competition, in order to be successfully persuasive in selling a product. Once a product became known, its identity brought supposed power, according to the desirable social values associated with it (Webb 2006).

Reputation was another aspect brought up as crucial to significant working practice in respondents' organisational operations. Chukwuma *et al*., (2006:68) verify this; '(We) developed a network of people... your reputation is everything. If you have a reputation for doing good work people will have faith in you.' A further respondent signed of the reputation their organisation built up, which resulted in an external partner's investment in their project:

> we were previously frontrunners to the new procurement direction – I proposed to the children's service director that we run a long life families project. We set it up ourselves – then the Council purchased the service from us: *it was on our terms*.

This demonstrated another pivotal point, namely that this product reputation was by 'normal' producers. There was no mention of providers being Deaf, and that beneficiaries of the project were mainstream families. Even on a local scale, organisational 'identity construction' could contribute towards one's business strategy and could determine aspects of financial viability:

> The phenomena of organisational identity, branding and image-making are presented as deeply concerned with the rediscovery of vision, imagination and creativity in rationalised organisations, but in practice they rely on extending rationalised control into the sphere of identity construction (Webb 2006:60).

Respondents discussed their incorporation of consultation and evaluation:

> We have grown in size, and in professionalism. We have a consultation forum on planning our organisation's development – they feed into the Board and have a direct influence on the direction we go in.

Respondents appeared to integrate evaluation for three basic purposes: firstly for required statistics for external funders and partners, secondly for internal poof of project success and for research and development purposes, and thirdly for the sake of those who work as a parallel social business, measuring aspects of commercial value (Webb 2006). The following indicates a pattern of respondents' reports collating pre-project required statistics as conditions of funding – in either statutory or grant sectors:

> The evaluation we provide for the council is based on their performance indicators – for their quality standards. We comply with monitoring compulsory aspects.

The second reason for evaluation is illustrated as follows:

> We record information and statistics for proof of service take-up, and we collect continual feedback from forums and meetings. This is partly for evidence to show policy makers that Deaf people exist.

The final statement demonstrates the third reason for evaluation:

> We are commercial, so it's simple. Customer satisfaction is shown through regular custom. And of course the better the business is running, the more confident the managers and staff.

A key challenge facing all organisations is the recruitment of appropriately qualified and able staff. This was a particularly acute difficulty for most agencies in this study. All respondents commented on how one cannot expect to employ a ready qualified and experienced staff member for an advertised post, as well as how difficult it was to access relevant staff training courses at all easily. All respondents comment that their own expertise comes from their previous work experience, some in mainstream companies, rather than from having specialist training, although many have obtained subsequent qualifications whilst in post: One respondent signed:

> Deaf people don't have access to universities, and so Deaf organisations are not seen to be 'professional'; it is difficult to access required professional aspects such as studies in collective advocacy, teaching, accountancy, human resources, and politics.

Lane *et al*., (1996) argue that Deaf people are under-educated to the extent that the prior attainment of an academic or vocational university education is rare, rather than the norm (see chapter 2, page 40). 'One-off' academic professional Deaf management courses are organised, inviting existing senior Deaf professionals to attend. (See for example 'Deaf Managers – Facing the Challenge, How Deaf People Can Succeed in Management' taught and facilitated at Heriot-Watt University, Edinburgh, 2011; Padden-Duncan 2007).

No respondents reported recruiting staff that had direct external credentials qualifying them to carry out their post. All organisations reported arranging internal training for staff, with five organisations having their own accredited courses. This respondent stated the value they placed on staff knowledge, and priority in training:

The most important aspect to us is the quality of our negotiations, campaigns and services. We need a high profile, which requires a good level of qualifications: Staff training is our responsibility and an investment.

Another respondent commented along the same lines:

Our training budgets are not significant but we aim for staff professional development. We have accredited our own qualifications on community and youth work which staff can achieve.

The following respondent may have been unusual in teaching the content of business management qualifications internally to staff;

we have taught business planning, the principles of business operation, budgeting, managing accounts, cash flow and two year forecasts. That's enough to set up a community business.

Another respondent concentrated on staff maintaining a forward knowledge of communications technologies: "We have technology training so that we can be up to date with ICT". This respondent focused on the appropriate language of education: "We have basic qualifications leading upwards, trained by Deaf people in our language". Finally two respondents stated their aspirations relating to professionalising their profile: "We have accredited advocacy courses. We wish to raise the level to diploma to qualify staff at a higher level. I want us to be seen as the professional equivalent to social work". And "I can't send staff to get training qualifications, but we have high quality in-house training. The world needs to know that our staff act in an accountable, standardised way. Recognised professional level is vital in us gaining credibility". Credibility and professional status, and ultimately power, may be secured through 'credentialisation' as discussed by Reed (1992:208):

The 'credentialisation' of an occupational group through formal training, qualifications and demonstrated competence are crucial to its success in establishing 'professional' status. ...The ability of a group to establish, protect and extend an effective 'jurisdictional claim' relevant to organisational performance is (equally) seen to be crucial.

All thirteen respondents shared a belief in their collective identity, their language and cultural status, as well as recognising their low socio-economic position in society. All organisations struggled in establishing their profile, and being recognised institutionally. All respondents experienced (varying) vulnerability because of their limited qualifications; similarly staff qualifications and training was restricted, both according to language accessibility, external cost and societal preconceptions (Perry 2001). All agreed that professionalising their

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existence and provision would assist and contribute to their 'professional' profile and status. All believed that it is possible for Deaf people to integrate in mainstream society, either through society integrating with them and learning their language (Ladd 2006b), or by Deaf people learning to be fully functioning bicultural people, and rely on English – as the majority spoken language (Breivik 1999).

Conclusion

Whilst there are evident categories within which to locate particular respondents and their organisations, classifications are not evenly distributed, and respondents vary within and across the various groupings. Agencies generally adopt a political awareness of collective standpoint. All organisations are Deaf controlled – although external economic, political and geographic factors influence the directions in which organisations travel and the risks and balances that they consider. This chapter also explored individual respondents' aspirations and influence over the directions in which their organisations travelled. The sociology of organisations has provided a theoretical foundation upon which data are based and analysed here. Reed (1992:187) writes of a:

> more 'open' view of organisational analysis (which) has reinforced a reawakened interest in the general intellectual resources (of) the social sciences ....(that is,) the shift from determinism to voluntarism has been located within a sustained search for a general theory of action.

It is not only (or wholly) an action approach that is a core theoretical perspective for some of the thirteen organisations in question. It would seem that group 1 fit into this initial category, whilst groups 2 and 3 may generally adopt a systems approach, for they accept that 'society makes person', and they accept the need to moderate ideal visions and aims in order to remain in existence by working alongside the established order (Silverman 1981:40). The limited social science literature assessing Deaf controlled organisations is taken from the parallel for-profit sector. There is scant social science literature on third sector Deaf organisations although supporting sources on Deaf entrepreneurialism and business cooperatives, as well as on mainstream third sector organisations, provide relevant information linking with the data of this chapter.

In summary, the thirteen respondents were divided into three classifications based on autonomy, financial source and viable stability. These three aspects appeared to be significant

factors in shaping agencies' vision, values, and subsequent provision. The business philosophy of an organisation generally explained their position relating to their income, and their approach towards political mobilisation linked to this philosophy. Organisational attitudes towards professionalisation merged across classifications since all groupings and respondents aimed to professionalise their organisations to an optimal extent, where institutional pathways, as well as finance, allowed. Organisational studies allow the consideration of a range of 'inherent partiality and limitations of preferred choices' in terms of the adoption of the fundamental organisational vision of a third sector Deaf led organisation (Reed 1992:188). Also, the value orientation of the organisation would seem to take prominence with regard to the way that being Deaf is to be externally constructed and deployed as both knowledge and practice within any particular agency. This would suggest a responsibility by Deaf organisations to promote their fundamental beliefs through a workable system, so that mainstream institutions can receive a Deaf political message through organisational provision and promotion. Twelve out of the thirteen organisations focus on collective political development, although their mainstream visibility and therefore significance is questionable. One's business philosophy shapes the extent to which organisations calculate their chances of securing funding, and surviving independently according to their goals. Arguably their income ultimately shapes who they are able to set themselves up as, and the direction and goals which can become achievable.

A fundamental aspect unique to Deaf organisations is that there is no official view of Deaf people in terms of their collective, and of the way they see themselves (Ladd 2003). Instead, Deaf people are legally individuals with hearing impairment, and therefore, disabled according to public policy. For this reason, Deaf organisations do not receive public funding or investment based on any specific understanding of local or regional agency representatives of the Deaf collective. In all organisational aspects discussed in this chapter (vision, values, provision, business philosophy and income, political mobilisation and professionalised level), all thirteen Deaf organisations expressed challenges characteristic of other third sector organisations which are publicly recognised and represented by third sector representatives. It would appear that a pivotal aspect for all third sector Deaf organisations is their establishing of credibility, which shapes public profile in terms of authoritativeness in this unique area where Deaf led organisations hold a monopoly. A question then is: do they establish such credibility as autonomous bodies where they are seen to represent holders of a medical

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impairment, or where they are agents of social services, working according to the legislative hearing impairment principle? Yet equally, do organisations establish credibility where they struggle to secure continuous independent funding, and their focus becomes fundraising over development? In seeking answers to some of these critical questions we now turn to a view of the Deaf collective and its organisations from the standpoint of hearing elites. As we shall see, matters of funding, function and credibility for Deaf organisations depends to a considerable extent on the perceptions and assumptions held by policy elites who make decisions about funding such agencies. It is towards this sector and its key players that we now turn.

Chapter 7

"You have to …give the best value for what is tax payers' money": hearing policy, funding and public sector orientations towards the Deaf
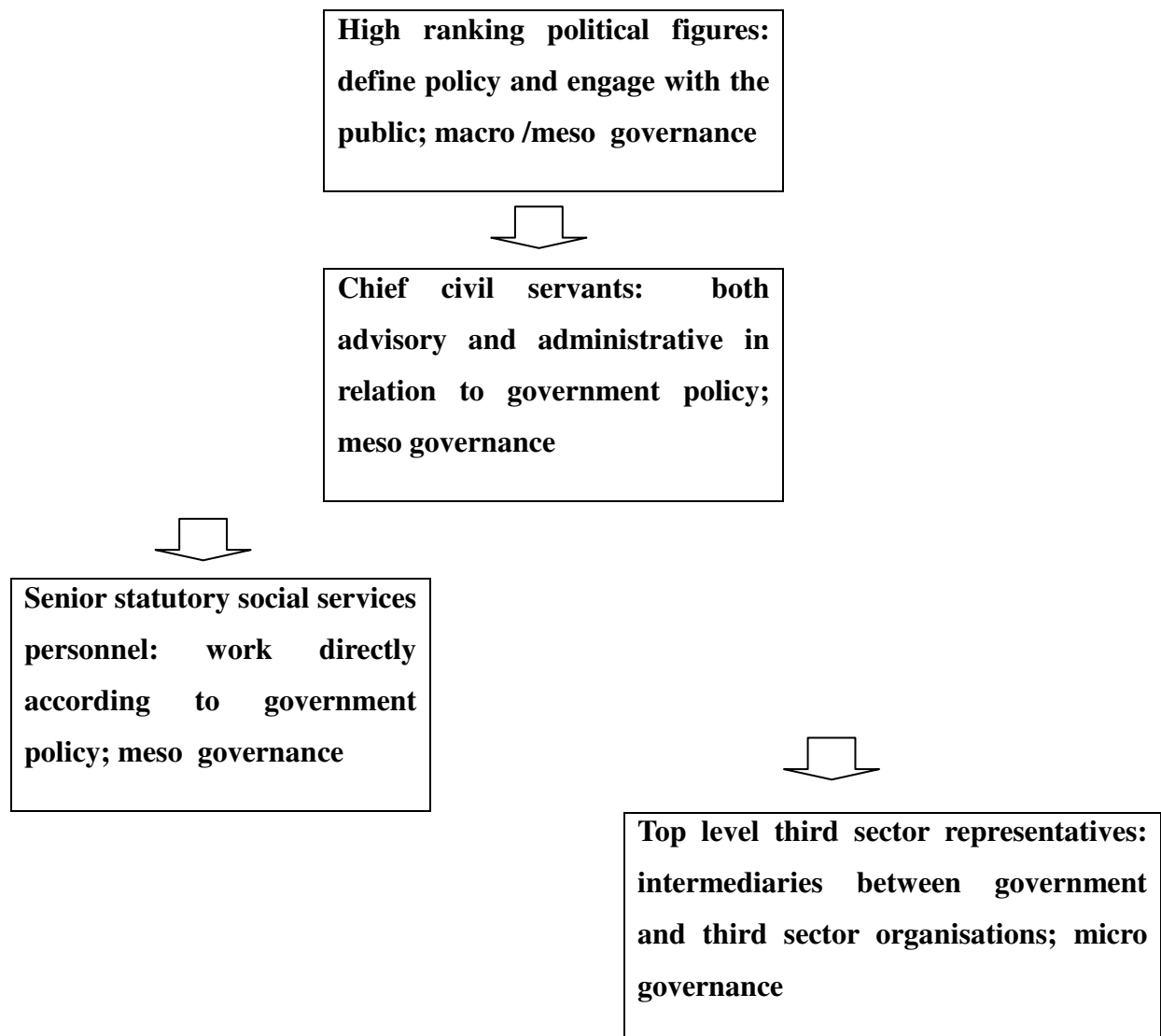
Introduction

This chapter presents findings from phase two interviews with nine hearing senior decision makers concerned with policy development and funding for public sector services. They were interviewed because their decisions directly or indirectly impact on the Welsh Deaf collective. As reported in Chapter Four, these include people working in four public welfare service sectors that bear upon Deaf people: the Welsh Government, the civil service, third sector umbrella bodies and social services departments within local authorities. The nine respondents are selected from Wales to supply a sample of perspectives that are claimed to be not untypical of British welfare institutions. Phase two interviews with hearing elites provide an insight into how existing forms of knowledge, collaboration and engagement in policy processes impact upon Deaf organisations and individuals. Elite perspectives reveal how institutionally established values might shape system, policy and resource allocation. As with phase one respondents, gender is not made known in order to ensure anonymity and to avoid gender stereotype assumptions. A diagram classifying the four participating sectors/organisations and associated hearing respondent backgrounds is presented below.

The quote in the chapter title sums up a general attitude inherent in the interview data. The respondent making this statement, like other phase two respondents, assumed the default position that hearing people decide what is best for Deaf people. A hearing person has the power to prioritise policy while Deaf people are deemed to 'need' support. This respondent was arguing that all policy decisions have to be based on grounds of monetary efficiency, implying that first, it is hearing people who can calculate this, and secondly, that Deaf people are to be assisted in financially monitored terms. The title quotation implies that individual tax payers who contribute to the funding of public services are largely hearing people and that accountability for spending is based on the majority norm.

Each respondent is identified individually in this chapter with pseudonym initials rather than from a possible fourfold classification: high ranking political figures, chief civil servants, senior statutory social services personnel and top level third sector representatives, in order to ensure anonymity.

The direction the interviews took depended to a large extent on respondents' policy or decision making role. In-depth interviews are rarely standard and data reflected the mood, personality and style of each individual. However, recurrent patterns and themes across the interview sample did emerge. Respondents' perspectives shifted between what they felt were their personal and professional views, and what they believed ought and could be the case in future. Five sub-themes are explored: The definition of Deaf, Deaf policy making and funding, engagement with Deaf organisations, Deaf representation, and Deaf Support. Each section is supported with an introduction and conclusion. The purpose of this chapter is to examine the views of nine hearing decision makers whose institutional role affected Deaf organisations and their members.

Hearing respondent bodies: public sector structure

> **High ranking political figures: define policy and engage with the public; macro /meso governance**

⬇

> **Chief civil servants: both advisory and administrative in relation to government policy; meso governance**

⬇

> **Senior statutory social services personnel: work   directly according   to   government policy; meso governance**

⬇

> **Top level third sector representatives: intermediaries   between   government and third sector organisations; micro governance**

Hearing respondent backgrounds

Group 1: high ranking political figures in Welsh Government

R is a Welsh government minister who generates social policy and engages with the public. R is open to the notion of Deaf people as existing differently (culturally / linguistically) from those with hearing impairment, but works according to their briefings and established knowledge.

S is also a Welsh government minister who generates social policy and engages with the public. S understands Deaf people as hearing impaired individuals who would have no need to become a purposive group. S believes that Deaf people are represented on the third sector partnership council under disability, and specifically under impairment.

Group 2: chief civil servants in Welsh Government

T is an administrative senior civil servant charged with decision making about funding. T understands Deaf people as individuals with hearing impairment, and fitting into the social model of disability. T believes that a transformation of the established welfare system regards removing deaf as 'disability' is not possible.

U is a senior advisor in a ministerial department who advises on policy making. U is interested in Deaf people existing in the manner of a purposive group, within the social model of disability.

Group 3: senior statutory social services personnel in Welsh local government

V is a chief officer in adult statutory services. V understands Deaf people as legally being individuals with need and at risk of their own independence, and endorses Deaf community partnership with social services, albeit in a secondary role.

W is a chief officer in adult statutory services. W believes that a lack of speaking and hearing implies a lack of independence and need for social care, and that a change of D/deaf label would not change the impaired identity of Deaf people.

X is a chief officer in adult statutory services. X understands Deaf people as having a community, whilst needing support as individuals who need to access mainstream society on an individual basis.

Group 4: top level third sector representatives in Wales

Y is a senior advisory officer to third sector bodies, and representative to the government. Y understands Deaf people as being part of a collective, although without confident knowledge through which to engage with or advise them. Y has had some involvement with a Deaf leader.

Z is a senior advisory officer to the third sector partnership council. Z understands Deaf people as being part of a collective, but again without confident knowledge with which to advise them. Z believes that Deaf people are not represented by the third sector partnership council.

The Definition of Deaf

A general institutional perception is that Deaf people who use British Sign Language are actually hearing individuals with impairment, and disability. They are not generally seen as being a part of any collective with a different identity (see also Harris 1997; Sainsbury 1986; RNID 1999; SSIW 2004). In exploring definitions of what it is to be Deaf, this section explores the ways in which senior decision makers think about 'deafness' as a medical problem shaping Deaf people's status in policy. There were differences between interviewees' views and this section also assesses a minority of respondents who hold contrasting views to the others, and the likely implications of this. The idea that a medical perspective is so authoritative, shaping the perspective of decision makers in terms of their understanding of the definition of Deaf people, is explored here. Seven out of the nine respondents saw Deaf people as individuals with sensory impairment, compared with the other two who partially understood Deaf people more as being part of a political collective. The two respondents answering differently were both senior representatives of the third sector, whilst senior representatives of Welsh political governance, senior civil servants and senior statutory sector representatives tended to hold more established views based on a medically defined view of deafness.

Mishler (1984:55) asserts that 'the pervasiveness of medical bias in interpretations of medical (assessments) makes it difficult to propose an alternative perspective....' The medical profession's view and authority remains a substantial influence in establishing the status quo, influencing systems, and thereby shaping the ways in which Deaf people are treated and

regarded. This view suggests that the technical-scientific assumptions of medicine as shaping the social order, contradict a part of the 'voice of the lifeworld' – in this case those of Deaf people. Gergen (2000:204) explains that:

> metaphorically, we are asked "to explain ourselves" in terms of the dominant ideology. As we answer ...our state of consciousness (is) absorbed by the ideology; gradually we come to reproduce the dominant order in our words and deeds.

This may allow 'us' (non-Deaf people) to explain the generalised belief in the medical hearing impairment of Deaf people, where the observation is that someone cannot hear or speak the dominant language. Respondent T stated their assumption of Deaf people as having a medical sensory issue, and of all deaf people as having a core aspect in common:

> I: What do you see as the difference between lower case d and upper case D?

> T**:** In that sense, it's only the degree of hearing impairment.

Similarly, respondent W displayed the view that lack of hearing and speaking implies lack of independence, and need for social care:

> We recognise that other people do not need social workers, they are quite able in themselves. It is only a question of impairment, and a question of communication.

The normative assumption may mean that the majority way is perceived to be universal. In a similar vein, there could be an assumed universal individual who amongst other 'rational' characteristics (Gone *et al.,* 1999, Brislin 1996) is also non-Deaf. Lister (1997:66) comments that 'the universalist cloak of the abstract, disembodied individual has been cast aside to reveal a definitely male citizen and a white, heterosexual, non-disabled one at that', and again no doubt non-Deaf unless Lister's own assumption of the universal understanding of 'disability' includes Deaf people, in which case the cloak incorporates abstract individuals without 'hearing disability'.

Lister (1997) discusses the gender differences which become apparent when each person fulfils their capacities as citizens. Rather than adopting a negative exploration of entrenched male controlled systems, Lister focuses on the successes of women, and the adapting and modernising of systems, when this need is accepted. In a parallel way, and in polarised contrast to the above responses, some phase two respondents identified useful Deaf mainstream involvement (Y):

A Deaf person joined our [named] committee, and that in itself was enough of an education for the rest of us. I can see they are an intelligent collective who have much to contribute.

Another respondent Z similarly stated:

I think it's vital that a Deaf representative is on the [named] council; but in wider terms, how will decision makers turn their views around and *really* know who Deaf people are?

Deaf people seen as hearing impaired

However the common understanding of Deaf people amongst respondents, apart from those representing the third sector, held a traditional medical view of impaired individuals, possibly in need of social care. Respondents from the statutory sector were clear (X):

whether they've got mental health problems, whether they are deaf, whether they have got a learning disability, the process of assessing social care services is the same.

And from this section of the interviews,

I: Do Deaf people *who sign* have sensory impairment?

X**:** That's the way the system is organised. Being Deaf might be one of their risks to independence.

Finally, V stated:

our role in terms of statutory responsibility is predominantly providing an assessment service, and ensuring *people with signing needs or whatever you want to call them* – get access to our services. ...We're there to provide responsive social care services (author's emphasis).

The assumption here was that deaf people (who use English) *and* Deaf people (who sign BSL) both have need which is so apparent, that their sensory impairment doesn't need to be explained.

Understanding or ignorance of the Deaf language?

Gergen (2000:53) writes of mainstream assumptions based on reinforced views of the normative way of needing to speak and hear, to be 'normal'. The science and medical worlds provide the 'rational supports' needed to establish and maintain this view: 'we develop a natural attitude, ...a sense of a natural, taken-for-granted reality (based on our socialisation of)

conceptual understandings of the world and rational supports for these understandings.' This is illustrated here with the following interview extract:

> I: do you see a difference between deaf people who *don't* sign, who use English, and class themselves as impaired – and Deaf people *who sign*, and see themselves as a different language and cultural group?
>
> S: Well that's obviously a communication skill that some have and others haven't. *No I wouldn't think so.* They *all* have impairment.

The respondent's view reflected Gergen's above statement that one measures others' positions based on one's own experience of what is the 'natural' way to function (see also Brislin 1996). Where it was suggested to the respondent that one group have a different type of language, this was discounted. This point also illustrates how little is known in public circles about the British Deaf language and that there may be an assumption of English or the predominant spoken language as the universal language. Another section of interview with another respondent T similarly illustrated both the above points:

> T You keep saying 'deaf people who sign'.
>
> I Yes, those who sign British Sign Language...
>
> T But why is your focus only on those deaf people?

Deaf people's 'need'

Fitzpatrick (2005:156) uses the philosophical standpoint of naturalism to deny a welfarist claim; 'social disadvantage is misleadingly attributed to the physical properties of (perceived) disadvantaged bodies.' That is, welfarism has offered a generalised given that Deaf people, seen in a mainstream view as having an individual communicating disability foretells their social deficiency and weakness, and inability to contribute as productive citizens. It also implies a 'natural' automatic need of social care services. In contrast, Fitzpatrick derives from naturalism that no values can be put on nature, (or for instance being Deaf) (Fitzpatrick 2005). Borges (1986:28) endorses this view; 'medicine, like science, permits the rational control of the individual under the rubric of caring and protection'. An (arguable) illustration of this might be rooted in comments by V:

> I'm less bothered about the label 'sensory impairment' as being 'incorrect', than I am about giving social care to someone *needing* support (my emphasis).

Spicker (2006:57) writes that 'the idea of 'need' is value-laden, and profoundly ambiguous.' It may be relatedly held that it is the social care identification of 'need' which leads Deaf

people from being categorised as individuals with impairment to being classed as being at risk to their own independence (Grosjean 1996; Blee 2007). The scale of such 'need' may escalate according to age of 'affliction' as one respondent U explained:

> The degree of deafness is in the sense of when in life it struck you... so there isn't a single category of need.

Fitzpatrick (2001:10) observes that 'it seems nonsensical to describe welfare as strongly objective since this is equivalent to claiming that Jack can be in a state of welfare even though he does not actually know it or feel it himself.' A parallel perspective could be the general Deaf view that they themselves are *not* in a state of welfare, but judged to be so by the majority non-Deaf culture which has the power to make an 'objective' decision (Lane *et al*., 1996; Roots 1999; Ladd 2003). An 'objective' measure of welfare is based on the opportunity to achieve, and of *what* (core type) achievements are secured (see Care Council for Wales 2007). One respondent X from local government asserted some unambiguous process for an assessment of an individual's state of welfare, from the relevant social services team:

> They're dealt with via the *physical disability and sensory impairment team*. People are assessed for eligibility of social care services; if they're eligible... then we have a responsibility to provide services that meet the individual's needs (author's emphasis).

The general welfare measures for Deaf people seem to be for opportunity and achievements relating to 'sensory functioning', based on the needs that majority non-Deaf people have for functioning: again, 'in scientific writing there are particular literary forms or devices that are accorded high status in terms of "truth-telling capacity" (Gergen 2000:56). An example of this is where respondent V's positive approach was to *not* focus on the non-functioning abilities of individuals, and rather, to attempt to empower these individuals. There remained a core assumption that these individuals have a default status of dis-ability:

> I mean our culture would be to try to move away from notions of disability and look at empowering vulnerable people and enabling people to fulfil lives in the community, *without majoring on disability* (my emphasis).

Respondent W explained how significant in practice the label of sensory impairment is seen to be by statutory welfare providers in anticipating service users' views. The entrenched nature of a previously unquestioned label appears to be treated as the universal default, and encapsulating the status of the relevant service user individuals:

> I: What if Deaf people don't accept the label of 'sensory impairment' or 'communication needs' but require a care package according to a domestic care need?

> W: I think pragmatically, if those terminologies meant that people wouldn't use those services then we'd have to think about that. But service users probably wouldn't want to challenge the significance of the terminology.

Fitzpatrick (2005) explains a theoretical process parallel to the collective socio-economic position of Deaf people: situations of under-education and under-employment are in a sense justified where Deaf people may be seen as owning and thereby contributing 'impairment' to society, which in turn prevents their economic contribution, and forces their 'invalidity'. There may be no possibility of recognition of whole scale measurement for such societal statistics, because Deaf people are seen not as a collective, but as impaired, hearing individuals who are not expected to achieve what a 'normal' hearing individual could (Roots 1996; Baker-Shenk 1986; Thoutenhoofd 2000):

> That (perceived) health inequalities relate strongly to social inequalities has become well established... Moral regimes underpin such distributive patterns. ..those who are deemed to be controlled *by* their bodies are regarded as second class citizens at best. (This links to) state-induced dependency, (and) reinforces injustice (Fitzpatrick 2005:156).

Understanding of the social position of Deaf people

In a similar sense, there could be an assumption of the predominant 'natural' culture also as the universal way. For seven respondents there appears to be an ignorance of Deaf people existing as a collective, *or*, there is some acknowledgement of it whilst assumptions of individual impairment are maintained. The following respondent S displayed a literal ignorance of any claims by Deaf people to exist as having any sort of separate identity:

> I don't think anybody has actually come along and claimed to have a separate cultural group... the organisations of representatives of deaf people haven't come to us and said 'you know we regard ourselves as being a distinct cultural strand, and consequently the implications of that are a, b and c...' That case has never been made.

Another respondent T similarly expressed their knowledge of Deaf people according to their own institution's understanding. Instead of being moulded by Deaf people's understanding of themselves, the formal categorising of Deaf people operated in accordance with the universal application of the social model of disability, in relation to people who are judged to be disabled, stemming from their medical position:

> I: Deaf led organisations do not actually believe in the social model of disability as applying to them...

> T: They haven't adopted it? Well that's odd because - well the social model of disability does not deal with *disability*, it deals with impediments caused by society, rather than whatever *condition* the individual may have.

In questioning the provision of welfare as individual or collective, Fitzpatrick (2001) also assesses whether welfare can co-exist with the political; can the provider of statutory services recognise another's political position? Welfare is clearly created to assess and provide for individuals who have needs that may be met and /or assessed by statutory services, in order to fit in with the functioning needs of society: 'Welfare must be an individual characteristic or property to some extent, for...such social well-being cannot be disassociated from the welfare of the individuals who live in that society' (Fitzpatrick 2001:11). The focus of welfare in that sense perhaps prevents political relevance, so that either only welfare *or* the political can only be considered at one point in time (see Care Council for Wales, National Occupational Standards 2007; Care Council for Wales, Code of Practice for Social Care Workers 2007).

The three statutory sector respondents however all asserted that Deaf people can be both recognised as having some sense of separate group identity, and also be identified for having a medical impairment. W stated:

> Yes deaf people do come under the legislation as 'sensory' so we are tied to that. We have a sensory service, and it is the medical model. ...But we have contact with the local Deaf organisation.

This view could display some sense of contradiction, where the policy cannot be questioned but a modern relationship can link to the representatives of Deaf people. A second respondent X believed more that differing fundamental views of Deaf people held by the statutory welfare system and by Deaf organisations do not matter in terms of the work of the statutory sector; social care in its current form is justified. This could imply that this person's view is that Deaf people fundamentally have impairment, and that they are simultaneously welcome to represent themselves politically, whether they ignore their own impairment or embrace it:

> I: Do social services assume Deaf people's 'sensory impairment', seeing as Deaf signers labelled with 'risk to independence' are categorised within this team?

> X: I don't think there should be a conflict between Deaf led organisations and social care services' philosophies. Yes we have different approaches but there is no need for conflict.

Further, the cultural mainstream may insist on applying the label of impairment where the norm identifies vulnerability and difference. In this case the vulnerable must be protected, and so excluded from label-free autonomy. Fitzpatrick (2005:154) states 'the vulnerable

body... requires protection and nurturing through paternalistic care. The vulnerable body speaks the morality of conservatism... (It) is both the cause and the victim of disease, concerned with a kind of 'coercive inaction''. A section of interview here illustrates this; respondent S stated that 'their' (Deaf people's) understanding of themselves and their capabilities are accurate if backed up by a societal view of them (those Deaf people):

> I: Could the 'hearing impairment' label associated with individual need and risk to independence conflict with the label of culture and language minority?

> S: ...You'd have to ask everyone with that impairment – do they regard themselves as having that special need? If so, and society reinforces that, that's the answer.

The following respondent R explained their understanding of the position of Deaf people in society, according to their institution's philosophy. There was an implied admission of personal (or possibly institutional) ignorance in relation to this issue; this would suggest there was no knowledge of whether 'their' (Deaf) views are indeed considered:

> Well *the briefing I've had* is that hearing impairment fits into the social model of disability. ... the services which are accessible for the disabled are better services for everybody. My view is that you need to keep reviewing, challenging policies and making sure their views are taken on board (my emphasis).

There was a clear stated aim of integrated politics, where consultation is central. However the use here of professionally applied labels as opposed to the general view of phase one respondents suggests (i) a divergence in political knowledge of a cultural group, (ii) a mainstream automatic acceptance of a 'scientised' or 'medicalised' definition of Deaf people, and (iii) the subsequent categorising of this group within 'social disability' (Bochel and Bochel 2003). Gergen (2000:168) argues that:

> Mammoth "scientising" efforts are not only misguided, but the results are often damaging... ("impairment") is only one of many possible constructions. To presume one is ill is also to invite practices of "cure".

This suggestion could be applied to the scientific and medical investment into hearing aids and cochlear implants, and the institutional assumption that a Deaf person ought to be 'turned into' a hearing person, where the spoken language can be prioritised, and the signed language abandoned (Branson and Miller 1992; Campbell *et al.,* 1998). Is trying to eradicate an alternative language collective a 'cure or a form of political *ignore*ance'? (see Gergen 2000:168). So where are the opportunities for changing the ways in which Deaf people are viewed and why the lack of change? Deaf people's claims to a distinct culture and identity continue to be dismissed, so that these individuals remain categorised as previously and thus

funded as they always have been: as disabled individuals. Does this suggest that the problem stems from the unyielding nature of policy making processes, or that Deaf people failed to make themselves known as a political group with a particular identity and purpose?

This section has explored aspects of the publicly known, assumed, and inferred definitions of Deaf people. Of the four public sectors represented, views of Deaf people's classification are polarised: seven understood Deaf people to be medically impaired individuals within mainstream culture and with varying links to a Deaf community, and two in some measure recognised a different language and cultural group identity. This section has explored the reason for, and effects of, different policy perspectives, with consideration of historically objectivised values, social norms, the so-called 'universal way', need and disability.

Deaf Policy Making and Funding

This section examines the basis upon which institutions' governing and operational systems are established and altered, and the factors shaping priorities for funding allocation. We here explore the idea that with the changed extent of devolved powers in Wales over a number of policy areas, public consultation is part of an open system and governance which invites engagement and communication (Chaney 2011). This is compared to the idea that policy creating systems are embedded institutionally and are accordingly prevented from inviting new dialogue. A sceptical perspective on policy making is thus adopted by Considine (2005:53): 'Policy communications can be seen as asymmetrical exchanges in which a dominant participant seeks to lay out the terms and direction of discourse, but must keep other participants engaged in this to succeed'. Such contrasting angles invite consideration of the views of phase two respondents about this perspective.

Mehan (1986:140) focuses on:

> the role that the *linguistic* process of persuasion plays in the *cognitive* activity of decision making in an institutional setting... where cognitive activities of decision making are made more visible, and the relationship between linguistic processes, cognitive activities and social structures are made more explicit...

Considine (2005:55) deploys this view, where 'the language of policy... is only possible because of the existence of rules or codes to organise concepts and attach values to issues and to the actors being described.' These both suggest that there is a powerful underlying influence of established assumptions held by key agents in a decision making institution, based on labels and the perceived role that particular 'labelled people' can fulfil, according to

more widely known normative values. Decisions typically do not go 'against the grain', but rather justify the status quo. As one respondent Z cogently stated:

> …the Assembly jointly funds its health and social care agenda. And they left out a decent equalities fund. Minorities were left out, so their right to a normal life was not covered... They've agreed to set up a single equalities fund, but I don't think it'll be big. Whether it can understand Deaf people as a minority in their own right, we'll see.

Along the lines of this observation, Wodak *et al.*, (1999) go further, in arguing that certain institutions relating to the arenas of politics and the media secure directive agendas with which to further the normative rule, and to exclude non-majority recipients. Wodak *et al.,* (1999:9) argue that analysis of prominent environments leading to policy making can display 'manoeuvres in politics and the media, which aim at linguistic homogenisation or discriminatory exclusion of human beings, and to heighten the awareness of the rhetorical strategies which are used to impose certain political beliefs, values and goals.' 'Linguistic homogenisation' may have affected an institutional assumption of Deaf people as hearing (majority) individuals who have medical impairment, who thereby do not qualify for recognition of any different policy status, or resources – whilst some acknowledgement of those with 'problems' using the majority language allows some attention. Respondent U, apparently minimising problems of linguistic homogenisation, stated:

> I don't think there's ongoing commitment to funding deaf people but that's because there's so many competing pressures – a finite budget. We have to pick priorities... There is however an ongoing commitment to translation services for those who have communication problems.

Sabatier (1993:33) similarly writes that established organisational views resulting in policy decisions and in further justification and reinforcement, tend not to alter in their core principles. It therefore takes a seismic sea change in order for new waves of policy direction to begin: 'Once something has been accepted as a policy core belief, powerful ego-defence, peer-group, and organisational forces create considerable resistance to change, even in the face of countervailing empirical evidence or internal inconsistencies'. This point is illustrated in the following interview extract about allocation of resources. Respondent Y describes how deep-rooted systems tend to influence the immediate future in policy creation:

> I: What is your view of the dual system of government funding, where statutory funding to social services (for hearing impairment) is assumed, and where third sector Deaf funding is not?
>
> Y: Well yes. In terms of the public service agenda, we argue that we need a more radical and user led way of being organised. There is an historical inevitability that

services are not fundamentally challenged. It really means challenging the legislation – because the welfare system controls all areas, and has the bulk of the funding.

The point made earlier by Sabatier (1993) about institutional stasis was illustrated by respondent Z who argued that as a consequence of being categorised as 'disabled', Deaf organisations were likely to be ignored. Until Deaf organisations make themselves publicly known their positioning within the welfare system may not be challenged:

> A 'Deaf led organisation' will become a sub-set of a sub-set, they'll be tossed aside. Deaf led organisations will continue to come under disability and hence are invisible. Profiling and networking are what makes organisations visible, and more wealthy – and attractive to funders (Z).

Chaney, Hall and Pithouse (2001:221) argue that '...during the transitional phases of the Welsh Assembly's development... the civil service had exercise[d] a good deal of power and influence over its political masters in the Assembly.' In relation to the stated view of Wodak *et al.,* (1999), as well as the above observation of the role that the civil service have assumed, the following respondent's civil service perspective appears to represent an institutional standardised understanding. Respondent T expressed a clear lack of knowledge about the Deaf collective perspective and about what purpose a Deaf collective could possibly have, and how they could justify a need to receive government support:

> Nobody has ever articulated to government to my knowledge what sort of things as a purposeful collective they could do to have funding.

This suggests that T had not considered that Deaf people *could* form a collective, or indeed have any sort of political identity. From this view point, it would therefore be nonsensical to even consider 'Deaf people' in funding and policy making. This may explain why Deaf issues are not recognised even within third sector umbrella body consultations (Bochel and Bochel 2003). When asked about projects which have been implemented by the Welsh Government in relation to Deaf people, respondent R recalled two projects. One, if not both of these projects may *not* have directly related to Deaf people, or their collective in terms of contribution to decision making and resource allocation:

> We have been making definite investments ...there was some investment into apprentice [hearing] interpreters working in public services, through a 'task and finish group', and also we've actually funded a project on volunteer support for hearing impaired users. This is a [region] impact study in which we'll develop a strategic partnership...The project is aiming to develop a successful volunteer hearing aid support service (R).

Respondent Y deliberated whether a Deaf led organisation (or any third sector organisation) accepting statutory ring-fenced government money prescribing support for medically impaired deaf people means that organisations no longer can claim independent political values of representing a political collective, with a different culture and language:

> If a third sector organisation accepts money from the local social services, and so accepts statutory conditions – at what point do they compromise their independence, and become an arm of government? (Y)

Those organisations which have not 'compromised' their values in accepting statutory funding in recent years may have suffered financially:

> Some organisations could not adapt to a harsher climate; some folded, and many are in survival mode. The surveys showed many organisations with paid staff reducing to just one employee, or to none at all. ...This is deeply destructive to a sector that is not immersed in corporate values such as profit margins, hostility and strategy (WCVA 2011: 5).

This issue was addressed by respondent T, although in a more positive light:

> We provide the core funding to [various Welsh regional d/Deaf organisations]. ...Core funding is to sustain the organisational presence... If we didn't fund them some wouldn't exist.

Chaney, Hall and Pithouse (2001:218) support the above statement, and explain that systems in the Welsh government are such that consultation is an increasingly open process, in which representatives of third sector organisations are invited to participate and defend their interests. Some routes invite further inclusion with a view to project development: 'There are now in place clear structures and mechanisms for consultation and joint development of strategy... there are a growing number of smaller schemes that promote a synergistic approach, and these might act as important pathfinders for more extensive ventures in the future.' One respondent Z however expressed reservations about the reality of a 'synergistic approach' in terms of Deaf organisations:

> The Government has invested in umbrella representative bodies, such as Carers Wales, Learning Disabilities Wales; I don't know about their knowledge of Deaf organisations – I think their contact is extremely limited.

Sabatier (1993:30) makes a not dissimilar point that in policy making arenas, 'experience reveals anomalies such as internal inconsistencies, inaccurate predictions, and invalid assertions – among the beliefs.' Problems arise if policy and decisions about resource allocation for Deaf people are not shaped through engagement and dialogue with

organisations that understand and represent their interests. In reflecting on the current situation with regard to shrinking budgets for public services respondent Y, thought it may be difficult for organisations that wish to retain too much independence:

> Funding is all about partnership working – and it accelerates as public funding reduces. There will be more pressure on everyone in the voluntary sector.... Organisations are merging – but ones that have philosophical unity. Deaf organisations need to find a similar agenda that they can pursue... because it will get increasingly difficult.

In apparent contrast, respondents representing the statutory sector discussed very different problems in relation to funding and purpose. V stated that:

> the total budget for the sensory team is [amount] in real terms, which doesn't include care packages. Yes statutory funding to Deaf people is through sensory impairment services. Our job is to do assessment and care management processes, so our funding is to fund assessed need.

Another respondent in the statutory sector W stated:

> you have to look at where's your demand, and how best can you meet that demand, and give the best value for what is tax payers' money.

There appeared to be an assumed justification for the policy of (UK) government money being ring fenced in funding intended for 'medical deaf need'. Considine (2005:55) indeed writes that 'power cannot be separated from the internal syntax and nor can knowledge itself be free or independent of the powerful logics or rationales which organise thinking and acting.' There may be an institutionalised acceptance that government money ought to be allocated to statutory social services to assess the risk to independence of Deaf people who are judged to have medical failing. There is apparently no thought given to the idea of funding representative Deaf led organisations on a parallel basis, let alone as an equivalent.

One section of interview with respondent X discussed the resourcing of an employee who is part funded by a Deaf led organisation and part funded by a statutory sensory impairment team, where the obligations required for the role may have become complicated:

> I: How does your half funding the position of a Deaf advocacy worker fit in with your statutory duty to assess individual sensory need?

> X: We have many people who don't act under that framework who work within our team, for example care development workers. The physical disability sensory impairment team work with a wide range of individuals.

It is interesting to consider the given justification, since their statutory money was spent under that budget, yet funding something contrary to individual assessment that is, a collective empowerment focus. That money still remained allocated to statutory social services; it was not allocated to a Deaf led organisation whose principles would advocate a collective advocacy role.

This section analyses the basis of decision making within systems, leading to funding allocation or lack of, to public bodies, and specifically to Deaf led organisations. Policy creation seems to be either led by new motivations of open consultation – with varying degrees of success, or by an established method of re-processing a policy course of action. Rationalisations of statutory social services policy relating to Deaf people, as presented by respondents, equally appeared as unchallenged.

Engagement with Deaf Organisations

This section explores what phase two respondents said, or did not say, about their engagement with Deaf organisations. This section is brief because approximately a quarter of respondents, those from the statutory sector did not answer these questions directly at all; instead they explained their contact with Deaf people more in terms of *the support* they provide to Deaf individuals. Different levels of engagement with Deaf organisations were expressed by respondents from the political, civil service and third sectors. For these respondents ideas about engagement varied in terms of how close a relationship might be required to achieve particular purposes. An example of a strong, knowledgeable theoretical relationship was suggested by R:

> I think real engagement is about changing attitudes and challenging the culture, so that when services and facilities are designed, that, you know, lobby groups' views are incorporated from the very beginning.

Levels of public body engagement in this arena may depend on degrees of knowledge by public representatives of the collective, political identity of Deaf people. This was presented in various ways by respondents; the reality of governmental engagement with Deaf people may not necessarily correspond with a Deaf collective perception of the current state of engagement. One indicator may be where respondents stated that *hearing impairment* should be considered (Lane *et al*., 1996; Roots 1999; Ladd 2003):

> The assembly is duty bound to have a process of engagement, it is under-written in the Government of Wales Act. I suppose part of it is how d/Deaf people themselves

wish to articulate to Government what their own views are. It's not a matter of *ranking disability* – it is how d/Deaf people should engage with society (my emphasis) (T).

Respondent Z presented a view from the same angle, whilst acknowledging a contrasting view of collective Deaf people:

> There's a challenge to Deaf led organisations – how the groups themselves engage to shape policy, how they promote their profile, how they convey the wishes of the collective they represent.

Whilst understanding Deaf people differently, both of the above respondents made the point that it is the responsibility of the extended group to make themselves known to the government in order to hold negotiations on an open footing.

Another apparent erroneous understanding of public engagement with Deaf people, and indeed of Deaf people's identity, was discussed with respondent S. S asserted their own previous engagement with Deaf people; the relevant contact appeared to be solely with deaf people who maintain a cultural hearing identity, and who use hearing aids to enhance speech. There was no acknowledgement of Deaf people who sign BSL. This would suggest that this person holding a senior governmental position did not have accurate knowledge of the Deaf collective, let alone having had any illuminating engagement with any members (Lane 2002):

> I: Have you had any links with Deaf organisations or people yourself as a (senior position held)?

> S: Yes a lot – when I was [in my previous profession] and with an audiologist. They involved me in their study on how hearing aids enhance life quality.

Respondent Z claimed that the evident lack of engagement with senior members of the government was because Deaf organisations had failed to make themselves known to policy makers and those involved in decisions about funding allocation. However for engagement to be initiated, *knowledge* of this community is required for any decision makers to consciously consider them:

> I suppose at the heart of the policy making process is the difference between organisations *for* and organisations *of* – it's about being 'citizen led'; but Deaf led organisations must become *known* to be invited by the Government (Z).

Chaney (2011) discusses a supposed anchor of society - citizenship as advocated by Oldfield (1994) and Miller (2000) (both cited in Chaney 2011). Chaney puts forward two contrasting theoretical directions where citizenship is either liberal or civic-republican. In the civic-republican sense 'citizens' can act on behalf of the 'invalid' in fulfilling their citizenly duty,

actively aware of their position as a political representative. A statutory social services connection with Deaf people is that they (Deaf) will be service users according to their legal disability and 'invalidity'. An assumption of service user may shape the relationship of citizen and institutional body. An example of this is where T stated:

> We need to look to setting up a process of guidance for practitioners and local service providers about special arrangements for those who are d/Deaf. I mean who do you consult with, who do you engage with to develop this for example?

There was perhaps an assumption that those 'd/Deaf' people have to be 'looked after' and represented by the universal hearing world of welfare. There did not appear to be a consideration of Deaf people with a political purpose, or that they may be able to consult with public bodies themselves (Cole 1998; Jenkins 2006).

In contrast, the liberal sense of citizenship means that the 'impaired' represent themselves (Chaney 2011). The Government of Wales Act 2006 (see Chaney 2012) requires direct engagement with all representative social and cultural groups in Wales; however how does this comprehensive engagement work in reality? One respondent Y explained, from a liberal citizenship perspective, that meaningful engagement is not just about membership of formal committees. Whilst attendance provides visibility, it is real negotiations incorporating meaningful Deaf input that would enable the institutional commitment:

> I always maintain that the *real* engagement isn't the symbolic role of the partnership council or of ministerial meetings – although a Deaf presence would doubtless have an impact, the *real* joint working should be at routine level – of involving the right organisations and the right groups (Y).

Similarly, one respondent U expressed an ideal state of affairs in their view, where Deaf people and their language ought to be fully considered and Deaf people engaged with as significant partners:

> I see consultation as existing outside of legal obligations – it is about a lateral re-think. If Deaf people have a British language which is forgotten about and their contribution to society could create an impact, we've got to focus on them! (U).

Respondents discussed whether Deaf organisations are in fact proactive in initiating engagement with themselves and their colleagues. Respondent R made the point that their own position was very senior, public and open, and yet no Deaf bodies had ever approached them. This respondent may have had secondary 'knowledge' therefore of where Deaf people fit into consultation and information procedures, in first assuming that Deaf people *do* positively engage with the government, and secondly in holding that Deaf people have

disability such that they (Deaf organisations) can support disabled representatives engaging on their behalf. There appeared to be no knowledge of any direct contact with Deaf led organisations:

> I: Do Deaf people make themselves known to you, or is it quite difficult to engage with them?

> R: As Assembly Member, and indeed as Minister, I don't recall having any specific representations with Deaf bodies. I am aware however that my colleague has had some contact with them. I mean before today I would have assumed that they would support disability or Government engagement.

Respondent U referred to local authorities' contact with Deaf organisations. U observed that the initiation of consultation may not have been assisted, insofar as Deaf bodies were assumed to be 'covered' by disability representatives:

> We need to question local authorities' mechanistic approach to consultation with Deaf groups. They may claim to have consulted with a disability group, but this may not reflect those who have BSL.

Respondents stated ideas on how Deaf organisations *can* initiate contact, and become visible as they identify themselves. Respondent Y presented two initial methods for access to external campaigning bodies. One way is to build a petition which has been signed by the relevant critical mass, and the second is to initiate contact with a Government Member who is known to have specific interest with that group;

> the sector has two methods available for making use of the law making powers of the Government; one is the petitioning process - which has to be properly considered, and the other is the minister's ballot, where they can put together a piece of private legislation. They consider voluntary organisations' proposals (Y).

This section examines respondents' perspectives of the extent and meaning of their engagement with Deaf organisations. Engagement appeared to span from assumed contact under the umbrella of disability and impairment, to understanding of the shortfalls of disengagement between Deaf organisations and the partners who hold policy making and funding influence over them. Deaf organisations may however be significantly lacking in the initiating of involvement with public sector bodies; this may have some bearing on their options for investment and potential to survive. One respondent Z with this latter perspective summarised:

> The Welsh Government has identified a range of organisations it works with. But how much they really understand them is questionable. Once a relationship is established - that will directly influence the standing of an external partner, which will mean more

money, and influence in policy development. That is where Deaf organisations should be.

Deaf Representation

This section explores the potential opportunities for Deaf organisations to profile themselves publicly and challenge assumptions concerning disability, and, finally, respondents' difficulty in anticipating any change in the modern welfare system. Respondents from all four sectors answered questions on this topic.

Dicks, Hall and Pithouse (2001:111) explain how the legally required role of the (then) new Welsh Assembly Government was to engage with voluntary (third) sector organisations in Wales in order to achieve the representation of all equalities strands:

> ...successful relations with the voluntary sector are ...a legal requirement. Under the terms of the Government of Wales Act the Assembly is required to establish a Voluntary Sector Scheme, setting out how it proposes, in the exercise of its functions, to provide assistance to and consult with the voluntary sector.

Respondent Z correspondingly stated:

> Deaf organisations need representation on the third sector partnership council at very least. 'Sensory impairment' organisations fit into 'disability' funding categories. And so if Deaf don't associate with that, in Government eyes they don't exist.

Z speculated that Deaf organisations which do not associate with 'disability' and 'sensory impairment' categories will inevitably remain unknown. Third sector organisations can get missed insofar as they are not understood to represent a collective. Deaf organisations presently do not have representation on the partnership council, a situation which may support the status quo, and perpetuate their invisibility to government. Chaney, Hall and Pithouse (2001:217) explain this issue:

> the [voluntary sector] scheme makes provision for a Partnership Council which consults with government over policy and advises on the working of the scheme. There are evident difficulties in representing the empirical diversity of the sector, and representatives to sit on the council are being drawn from but a fraction of the thousands of (Welsh) voluntary groups and organisations.

To the question, "is there an area of the (third sector) partnership council that covers Deaf interests?" respondent Z answered that indeed:

> The Partnership Council itself has agreed twenty-four categories of interest. Sensory impairment is not one of them. On occasions we have consulted with members on the

make-up of those. There may be an assumption that sensory impairment will be picked up by disability.

This would mean that not only are Deaf people unrepresented, but that also sensory impairment is not a pivotal area for challenge or adaptation. This would suggest that an established system for sensory impairment will be inadvertently protected. Deaf people might choose to be represented by another of the twenty-four categories of interest other than disability; however this is unlikely if there are no contacts in place for initiating interaction.

In interview, respondent S spoke about their awareness of third sector Deaf organisation engagement with the Welsh Government. This view was in parallel with Z's above, and demonstrated a potential cul de sac in options for the promotion of Deaf interests:

> I: In your view, are Deaf led organisations in the third sector proactive with engaging with Government on public policy?
>
> S: Certainly they are active with the [umbrella third sector representative body], and contribute to the strand on hearing problems... with the Third Sector Partnership Council it depends on who they [disability] put forward; it could be a blind person, it could be a person with arthritis, it could be a hearing impaired person – as to who is the disability representative.

Other respondents answered questions about exploring whether Deaf people ought to be publicly represented as having disability. The first respondent T gave an interesting, rather fixed answer of policy based understanding:

> I: Do you think there are alternative ways that Deaf people can be recognised and represented – other than as if they have a disability?
>
> T: Well the social model of disability is based on that premise!

Another quote from the same respondent T did claim some knowledge of alternative recognition for Deaf people as having an independent language, whilst disability remained core:

> One thing the Government did according to the social model of disability was that they adopted BSL as an official language. So ...there is this formal recognition.

A second respondent U also answered with an interesting understanding of culture and language inherently combined with disability:

> I think we acknowledge the culture and language of the Deaf community – we recognise their diverse needs where their impairment is the underlying feature, and influences their lifestyle choices.

A later remark by U however considered a uniquely new perspective, given following discussion with the interviewer about potential views of the general Deaf collective:

> I'm interested in the idea that Deaf people do not have a disability. I can see from a different perspective the complaints of Deaf representatives of their misrepresentation, and of the misdirected investment (which does not go) into Deaf training and employment.

Another issue of representation is that a hearing /Deaf binary of oppressor and oppressed is generally not known of in terms of mainstream social science academic assessment of discrimination (although this is a part of Deafhood studies (Ladd 2003)). 'The big five' equality strands of gender, ethnicity, age, disability and sexual orientation (Thompson 2001) exclude other minorities, which could assist otherwise to develop a core profile for the Deaf. There is also the added dimension that Deaf'*ness*' is publicly perceived to be one *of* the 'five', i.e., disability. Cooper (2004:52) observes:

> there is a tendency ...to much Western (minority) writing in which relations of inequality such as gender, class and race, are reduced to simple binaries of oppressor and oppressed. But ...some principles may operate (more) as terrains, discourses or webs of practices that work to consolidate, or conversely to undermine, other inequalities.

The equality strand of Deaf is possibly reduced to the point of invisibility through inadvertently maintained ignorance by those with authority. An established understanding of Deaf people appears to prevail, so that the proposal to respondent S to review the 'Deaf collective' brought some scepticism:

> I: Do you think that a question asking about them on the Census would mean the Deaf collective would become recognised?
>
> S: But what follows from that? I mean what if the campaigners were extremists who do not represent their peers? That doesn't 'prove' they are a distinct group.

S here may assume that anyone who claims to be 'D'eaf would possibly not be representative of their community of people with 'normal' hearing impairment. Dicks, Hall and Pithouse (2001:105) support the prevailing impression that the third sector umbrella body has engaged comprehensively with third sector organisations: 'The umbrella body serving and representing the voluntary sector across Wales, has provided a sense of coherence to the voluntary sector in Wales that is arguably not as evident elsewhere in the UK.' However when describing the funding system that a Deaf organisation fits into, respondent Y from the third sector stated that "they'd (Deaf organisations) have to claim disability to bid for available funding." From the perspective of the Deaf collective this view does not accord

with the advancements suggested with regard to third sector representation. The Deaf /hearing binary may here be so inequitable that it is not publicly seen as being one. In a sense respondent T recognised this point:

> I think part of the difficulty that people with hearing impairment face is within their own particular specialist services; *their voice is not heard* (my emphasis).

Although there was an inherent assumption here that hearing impairment specialist services were the home to Deaf people, this respondent made the point that Deaf people do not have the opportunity to express their own views, or to represent themselves. T also may have relied on an audist assumption to make this pivotal point, since the focus was on the service users using English in order for their view to be taken into consideration.

Dicks, Hall and Pithouse (2001:105) comment that 'recent years have seen a significant rise in the profile of the voluntary sector across the whole of the UK; incomparably so in respect of the delivery of welfare, and the Welsh voluntary sector has benefitted to some degree from this wider development.' In terms of Deaf organisations this may incorporate their involvement with statutory welfare services in negotiating service level agreements, and taking on statutory obligations of individualised support (see chapter 6, p124). One respondent Y supported this point:

> You could say we're [the third sector] in the position to provide a much better service because we know our audience; we're specialists, we have values that underpin our work. We are of the view that third sector organisations can provide services as mainstream organisations.

This view could either feature third sector organisations taking on the role of some statutory welfare support, or give rise to the view that investment into communities ought to be addressed differently, and communities be supported according to different values (see chapter 6, p136). There is however an assumption on the part of some that welfare legislation will remain the same, so that third sector involvement will remain secondary to the core system (personal communication g: 2012). Respondent V defended the status quo in their recognition of the clear hearing support system to Deaf people as individuals:

> The legislation ...wouldn't need to change. The social worker will have specialist knowledge, and the issue is, if you have particular hearing impairment or communication needs you will expect the appropriate response.

Another respondent W could not imagine the Deaf support system as being any different, because the diluting of their statutory social services budget across a larger population such as a Deaf community would mean a diluted front-line service:

> It is very difficult to ration resources – if you do go wider than very specific interventions it almost becomes impossible. That's where I doubt that any legislative change will last or move away from very specific definitions.

Two respondents X and T discussed how Deaf people's identity can be politically understood. X expressed some reservation of the fixed category of Deaf people as having 'risk to independence':

> I: Do you think there could be alternatives to the disability approach – beyond the objectives of welfare legislation – so if they weren't seen as having disability or risk?

> X: If you look at the principles of Unified Assessment which is the way adults should be assessed, it is about risks to independence. ...I'm not sure we've got there yet actually...

Unified Assessment is based on risk to independence, which is based on an assessment of individual need, which is all informed by the inherent assumption of impairment and disability (for example see Cardiff Council Unified Assessment 2012, see chapter 2, page 22). The above quotation illustrates how a statutory view shapes the unchanging mechanisms which affect people's politically perceived image. Fitzpatrick (2001) considers whether welfare is universal or relative; whether if universal, the statutory welfare system is assumed to be the single provider of support, and whether investment in a long-term core system enables an appropriate fundamental provision, as opposed to alternatives such as investing in a collective of people who do not see themselves as impaired, where representatives of that collective can support and teach a language, and provide an education and facilitate empowerment: 'Is welfare the same for all people, regardless of their location in space and time, (language and culture)?' (Fitzpatrick 2001:10). The welfare system alternatively could, Fitzpatrick suggests, be described as relativist, where it is recognised as being underpinned by relative values and norms of the cultural mainstream. It may be that neither fundamental strand challenges the implementation of a fixed individualised system, which objectivises its methods. Respondent X goes on to explain a validation of the current welfare system:

> I: Why do you assume Deaf people may have risk to independence where hearing people might not?

> X: That's the way the system is organised.

There appears to be an acceptance of historical statutory foundations where an underlying assumption of Deaf as sensory impairment remains. Respondent T explains that this may be due to Deaf people themselves not having made themselves known to hearing elites as they wish to be seen. T states uncertainty as to who Deaf people who sign *are*:

> There is not universal acceptance that BSL is 'the' language. Some believe speech is better. And if you do talk BSL – which one? Is it in essence for someone who has acquired deafness? Their needs are going to be different from those who have a congenital hearing defect from birth.

Deaf Support

This section is grouped together by single respondent statements. Some statements appeared to contrast with other statements made by the same person, albeit in a different context. Statements presented as sections of two-way interview conversation demonstrated the presence of reasoning on the part of respondents. Respondents who are largely statutory and civil service representatives talked about their view of the support that Deaf people need. This widely held perspective was clearly challenged by another single respondent – where they raised the subject of the appropriateness of welfare legislation, and further, how strong the collective would have to be to formally question it, and to recognise Deaf collective identification in a space outside welfare.

Respondent T explained the fundamental direction of the sensory impairment approach within social services: Deaf people are invariably seen as suffering medical impairments. Their 'main' disability is then identified in order that need, and subsequent support from the social services department, can be met (Young, Ackerman and Kyle 1998; Young *et al.,* 2004). T stated:

> social services treat sensory issues all the same because they assess people's individual needs... whatever the lead disability is, that service will hold the lead.

Spicker (2006) suggests that 'need' is an interpretable term, where established values shape perceived normative abilities. If Deaf people, however, are to be seen as a cultural collective then this questions the assumption that all 'deaf' people should be treated as in medical 'need' (Priestly 1999).

Respondent T initially presented a traditionally understood view as to the categories and self-description of Deaf people (Ladd 2003; Lane *et al.,* 1996). The problem was presented as one

of entitlement to social services support, where all types of deaf people would *want* receipt of social services, but may not actually be allocated them. T stated:

> the mere fact that someone may have hearing impairment whether it is a capital D or small d, does not necessarily mean that there will be an automatic entitlement to social services.

Similarly T later stated somewhat ironically:

> the complementary approach is to sign-post deaf people to voluntary sector organisations who can provide *other* support and help (author's emphasis).

This understanding remained strongly in conflict with a general Deaf collective one, in which social services were expected to be the predominant provider who were thought of as the universal service. T, by contrast, held that an option to address the limited 'support' available in social services is to send Deaf people on for extra help to 'voluntary sector organisations'. However T did not specify 'Deaf' organisations , let alone organisations that are Deaf run. This point is interesting because the 'Deaf collective organisational view' (Jones 2006; Batterbury *et al*., 2003) is a general one of a political identity, something that social services *do not* provide.

T went on to advise practitioners to use professional guidance, again as if (social services) 'practitioners' perhaps were the appropriate workers in providing support to Deaf people, considering that all Deaf people who sign also have need:

> There was a new hearing impairment benchmarking report published in 2007. There are examples of good practice across the principality. Practitioners should use this. ....It must remain as an organic process.

W also discussed this report of guidance for social workers with deaf people:

> The Welsh Government commissioned a recent report on the role of social work with deaf people – focussing on working with other agencies, and educating in terms of what they should provide. ...It's not new policy, but they're newly raising previous issues.

This would mean that in practice, social workers with deaf people remain using the fundamental principles from the 1999 RNID 'Best Practice Standards' as discussed in chapter 2 (see page 21).

When W discussed service provision with 'the Deaf community' , words like 'care management' suggest that an individualistic and medically based idea of deafness underpinned their understanding of deaf policy and provision. W's stated work with the Deaf

collective (see below) therefore seemed ambiguous, although it was clear that W assumed social services' intervention. W referred to ease of communication – perhaps in referring to language difference in which connection (*at least)* social services were better at communicating than a rival department of housing. W seemed to imply that where common language was difficult, a care plan could be used also for communication with common indicators. This would suggest that a practitioner and service user would not otherwise share the same language skills in which to have shared, fluent conversation:

> our engagement with the Deaf community will be richer because it involves care management. Our ability to communicate with them is probably better than, say, housing. Using care plans as an indicator is a good sensible idea.

W went on to explain the resources provided by their statutory social services, which indicated a lean towards community provision, and perhaps some legacy from an old-fashioned paternalistic approach to resourcing:

> We do provide a facility for the cultural Deaf to meet at [Deaf club]. We don't run it, but we do provide it. ...We are trying to open the ways for independence.

Whilst not a new provision and thereby not a new method, the described facility appeared to enable a self-run community operation. This service is an interesting phenomenon, seemingly resulting in outdated, paternalistic welfare, whilst providing a useful purpose to a section of the modern day Deaf collective (Lee 2004; Ladd 2003). In this example maybe the Deaf club were not in fact being 'opened' towards 'the ways for independence' because they may have remained being looked after by the provision of a statutorily controlled welfare resource being made freely available to them. The statutory welfare service funded the continuation of this club, and there seems to have been no question of the funding for this budget being re-allocated to Deaf organisations themselves to manage.

V stated:

> In terms of supporting people there's a wider set of responsibilities there which councils have. I feel that community development and social work is the best place to do that work. How you do that in specific communities I haven't worked that through yet.

This view indicated an assumption of the universal (statutory welfare) provider who ought to support vulnerable service users. This is welfare providers' responsibility; however they are not certain of the best method of care and support to help some vulnerable service users. Respondent V acknowledged that the people in need of support include the Deaf community.

This thought process did not involve a stated notion that on some level Deaf people may be able to support themselves (Harris 1997; Sainsbury 1986; Young *et al.,* 2004). The following interview extract illustrates this perspective further:

> I Why do you provide care to this section of society? Is it because of society's barriers, or is it that they are naturally impaired?
>
> V It is definitely both.

This stated view is that such service users of a specific (Deaf) community have both medical impairment, *and* experience social barriers, and it is for both reasons that they need support. This view conflicted with other views from representatives of the statutory sector that someone being Deaf per se does not imply that they require support (see X below). As well as this view however, V expressed concern that an inappropriate level of intervention may be detrimental to someone's independence: "If we work with people in the wrong way you can disable them rather than enable them." This would mean that it was felt whilst Deaf people were in need of support, too much support could cause them harm. In the following extract V expressed some feeling of threat by such community led third sector organisations, intimating that these ought not to have control of how services are provided:

> Independent organisations are not an alternative to our social work service – it's a partnership process.... We don't want an outside organisation to take control and develop their own route in (V).

V's perspective appeared to balance on a swaying pivot. Whilst maintaining that Deaf people have impairments and therefore needs that should be met by statutory provision, V also believes in working in partnership with Deaf organisations, some of whom challenge the very definition of need with which the service operates. In addition, whilst there is a concern about duplicating provision and creating dependency, V is also reluctant to allow Deaf organisations to shape how Deaf services ought to be defined and provided.

Respondent X explained the purpose of Deaf individuals being supported by their sensory team, as opposed to being supported by other social work teams, with the use of an interpreting system:

> I: You say that Deaf issues are *not* the main focus. But once they have been identified as having risks to independence for different reasons, why would they then be dealt with by the sensory impairment team?
>
> X: The team has sign language.

X expressed a natural link to medical sensory impairment with political language. This view perhaps raised the question of how paternalistic this system could be, whether or not the team indeed had BSL (Crowe 2003; Fine 1994). When asked the question, "Do you think that Deaf people have institutional barriers causing their artificial vulnerability, or that they have 'natural' vulnerability?" X responded:

> I think the fact that organisations find it difficult to communicate with Deaf people means that people who are Deaf will struggle to get their needs heard.

This suggested X's belief that Deaf people's impairment *is* partly organisations struggling to communicate with Deaf people. Could that therefore be a justification for hearing people to support Deaf people within the welfare system? X explained further how a hearing welfare body is an appropriate core service provider for Deaf people:

> I think local authorities need to commission the voluntary sector to provide that preventative arm of the service, so Deaf people are less likely to have individual need.

In some contrast, respondent Y uniquely considered a fundamentally opposite perspective, according to which maybe a hearing welfare body could not after all be an appropriate core service provider for Deaf people:

> I'm wondering what would be the support from the Deaf collective that welfare legislation would not provide. I wonder if Deaf organisations are strong enough to challenge institutions. A strong collective with negotiation power engaging with the Welsh Government to change legislation – can you imagine the impact!

This view posed interesting issues. First, whether the welfare system is the appropriate system of support for Deaf people, and secondly, whether the Deaf collective has strength, conviction and authority to persuade an established institution to redirect its investment. This perspective of a third sector respondent contrasted notably from that of the above civil service and statutory representatives; perhaps unsurprisingly.

The statutory and civil service respondents who answered questions in this area tended to share a similar view of established, rationalised hearing welfare control, offering supportive intervention to Deaf individuals, and in some cases to a whole community (Shklar 1990; Frazer 1997). Respondents differed in terms of the extent to which they believed intervention was necessary, and whether it would always be required.

Conclusion

The respondents' knowledge about the Deaf collective contained assumptions and views which may have affected their policy decisions about institutional relationships, engagement, investment, support and representation. A pivotal issue concerns how Deaf people are seen and positioned within policy: as having a medical impairment with corresponding needs (Harris 1997); as having a collective identity with claims to an equal, diverse language and culture (Ladd 2003), or thirdly as having *both* individualised medical impairment *and* a different cultural identity (Young *et al*., 2004). The third perception of Deaf people owning both positions is seemingly internally contradictory according to the Deaf generalised view (Lane *et al.,* 1996; Ladd 2003). These three possible depictions are variously assumed by respondents as revealed throughout this chapter. The recognised representation of Deaf organisations ranges from less than limited, to an appreciation of a need for Deaf organisations to challenge existing systems, and to develop their profile. This raises the question of why Deaf organisations may not be represented in the way that they would wish; that is, are Deaf organisations aware of the understanding of their collective existence that hearing elites may or may not have of them? An institutionalised statutory welfare system ensures that Deaf people remain categorised as they have been since 1948. Welfare legislation may influence the continuation of the mainstream interpretation of the identity of Deaf people, and consequently their public profile and engagement with governmental and other decision making bodies. An institutionalised 'known' may mould society (hearing and Deaf people)'s perceptions, as well as mould Deaf people's perceived abilities to challenge such an established norm. Dunne (1999:14) describes an example of collective Deaf autonomy and persuasive effect in a Deaf broadcasting campaign in Britain, where reflections specifically indicated:

> (First a) lack of political skills among Deaf people regarding the process of policy-making at higher levels of government. (Secondly a) lack of adequate research by Deaf people to gather any vital information needed to achieve a successful outcome to a campaign. (Thirdly a) lack of information – exchange and networking among Deaf people at local, national and international levels.

Breivik (1999:26), from a Norwegian perspective, hypothesises an explanation for this situation, using an example of mainstream political involvement, 'Deaf people are less likely to participate in both national and local elections... Deaf people are excluded from most of the flow of information from the national broadcasting corporation and that ...they neither feel attached to nor embraced by the (Norwegian) nation.'

The following chapter will summarise and reflect on the key findings in this and previous chapters in regard to hearing and Deaf elites and how they differ in their construction of Deaf identities and the status of Deaf organisations in policy and politics.

Chapter 8

Discussion of key findings

Introduction

This chapter seeks to explore further a selection of key themes and theoretical patterns from the preceding findings chapters. This will allow a deeper understanding of the position of Deaf elites in relation to their own perceptions of their personal and institutionalised positions throughout different time periods and their perceived status and authority within mainstream public welfare and government systems. This chapter also takes account of the views of hearing elites and their difficulties in establishing engagement with Deaf third sector bodies, either through an institutional lack of recognition of Deaf people as having purposive groups, and /or through an absence of attempts - perhaps on the part of either party - to secure consultation. When analysed overall, the findings help distinguish pivotal themes which extend across chronological periods and lifetime stages of phase one respondents and which overlap and converge with themes derived from phase two respondents.

Dissonance and difference – the Deaf political agenda

There is an apparent dissonance between Deaf organisations claiming they organise political campaigns to influence government and government representatives and other public sector body representatives stating that either this does not happen or that they are unaware of the existence of the Deaf collective or its regional bodies. There are two possible reasons for this. The first may be to do with the limitations of the study design, that is, Deaf elites were interviewed from English and Welsh Deaf organisations, whilst hearing elites were only interviewed from public sector bodies in Wales. That said, many examples presented in chapters 5 and 6 demonstrate an institutionally held perception of Deaf people by the Government as disabled, and the inability of representations by Deaf organisations to challenge or change this. One example of this is the UK government recognition of British Sign Language as an official British language in 2003. (This was discussed by two Deaf respondents who explained how in their view such recognition did little to promote the interests of the British Deaf collective). The (then) UK Government Secretary of State for the Department of Work and Pensions, and the Minister for Disabled People acknowledged this official recognition in their pronouncements about needs and disability (see chapter 5). Yet, not only does it seem that Deaf people were thereby 'celebrated' as disabled individuals who

manage to have a language, but also that the disproportionately small amount of investment allocated to BSL development was awarded to hearing people to train and employ other hearing people to become interpreters, for hearing organisations. This meant that the fund was not allocated to Deaf people to control or invest in (for example) Deaf education, employment or empowerment. A second example cited by respondents is the recent Human Fertilisation and Embryology Act 2008, Clause 14 (a UK Government measure) where embryos known to be deaf may legally be destroyed. A third example of the direction of UK Government policy affecting Deaf people cited by respondents is the UK funded programme of investment in cochlear implants to 'cure' deafness. These three examples might suggest that the policy campaigns cited by Deaf chief executives in policy areas such as the above have been unsuccessful in terms of pursuing a Deaf agenda, or generating a more informed consideration of the authentic status and interest of Deaf people.

A second reason for the apparent dissonance is perhaps more illuminating, and can be found in data provided by five of the 13 respondents about the limitations of their lobbying. These five respondents reported being members of a chief executives lobbying group, which represented Deaf organisational bodies in presenting a unified political identity and demands to UK and Welsh Governments. The capacity of these five respondents and their organisations to lobby effectively to government was scrutinised and found to be limited at best (see chapter 6). None of the five members of the chief executives lobbying group had autonomous powers of decision making regards their disbursement of funding, but rather receive conditional funding to provide services for disabled or hearing impaired individuals. This means that as well as representing Deaf collective members, they also represent culturally hearing medically deaf people, and thereby dilute their organisational coherence and capacity to influence in that they may be seen more as disability organisations than advocates of Deaf interests. Arguably what is heard as their 'voice' is not of a political Deaf agenda. By contrast the eight respondents who claimed to engage with local and regional government conveyed that for them it is a higher priority to inform key constituencies and publics in order to achieve political influence and change. Yet overall the data suggest that Deaf organisations exist in varying states of financial strength and political influence. That is, there is no inclusive unified Deaf political mobilisation which has a demonstrable persuasive effect on government or other public sector hearing bodies.

In terms of what could be recommended to Deaf people to address this issue, the notion of meaningful and structured mobilisation amongst Deaf led organisations, alongside

partnership with university Deaf Studies centres, may facilitate some public impact. Were such mobilisation to be regenerated, and presented on an international (Deaf) stage, the impact could accelerate with evidence of a tangible organised international Deaf collective, with a valid and distinct language and culture, and with persuasive proposals for investment towards the reconstruction of their socio-economic position and citizenship.

Hearing respondents

Out of the nine hearing respondents, seven did not know of the existence of any purposive Deaf group based on cultural, political or social agendas for change. Establishing this lack of awareness is itself valuable as a first step in informing both hearing welfarist and Deaf worlds of the polarised positions that they occupy. Another characteristic of hearing respondents was that five interviewees did not accept my suggestion that Deaf people may see themselves in a different way from that of public sector bodies (or indeed the interviewees themselves). This shared characteristic was notable and perhaps remarkable given that I had informed them of the views of Deaf representatives about their membership of a collective with a different language and who rejected the notion that they have a disability or impairment. The five respondents shared in the essential view – as one put it – "No, Deaf people do not exist like that."

The rationale of the three sets of data

Chapter 5 focused on the memories and experiences of phase one respondents in regard to their becoming, over time, organisational leaders and by implication role models with the Deaf collective. The backgrounds of phase one respondents informed the basis of interviews and findings for Chapter 6, with its focus on Deaf interviewees' professional lives in holding senior positions of chief executive or chair of Deaf controlled third sector organisations. Their organisational ambitions and experiences, their relationships with external public sector partners, and their views of their partners' sense of understanding of the Deaf collective were all investigated. The third findings chapter, in contrast, focused on the institutional perceptions of nine elites representing hearing public sector bodies from within Wales that provide or promote services likely to impact upon the lives of Deaf people, whether inadvertently or deliberately. The findings chapters present discussion on the knowledges or ignorances of each side.

It was no accident that my research did not focus on hearing respondents' personal lives in order to 'balance' the research; this was deliberate, since I did not consider that the research needed any such supplementation. This is because phase two hearing respondents were clearly secondary in focus to phase one Deaf respondents. The aim of interviewing particular hearing elites was to ascertain and explore the assumptions held by bodies that make and implement policy and funding decisions which directly affect Deaf organisations such as those that participated in this study. The interview schedules for both phases were again 'non-matching' because the focus on phase two questions was specifically directed at exploring their knowledge of Deaf people and related institutional structure and policy. The findings for the three chapters 5, 6 and 7, have produced a clear and consistent pattern of relevant considerations and comparisons.

A reflection on the role of 'social welfare colonialists'

The public prominence of bodies playing the role of social welfare colonialists (arguably such as the former RNID) could well have an impact on hearing respondent 'knowledge' of Deaf organisations and their collective. Two out of thirteen Deaf organisations had partnerships with organisations similar in medical and oralist orientation to the RNID. The RNID is well known for its public profile especially within the Welsh Government, as claiming to represent the Deaf community. The RNID published the 1999 practice standards to which social workers with Deaf people still work, as advocated by national statutory social services with Deaf people. Public sector bodies such as the Welsh Government would not search for any alternative Deaf organisation if an organisation such as the RNID presented themselves as the comprehensive representative, open to engagement, as well as financially attractive and reliable, with existing networks and a history of partnership working. This is even clearer if the RNID reinforce a 'known' portrayal of Deaf people as poor, suffering individuals in need of cure, and where this categorisation 'fits' with welfare system orientations.

A reflection on how some hearing respondents began to change their views of the Deaf collective

It is significant that two hearing respondents were open to slightly changing their views of the Deaf collective as a result of being interviewed. That is, when I suggested that Deaf people may see themselves in a different way, they independently showed interest in the new alternative. On both occasions I continued this line of conversation at separate points, by

asking about the possibilities of changing the way a group is categorised in policy. One respondent was more willing to pursue this angle than the other. The first answered in optimistic theoretical terms, and following that, reverted back to the important work they had done with hearing aid users. The second answered that it would be costly to see Deaf people in a new category that would inevitably require much more investment. This was an interesting point; a seismic sea change in government recognition and new knowledge would involve a significant acceptance of government cost, time and resources. I did not pursue these lines further however because of holding the role of an exploratory researcher with aims of securing respondents' perspectives, rather than of educating them any further than suggesting the existence of a different perspective.

The Social Services and Well-Being (Wales) Bill 2013

This bill announces welfare reform changes to the structure of social care (in Wales). The ambitions in the Bill would appear to ensure a new standard of clarity and simplification of the system, whilst ensuring more comprehensive and efficient provision of information as to eligibility, assessments, and early intervention. Were Deaf individuals ever to require social work services, or, come to that, hearing people, it would appear that the system will be more seamless and efficient in directing service users towards preventive intervention. There are no specific details as to eligibility for social services categories. Therefore it is unclear as to how Deaf people are to be defined under the new Bill, or indeed if a new definition is to be included at all. Deaf people will be concerned to know whether they remain categorised as individuals with hearing impairment and at risk to their own independence. It will be interesting to see what kind of code of practice for social work with d/Deaf people will be set out. Such a code of practice is currently circulated (in repeated iterations) as a set of advised practice standards deriving from a code originating in 1999. Deaf organisations would be included in providing new models of delivery as third sector services; this may be of interest to some of those organisations. However, more importantly, the Bill does not appear to consider government funding in terms of *investment* to such Deaf-led third sector organisations beyond the statutory social services boundary.

Hearing Colonisation and Deafhood

Ladd (2003) refers to the hearing colonisation of the mind (see chapter 1 and 2), that is, societal control systems of the Deaf. Ladd (2003) discusses both linguistic and welfare colonisation. It is the latter which is drawn upon here and we now reflect upon those key

messages from respondents set out in detail in Chapter 5 that addressed pivotal issues for the collective relating to welfare colonialism. The investment in and promotion of cochlear implants as a treatment option for young deaf people, the categorising of Deaf people as having an individual disability, and a specific section of the Human Fertilisation and Embryology Act 2008 where the non-termination of a d/Deaf embryo is deemed *illegal* are cited by Deaf academic researchers as examples of welfare colonialism (Emery 2009; King 2009). 'Deafhood' as coined by Ladd (2003) is a reaction to such attempts at institutional control by the hearing world. It is the Deafhood, that is, the collective strength of a Deaf constituency that enables challenge to welfare colonialism. In attempting to represent their members, respondents typically cited their organisational aim of defending political Deaf rights, and rejecting these aspects of welfare colonisation derived from mainstream hearing values. Such ambitions are of course considerable given the weight of normative logic, thus to challenge the objectivised knowledge derived from those in power about what it is to be d/Deaf requires a complete reframing of the knowledge from which being d/Deaf is currently defined by medicine and welfare. Thus we might ask from a post-modernist perspective (as in Dickens 2000:78), what do the conventional knowledges about the Deaf do and what ends or purposes do these serve? Only then can a more progressive understanding of difference and the possibility of an authentic social positioning for Deaf people obtain. Thus, a critical turning point aspired to by Deaf respondents was a change of mainstream perception that would construct Deaf people in terms of their worth, their non-disability and non-impairment, their functional lives using their visual language, culture and collective, and their ability to contribute to society at the highest levels. Hence in chapter 6 we find that the majority of respondents stated their organisational vision being, inter alia, to re-educate Deaf people about their individual and collective worth, and to substitute any internalised negative images of their members with the ideals of a confident collective, assured of their political relevance. To achieve such a transformation was recognised by most Deaf interviewees as a long and slow process of persuasion of members to move forward in questioning the status of their citizenship (see also Lane *et al*., 1996; Ladd 2003; Branson and Miller 2002).

There appears to be relatively scant engagement in public bodies and other forums of public representation (local and national) by the Deaf. This could be due to Deaf people and their collective not initiating sufficient challenge to the objectivised medical label of their having an impairment and needing to learn to be a hearing person to function in society. Deaf elites, (e.g., academics, social business and collective leaders), as well as those with a long history

of Deaf families, sought to remind and educate local and regional members of the collective of the confidence that is needed to challenge relevant hearing policies. Respondents discussed how typically their members did not receive social services but neither did they challenge the rules which inflexibly identify them as legally eligible for welfare intervention. Part of the reason for this could be that many Deaf people become culturally Deaf after a lengthy formal education as culturally hearing with impairment and so may lack the confidence and conviction to resist. Other deaf people may never at any stage change their cultural hearing identity; indeed two Deaf respondents expressed sympathy and empathy for such individuals, and believed in supporting an extended community of Deaf and deaf people, thereby potentially diluting the political project of the Deaf collective. Such complex sentiments and loyalties are noted elsewhere (see Padden 1996; Ladd 2003; Grosjean 1996). Deaf respondents recognised the importance to the membership of education about the nature of being Deaf and the importance of confidence building and recognising and enhancing the skills already present within the collective. Indeed, some Deaf Studies academics argue (see Ladd 2006a) as have European Deaf scholars long claimed, that the language of the Deaf collective may have much wider utility. Thus if deployed universally, signed language as a single international language system with the additional core inclusion of Deaf contributors, has the potential for accelerating social and economic development.

All Deaf respondents aimed to professionalise their organisations but in a context of financial difficulties that impeded an investment in human resource capacity. Their Deaf staff also suffered from being an unrecognised cultural minority that had not been able to access mainstream college courses and therefore most did not have pre-existing qualifications. Organisations need to orient their operating knowledge and practice to their values (Reed 1992) and hence it was perhaps predictable that Deaf organisations would seek to enhance the skills and competences of their staff via educative and training processes, employing Deaf teachers to develop staff capacities. The matter of 'expertise' within the Deaf organisations and within the wider collective stems in considerable part from the knowledge generated through the culture of Deafhood (Lane *et al*., 1996). Deafhood means 'the development of a larger collective Deaf identity, and indeed of a network of national and international Deaf communities' (Ladd 2003:109). If this collective and its communal knowledge is the root to counter normative assumptions held by the hearing world this poses the question, what is the strength of Deafhood and does it lend itself to an authoritative voice that can challenge hearing colonisation? It would seem evident that Deafhood remains at a more grass roots

level and is yet to neutralise the power of hearing mainstream society over the collective cultural and language values of Deaf people and their journey to full human status (Ladd 2003:114).

Chapter 9

Conclusion

Reasons for Research: Exploring the Circumstances of an 'Invisible' Minority

The social science path of exploring 'the unexplored', and the possibility of partaking in discovery of the 'different' social activity of a particular minority group in their regular living, is intrinsically interesting and rewarding (Hayden 2000). What is of additional interest is exploration of a social group which is relatively 'unexplored' because it is perceived by a majority system of belief which objectivises and generalises its own values and norms and in so doing impedes an alternative understanding of minority worlds – such as the Deaf collective (see Pestello and Saxton 2000; Rosenau 1992). The minority group in question is labelled by powerful institutions as comprising physically defective people having a medical impairment – they are deaf (Hansard 2007) and thereby socially disabled too. By contrast, those so defined often label themselves as being members of a collective that owns a distinct cultural, language and political identity (Lane *et al*., 1996). Society and its key welfare institutions may be largely ignorant of this minority world through an unshakeable assumption that one needs to have a certain oral 'ability' to function as society expects: thus 'social policy has constructed its own truths and legitimations for its own normalisation process' (Gibbins 1998:42). This thesis has sought to explore the understandings held by elites who represent selected key institutions as well as leading figures in the minority group which the majority categorise as 'disabled'. The study has attempted to reveal aspects of the minority group's independent and collaborative functioning. It has attempted to examine how welfare institutions which claim responsibility for this minority do so as individual clients and not as a collective. I was interested to investigate how these two perspectives might conflict conceptually and practically and to explore why these very different worldviews do not seem to clash within the discursive realms of welfare policy and related research. In short, the two worlds of the Deaf and the hearing institutions of welfare do not appear to converge or indeed overlap within welfare policy and much of the relevant academic research.

Reasons for Research: Exploring the Minority Perspective

A secondary aspect of research interest derives from a social work academic perspective which is concerned to give means of expression to minority communities, through initiating a platform where their claims to authentic and distinct cultural and political values can be

explored (see Fawcett and Featherstone 1998). This can be a difficult balance to achieve in that research can sometimes provoke or alienate elements of the minority one wishes to explore. Thus, one senior Deaf leader I approached to request an interview responded that their involvement in my research would surely collude in reinforcing a paternalistic hearing oppressive perspective which endorses a limiting conceptualisation of Deaf people (see chapter 4, page 82). The respondent could not envisage that social science research would benefit the minority in question particularly where the minority may well want to lead or participate jointly in this field of academic research (see also Carter 1998). Thus, the fascination of this specific domain is that being Deaf has largely been understood hitherto via the conventional values of the cultural majority, including social science research too, hence a more open and properly informed grasp of their world became a primary motive for this study.

Limitations to the Research

Notable limitations of the study were experienced in relation to scale, time and resource. Researcher identity and background will also have affected the collection and construction of data and subsequent analysis. The research comprised in essence a comparative design based upon two phases of in depth interviews with targeted Deaf and hearing elites in the UK but particularly Wales. Predictably, not all those invited for interview came forward. Given more time and resource I could have extended the study to different countries in order to compare policy perspectives. The length and depth of the project would have been extended significantly in that regard. However, it proved feasible only to generate a modest purposive sample of (a) Deaf organisation leaders and (b) hearing welfare elites. My primary focus however was upon the individual and shared experiences of key participants in the Deaf collective. Here, I often felt 'disabled' myself in that I did not share an authentic cultural affinity with Deaf people. If I were Deaf I might have been able to establish a more empathetic and nuanced degree of engagement (although I would then have had to interview hearing respondents with an interpreter with all the cultural complications this might engender, see chapter 4 p85).

Resources were limited not least because this area of Deaf Studies and this area of social science are both an emerging field. On occasion relevant academic journals (British and international) were difficult to source and took time and persistent requests and searching.

The Research Scope

I chose not to focus on 'service users' due to my research interest in structural or institutional themes around decision making and policies having a direct impact upon this minority collective. I also could not focus on 'service users' as a labelled group of people, where grounds for such labels and their underlying assumptions were challenged by the very minority studied. Thus I focussed on elites of the Deaf collective from England and Wales most of whom were leaders of third sector charitable organisations which served their regional collective in facilitating support, education and engagement. My interest lay in these individuals' own experiences, motivations, and ambitions for the promotion of the Deaf collective as a recognised group in mainstream society. I also interviewed a purposive sample of hearing decision makers from key public welfare institutions, the policies of which directly affect Deaf organisations and /or Deaf people, and by extension the Deaf collective. From these respondents I wished to ascertain hearing normative perspectives about the identity, status and capacity of Deaf people in society. I did not focus on the education system as relating to Deaf people, but rather on the policies and practices of public welfare, as in Ladd's (2003) exploration of hearing colonisation which describes majority institutional policy directions and public social services (see chapter 1, page 7).

Methods and Methodology

I constructed the methodology and methods (see chapter 4) in such a way as to make it possible that another social science researcher could replicate much of my research design and data sourcing. However the nature of qualitative research is that the relationships developed between researched and researcher co-create the data obtained and this would suggest that a replicated study could produce a different analysis of social patterns. Through using a mixed methodological approach of narrative analysis, interactionism and post-modernism, it became possible to produce rich and extensive data sources which were categorised and challenged according to a reflexive and deconstructive analysis. The data from Deaf and hearing respondents provided contrastive insights and recurrent categories that allowed for modest comparison within and across samples. However it was recognised that my categories and interpretations cannot be assumed as fixed and immutable, for as Roseanau states:

> representation takes for granted the referential status of words, images, meanings and symbols; it assumes that each constitutes a fixed system of meaning, and that

everybody understands them ...the same way. An anti-representational stance assumes the opposite: many diverse meanings are possible for any symbol, gesture, word and these diversities are to be explored (Roseanau 1991:96).

Thus, the qualitative small scale nature of this research adopted the above view that the findings of this thesis are not generalisable, but rather, exploratory and indicative. I now turn to the core research questions and related findings.

Answers to Research Questions

On whose terms is the societal presence of Deaf people and the broader Deaf collective to be based and understood?

The first findings chapter demonstrated the life-course vulnerability of Deaf respondents and the personal impact upon them of internalising objectivised mainstream values. The chapter traced their pivotal realisation and transition to being Deaf upon securing membership of their collective and through this learning to question, challenge and re-learn their identity and purpose. The second findings chapter revealed a shared sense of frustration by Deaf respondents at the way the collective is, in their view, either denied recognition or ignored by institutional decision makers in welfare policy or funding. This frustration that Deaf people are still only recognised as having invalidity and requiring intervention or cure led respondents to report a lack of credence for their collective as worthy of public investment in their untapped cultural and economic capital as opposed to recipients of welfare funding (see chapter 6, page 145 and chapter 8, page 199). The third findings chapter explored the perspectives of the public sector decision making hearing elites vis a vis Deaf people and their collective. Their general perception was that hearing welfare institutions were legitimately placed to respond to the needs of Deaf people as individuals or as a community, in terms of the provision of support and funding. This was grounded in an explicit institutional ordering of Deaf people as typically having medical impairment as well as a social disability, whilst a hearing minority discussed an idea of Deaf people as having a united identity.

But typically, mainstream public welfare institutions and their policies do not appear to recognise Deaf people existing as a collective. Hence the Deaf collective cannot be somehow 'socially included' in the mainstream because of their own rejection within the normative assumptions at play. The societal presence of the Deaf collective is hence to be based and

understood from their own perspective and to the seemingly few extended mainstream partners with whom they work successfully.

What is the nature of Deaf led membership organisations, and what is their purpose and authority in relation to the Deaf collective?

Deaf led membership organisations confidently uphold the principle of Deaf people controlling and supporting their own groups. However, their varying positions of financial vulnerability and their need to survive lead to some equivocation over aims and ideals. Deaf led organisations are made up of members where individuals are not automatically cast as service users but participants in cooperatives developing shared skills of support, education and empowerment. Where SLAs (service level agreements with social services departments) are held by them, Deaf led organisations are also funded to carry out a more social work oriented engagement with D/deaf people. It was notable that where Deaf organisations had partnerships with organisations intended to support deaf people, their work was divided into support for medically deaf people as well as cultural, linguistic and political Deaf projects. Deaf respondents reported their organisational purpose and authority as representatives and co-ordinators of their regional or national collective. Organisational visions typically involved a desire to serve members of their collective and to enhance their lives through cooperative development, with members often becoming staff.

What is the understanding that hearing elites in public sector institutions possess of Deaf organisations and their collective?

The extent of recognition and understanding of Deaf organisations by hearing elites in mainstream public welfare hearing institutions ranged from severely limited (on the part of the majority of the phase two sample), to an appreciation by a few respondents of a need for Deaf organisations to challenge existing systems and to develop their own authentic profile. Hearing respondents typically displayed little or no knowledge of Deaf organisations or the Deaf collective. It appears therefore that Deaf organisations as culturally, linguistically and politically independent bodies have limited relationships with prominent public sector institutions (see chapter 7, page 180). Hearing elites defended the provenance of their policies (which assume Deaf people's need and vulnerability), by reference to a traditional but still fundamental construction of Deaf people as having medical impairment and consequently a social struggle to communicate or function. Hearing elites tended to dismiss the notion of the Deaf collective as some relevant and viable entity where they had not previously known of it.

What typifies the normative relationships between hearing institutions and Deaf people and their representative organisations?

The research depicted varying senses of collective confidence in terms of Deaf respondents' own societal positioning and their commitment to initiating change via their organisations, despite an apparent clarity about their own Deaf identity. A crucial issue appears to be the extent that Deaf people more generally can reject the internalisation of a hearing oralist and welfarist identity deriving from their upbringing as requiring 'help' to survive. Ladd (2003:428) suggests that Deaf people should be enabled to explore their 'cultural consciousness' through future research participation, in order that they learn 'how colonialism has shaped their own responses, ...(and how) certain 'Deaf ways' are internalisations of colonial features'. Deaf respondents claimed their organisation mission was in part to educate members in order to challenge their expectations. Such Deaf understanding could in Ladd's view (op cit) lead to 'accelerated action and conscious cultural renewal'. Deaf organisations typically appear to address political challenges in the form of discrete reactive responses to government research or policy. Were they to initiate a more controversial and proactive challenge they would perhaps be ignored by or perceived as engaging in infantile or revolutionary action by mainstream society. An instance of this may be noted in an interview in which a hearing elite respondent immediately dismissed the idea of Deaf people existing as a purposive group with a distinctive identity:

> I: do you see a difference between deaf people who *don't* sign, who use English, and class themselves as impaired – and Deaf people *who sign*, and see themselves as a different language and cultural group?
>
> S: Well that's obviously a communication skill that some have and others haven't. *No I wouldn't think so.* They *all* have impairment.

Such deep rooted and fixed viewpoints of d/Deaf as impaired and disabled would seem to illustrate the challenges faced by the Deaf collective in persuading key opinion formers and institutional leaders of the significance and value of their culture, heritage and language. An institutionalised statutory welfare system directs that Deaf people remain categorised as they have been since the 1948 Act (see chapter 2, page 16). Welfare ideology may promote the continuation of a mainstream interpretation of the identity of Deaf people, and consequently shape their public profile and engagement with governmental and other decision making bodies, even with the new replacement Care and Support (currently) Bill (www.justice.gov. uk/lawcommission/areas/adult-social-care 2012). An institutionalised 'known' may mould the

perceptions of society (both hearing and Deaf people), as well as mould Deaf people's perceived abilities to challenge such an established norm.

Why do the two worlds of Deaf-led services versus hearing-led services for Deaf people appear not to overlap?

The question of why the two worlds of Deaf-led services and hearing-led services do not appear to mesh or overlap, whilst having a common concern for the same minority (and particularly when these two outlooks seem to conflict), is complex to answer. Findings suggest that hearing-led welfare services tend to work with that (presumably) minority proportion of cultural Deaf people who have not challenged or are content with their internalised view that they function in large part through their dependence on social services. In contrast, those who are active members of their Deaf-led collective were deemed by Deaf respondents to be significantly larger in proportion – irrespective of whether they attended to facilitate events and participate proactively, or engage to receive assistance. That is, the two service worlds are working with *different* cultural Deaf people. Yet both types of Deaf people may, for example, play bingo together on a club night, yet may not challenge each other about their political views on being Deaf at a social evening, just as the Deaf collective may not initiate challenges in their dealings with hearing institutions, or indeed challenge aspects of their own collective identity deriving from normative assumptions about their impairment and supposed social vulnerability. Indeed some academic schools of thought, and those of mainstream social work research as well as Deaf Studies research, may recycle deep-rooted assumptions derived from their mutually exclusive world-views, so that their intellectual paths do not converge, let alone cross. The policies of key public bodies similarly may not have been sufficiently challenged given that representative hearing elites in this study were typically unaware or not persuaded of the viability and value of the Deaf collective.

How far are these matters of concern to either the Deaf or the hearing party, and in what ways?

The findings from this study suggest that Deaf-led organisations exist to maintain a political identity, and to support and educate fellow Deaf members informed by core values emanating from their unique language and culture. But the research in reflecting the views of both samples does not demonstrate that Deaf people and their collective have secured a distinctive and widely approved societal profile. The hearing elite's perceptions of Deaf led organisations are not how the Deaf collective wishes its organisations to be understood. Deaf-

led organisations typically avoid a focus on deafness and on medical notions of impairment and are not run by hearing welfare professionals. They exist as third sector charitable bodies, which raise money to fund co-produced projects with their members. The typical purpose of these organisations is to promote Deaf identity as an approved social status and to educate their members in securing this. Owing to the widespread ignorance about the Deaf collective, mainstream institutions are unlikely to challenge their own oralist and welfarist ideologies (Batterbury *et al.,*; Lane 2005), or facilitate a radical and determined investment programme that will help mainstream Deaf people into economic life.

Hence, Deaf organisations may need to radicalise their political stance in order to persuade public institutions that they are a significant constituency in size and number and exist as a valid social entity. Partnerships among Deaf organisations may be one way to validate and bring together the claims of their collective. Those Deaf organisations which accept funding tied to mainstream and dominant values of disability and deafness may contribute to some occlusion of the ideals of the Deaf collective. How far these matters are a pressing concern to Deaf people as well as hearing people is unknown. Thus the social position of Deaf people in UK society as well as the institutional location and future of the Deaf collective is difficult to predict but will doubtless evolve and change as has been the case for hundreds of years. From the perspective of Deaf supporters there is the hope that the collective's profile and significance will slowly return to its former prominence in the 1830s Paris Banquets and the related Deaf public profile (see Ladd 2006b). However, the perception of public service hearing elites in this study suggest that Deaf people and their culture and collective are barely acknowledged let alone visible in any purposive political form.

Recommendations for Deaf Studies research

Recommendations deriving from this study apply at different levels. In terms of academic enquiry Deaf Studies researchers could investigate more deeply the consequences of 'the hearing colonisation' of Deaf people by encompassing hearing as well as Deaf people as research subjects. This may help illustrate more clearly the challenges to political and economic significance that the collective can anticipate from majority society which categorises Deaf people in ways that are incompatible with how they wish to be understood. These fundamental differences of perspective could be illuminated and exposed to more thoroughgoing critique. Deaf academic studies could also examine the domain assumptions of statutory welfare organisations that position Deaf people as vulnerable individuals who are

in principle eligible for social services assessment and intervention. Such studies could investigate why this deep-rooted, seemingly unshakeable institutional belief continues.

Recommendations for Deaf sector partnerships

Deaf Studies centres, in association with Deaf-led third sector organisations, could initiate research, as well as facilitate group dialogue opportunities for the wider membership of the (British) Deaf collective to explore the extent to which they may have internalised values associated with hearing colonisation – particularly relating to oralist and welfarist aspects. Deaf Studies could explore the notion of 'Deafhood' to enable a deeper and more authentic understanding of the social and cultural contours of Deaf identity and its associated value system (as discussed by Ladd 2003). Such insights may help Deaf organisations to develop their organisational vision with new meanings and aspirations and to promote a more engaged participation and contribution from its membership. Deaf organisations and Deaf Studies centres may benefit from collaboration in this endeavour, furthermore, partnership between the two bodies may help reduce their respective isolation caused by the 'fixed' and seemingly immutable barriers of mainstream ordering in respect of impairment. Such collaboration might enhance access to and negotiations with governmental and welfare institutions in order to persuade policy makers of the existence and virtues of the Deaf collective and thereby initiate some change.

Recommendations for social science research

British universities should consider the case for inviting Deaf Studies to become a more prominent element of the social science academy. Those universities with Deaf Studies could become beacons in their field. Social science researchers, both Deaf and hearing, could conduct essential investigation into the institutional categorising and ordering of Deaf and particularly the issues of equity and distributive justice in relation to the proper economic contribution of Deaf people, as well as revealing more of the authentic character of Deaf heritage, culture and language. In accepting pluralism and diversity (as is the claim of much UK public policy) governments are expected to engage with third sector organisations in order to achieve the representation of all equalities strands (for example see - wales.gov.uk/topics/equality October 2012). In so doing, government and its administrative policy arenas should, with the support of Deaf Studies centres and social science research, debate with vigour the ethics and continuing relevance of mainstream welfare and linguistic definition of Deaf people.

Finally, it is recommended that at the next four yearly World Congress of the Deaf to be held in 2015 (see World Federation of the Deaf 2012) invitations should be extended to key hearing opinion formers from policy and the academy who would accordingly meet and engage with members of the international Deaf collective. Signed language is of course the medium of presentation by Deaf leaders who use such Congresses to influence international politics to help re-align the place of Deaf people in society. This occasion would offer to hearing witnesses an externally visible international initiation of a Deaf presence and signal its rightful claim to an equal share of institutional recognition from mainstream policy and academic circles.

References

Aberbach, J. and Rockman, B. (2002) 'Conducting and Coding Elite Interviews', *PS Online,* www.apsanet.org December pp. 673 – 676.

Agboola, I. (2006) 'A comparative investigation of entrepreneurship among Deaf populations in developed and developing countries', in Goodstein, H. (ed), *The Deaf Way II Reader*, Washington D.C., Gallaudet University Press.

Ahmad, W., Darr, A., Jones, L. and Nicar, G. (1998) *Deafness and Ethnicity Services, Policy and Politics*, Bristol, The Policy Press.

Alker, D. (2000) *Really not interested in the Deaf?*, Darwen, Lancs., Self-published.

Anderson, B. (1999) *Imagined Communities*, London, Verso.

Atkinson, P. and Housley, W. (2003) *Interactionsim*, London, Sage.

Bahan, B. (2004) 'Memoir Upon the Formation of a Visual Variety of The Human Race' in Eldredge, B., Stringham, D. and Wilding-Diaz, M. (eds), *Deaf Studies Today: A Kaleidescope of Knowledge, Learning and Understandin*g, Utah State Valley College, Orem.

Bahan, B. (2006) 'Face-to-face tradition in the American Deaf community: dynamics of the teller, the tale, and the audience', in Bauman, H-D., Nelson, J. and Rose, H. (eds), *Signing the Body Poetic: Essays on American Sign Language Literature*, Berkeley, University of California Press.

Baker, M. (2006) *In Other Words: A Coursebook on Translation*, London, Routledge.

Baker-Shenk, C. (1986) 'Characteristics of oppressed and oppressor peoples: Their effect on the interpreting context', in McIntire, M. (ed), *Interpreting: the art of cross-cultural mediation*, Silver Spring, MD, RID Publications.

Bang, H. (2003) (ed), *Governance as social and political communication*, Manchester, Manchester University Press.

Banks, S. (2001) *Ethics and values in social work*, Hampshire, BASW, Palgrave.

Barnes, M., Gell, C. and Thomas, P. (2010), 'Participation and Social Justice', in Greener, I., Holden, C. and Kilkey, M. (eds), *Social Policy Review 22 Analysis and Debate in Social Policy 2010*, Bristol, Policy Press.

Barth, F. (1966) '*Models of social organization', Royal Anthropological Institute Occasional Paper,* No. 23, London.

Batterbury, S.C.E., Ladd, P., Alker, D., Gulliver, M., Turner, G. H. and Krausnecker, V. (2003) 'An agenda for change: principles and guidelines for policy making and research in Deaf-related areas', *Deaf Worlds International Journal of Deaf Studies*, 19(2) pp. 66 – 77.

BBC Radio Four, (2008) 'The Today Programme', March, www.bbc.co.uk/archive.

BBC Radio Four, (2008) 'The moral maze', March, web-archive www.bbc.co.uk/archive.

BBC Radio Four, (2008) 'The Right to be Deaf: Stop Eugenics!' March, www.bbc.co.uk/archive.

BBC Radio Two, (2008) 'Jeremy Vine Show, Deaf Babies, Stop Eugenics!' March, www.bbc.co.uk/archive.

(BDN) British Deaf News, (2010) 'BSL as a tool for English?', *British Deaf News*, February, pp. 10 – 11 London, British Deaf Association.

(BDN) British Deaf News, (2003) 'Recognition of BSL the first step', *British Deaf News*, April, pp. 6 – 7 London, British Deaf Association.

(BDN) British Deaf News, (1994) 'Deaf people and self-employment', *British Deaf News*, June, pp. 8 - 9 London, British Deaf Association.

Becker, H. (1970) 'Whose Side Are We On?' in Douglas, J. (ed), *The Relevance of Sociology*, New York, Appleton-Century-Crofts.

Becker, H. and McCall, M. (1990) 'Introduction' in Becker, H. and McCall, M. (eds), *Symbolic Interaction and Cultural Studies*, Chicago, The University of Chicago Press.

Berman, A. (2005) 'Translation and the Trials of the Foreign', in Venuti, L. (ed), *The Translation Studies Reader*, London, Routledge.

Berry, J. (2002) 'Validity and Reliability Issues in Elite Interviewing', *PS Online,* www.apsanet.org December, pp. 679 – 682.

Bienvenu, M.J. (1993) 'Deaf studies in the year 2000: new directions', in (ed), *Deaf Studies III: Bridging Cultures in the 21ˢᵗ Century*, Gallaudet University, College for Continuing Education, pp. 7 – 18.

Blee, K. (2007) 'Ethnographies of the Far Right,' *Journal of Contemporary Ethnography,* 36 (2) pp. 119 – 129.

Bloor, M. (1997) 'Techniques in Validation in Qualitative Research: a Critical Commentary', in Miller, G. and Dingwall, R. (eds), *Context and Method in Qualitative Research*, London, Sage.

Blum-Kulka, S. (2005) 'Shifts of cohesion and coherence in translation' in Venuti, L. (ed), *The Translation Studies Reader*, New York, Routledge.

Bochel, C. and Bochel, H. (2003) *The UK Social Policy Process*, Basingstoke, Palgrave, Macmillan.

Borges, S. (1986) 'A feminist critique of scientific ideology: an analysis of two doctor – patient encounters', in Fisher, S. and Todd, A.D. (eds), *Discourse and Institutional Authority: Medicine, Education and Law*, New Jersey, Ablex Publishing.

Branson, J. and Miller, D. (2002) *Damned for Their Difference The Cultural Construction of Deaf People as Disabled*, Washington D.C., Gallaudet University Press.

Breivik, M. (1999) 'Deaf cultural identity politics in Norway', *Deaf Worlds International Journal of Deaf Studies*, 15(2) pp. 21 – 32.

Brinberg, D. and McGrath, J. (1985) *Validity and the Research Process*, London, Sage.

Brislin, R.W. and Cushner, K. (1996) *Intercultural interactions: a practical guide*, Thousand Oaks, Sage.

British Deaf Association, (2004) Deaf Equality course material (unpublished)

British Sociological Association (The) (BSA): Statement of Ethical Practice (2002) www.britsoc.co.uk/equality/63.htm (accessed April 2012).

Bryman, A. (2004) *Social Research Methods*, Oxford, Oxford University Press.

Burke, P. (2005) *History and Social Theory*, Cambridge, Polity Press.

Burns, S., Matthews, P. and Nolan-Conry, P. (2001) 'Language attitudes', in Lucas, C. (ed), *The Sociolinguistics of Sign Languages*, Cambridge, Cambridge University Press.

Butler, I. (2003) 'Doing good research and doing it well: ethical awareness and the production of social work research', *Social Work Education,* 22(1) pp. 19 – 30.

Campbell, R., Dodd, B. and Burnham, D. (1998) 'Introduction', in Campbell, R., Dodd, B. and Burnham, D. (eds), *Hearing By Eye II Advances in the Psychology of Speechreading and Auditory-visual Speech*, Hove, Psychology Press.

Cardiff Council, Unified Assessment, (accessed January 2012) www.cardiff.gov.uk/objview.

Cardiff Council, Education policy, (accessed April 2011) www.cardiff.gov.uk/content.

Cardiff University Registry, (accessed June 2008) www.cardiff.ac.uk/regis.

Care and Support Bill 2012, (accessed November 2012) www.dh.gov.uk health/2012/07/ Care and Support Bill.

Care Council for Wales, (2007) Code of Practice for social care workers, (accessed February 2009) www.gscc.org.uk.

Care Council for Wales, (2007) National Occupational Standards, www.ccwales.org.uk/ national-occupational-standards.

Carter, J. (1998) 'Studying social policy after modernity' in Carter, J. (ed), *Post modernity and the fragmentation of welfare*, London, Routledge.

Chaney, P. (2011) *Equality and Public Policy: Exploring the Impact of Devolution in the UK*, Cardiff, Cardiff University Press Wales.

Chaney, P. (2012) 'Quasi-Federalism and the Administration of Equality and Human Rights: Recent Developments and Future Prospects – A Preliminary Analysis from the UK's Devolution Programme' *Public Policy and Administration*, January, 27(1) pp. 69-88.

Chaney, P., Hall, T. and Pithouse, A. (2001) 'Reading the Runes', in Chaney, P., Hall, T. and Pithouse, A. (eds), *New Governance – New Democracy?*, Cardiff, Cardiff University of Wales Press.

Choudhury, P. (1999) 'The significance of empowerment and facilitation', *Deaf Worlds International Journal of Deaf Studies*, 15(1) pp. 39 – 48.

Chronically Sick and Disabled Persons' Act (CSDPA), (1970) London, HMSO, www.legislation.gov.uk/ukpga/1970.

Chukwuma, E., Sutcliffe, R., Macfadden, J., Maximenko, Y., Barber, D. and Brown, B. (2006) 'Successful Strategies for Deaf Business Professionals', in Goodstein, H. (ed), *The Deaf Way II Reader*, Washington D.C., Gallaudet University Press.

Clarke, J. (2001) 'Deaf People and Disability Issues' in Kurht, G. (ed), *Ministry Issues for the Church of England: Mapping the Trends,* London, Church House Publishing.

Clements, L. (2000) *Community Care and the Law*, London, Legal Action Group Education and Service Trust Ltd.

Coates, J. and Sutton-Spence, R. (2001) 'Turn-taking patterns in Deaf conversation', *Journal of Sociolinguistics, November,* 5(4) pp. 507–529.

Code of Ethics for Social Work, (2012) BASW, The Policy, Ethics and Human Rights Committee, (accessed January 2012) www.basw.co.uk.

Cohen, A. (2003) *The Symbolic Construction of Community*, London, Routledge.

Cole, P. (1998) *The Free, the Unfree and the Excluded, a Treatise on the Conditions of Liberty*, Aldershot, Ashgate.

Coleman, J. (1988) 'Social Capital in the Creation of Human Capital', *The American Journal of Sociology, Vol. 94, Supplement: Organizations and Institutions: Sociological and Economic Approaches to the Analysis of Social Structure,* pp. S95 - S120.

Colins, M. (2007) *Achieving in Social Business*, London, Co-op Business Press.

Collins, P. (1998) 'Negotiating Selves: Reflections on 'Unstructured' Interviewing', *Sociological Research Online,* 3(3) www.socresonline.org.uk.

Considine, M. (2005) *Making Public Policy*, Cambridge, Polity Press.

Cooper, D. (2004) *Challenging Diversity*, Cambridge, Cambridge University Press.

Cooper, J. (1983) *The Creation of the British Personal Social Services 1962-74,* London, Heinemann Educational Books Ltd.

Corker, M. (1998) *Deaf and disabled or deafness disabled?,* Buckingham, Open University Press.

Cortazzi, M. (1993) *Narrative Analysis*, London, Routledge Falmer.

Crowe, T. (2003) 'Using Focus Groups to Create Culturally Appropriate HIV Prevention Material for the Deaf Community', *Qualitative Social Work*, 2(3) pp. 289 – 308.

Cutler, M. (2006) 'Minority Group, Majority Space Negotiating Jewish Identity in a Southern Christian Context', *Journal of Contemporary Ethnography,* 35(6) pp. 696 – 728.

de la Porte, C., Natali, D. and Pochet, P. (2009) 'Self-governance through the committees in the open method of co-ordination: the cases of employment and social inclusion', in Sorensen, E. and Triantafillou, P. (eds), *The politics of self-governance*, Ashgate, Surrey.

D'Cruz, H. and Jones, H. (2004) *Social Work Research*, London, Sage.

Daiute, C. and Lightfoot, C. (2004) 'Theory and craft in narrative inquiry' in Daiute, C. and Lightfoot, C. (eds), *Narrative Analysis: Studying the Development of Individuals in Society: Editors' Introduction,* Thousand Oaks, Sage.

Dawkins, R. (2006) *The Selfish Gene*, Oxford, Oxford University Press.

Dean, M. (2003) 'Culture governance and individualisation', in Bang, H. (ed), *Governance as Social and Political Communication',* Manchester, Manchester University Press.

Delamont, S. (2004) 'Ethnography and participant observation' in Seale, C., Gobo, G., Gubrium, J. and Silverman, D. (eds), *Qualitative Research Practice,* London, SAGE.

Denzin, N. and Lincoln, Y. (2000) *Handbook of Qualitative Research*, London, Sage.

Dexter, L. (1970) *Elite and Specialised Interviewing*, Evanston, Northwestern University Press.

Dicks, B., Hall, T. and Pithouse, A. (2001) 'The National Assembly and the voluntary sector: An equal partnership?', in Chaney, P., Hall, T. and Pithouse, A. (eds), *New Governance – New Democracy?,* Cardiff, Cardiff University of Wales Press.

Dickens, D. (2000) 'Attitudes and platitudes: post modernism and interactionist thought' in Denzin, N. (ed), *Studies in Symbolic Interactionism*, vol 23, London, JAI.

Dimmock, A. (1992) 'Deaf people's problems in job opportunities and social integration', in Lee, R. (ed), *Deaf Liberation*, Feltham, National Union of the Deaf.

Dimmock, A. (1993) *Cruel Legacy: An Introduction to the Record of Deaf People in History,* Edinburgh, Scottish Workshop Publications.

Dimmock, A. (1995) *Muted Passion: the Private and Public Career of a Deaf Optimist,* Feltham, British Deaf History Society Publications.

Doe, L. (2007) 'Cochlear implants: are they really a threat to the Deaf community?', *Deaf Worlds International Journal of Deaf Studies,* 23(1) pp. 1 - 17.

Dominelli, L. and Holloway, M. (2008) 'Ethics and Governance in social work research in the UK', *British Journal of Social Work,* Vol 38, pp. 1009 - 1024.

Drakeford, M. (2007), 'Progressive Universalism', in *Agenda,* Institute of Welsh Affairs, Winter, pp 4 – 7, Cardiff.

Dutch, K. (2004) *Deaf biculturalism and the statutory and voluntary service agencies: an exploration of Deaf people's self-identity and their cultural experience of the contrasting services*, Masters Dissertation, Cardiff University.

Dunne, P. (1999) 'The consequences of low levels of Deaf education and political skills', *Deaf Worlds International Journal of Deaf Studies,* 15(4) pp. 11 – 19.

Edwards, B. and Foley, M. (1998) 'Civil Society and Social Capital Beyond Putnam', *American Behavioral Scientist,* September, vol 42, pp. 124 - 139.

Elliot, C. (2007) 'Civil rights, disability discrimination and Deaf people', *Deaf Worlds International Journal of Deaf Studies,* (22)3 p. s88.

Elliott, J. (2006) *Using Narrative in Social Research Qualitative and Quantitative Approaches*, London, Sage.

Emery, S. (2009) 'In space no one can see you waving your hands: making citizenship meaningful to Deaf worlds', *Citizenship Studies*, 13(1) pp. 31 – 44.

Emery, S., Middleton, A. and Turner, G. (2010) 'Whose genes are they anyway?: The Deaf community's challenge to legislation on embryo selection', *Sign Language Studies*, 10(2) pp. 155 – 169.

Eriksson, L. (2009) 'Self-governance in micro level theory' in Sorensen, E. and Triantafillou, P. (eds), *The Politics of Self-Governance*, Ashgate, Surrey.

Esmark, A. and Triantafillou, P. (2009) 'A macro level perspective on governance of the self and others' in Sorensen, E. and Triantafillou, P. (eds), *The Politics of Self-Governance*, Surrey, Ashgate.

Fawcett, B. and Featherstone, B. (1998) 'Quality assurance and evaluation in social work in a postmodern era', in Carter, J. (ed), *Post-modernism and the fragmentation of welfare*, London, Routledge.

FDP (2000) 'Report of the FDP conference', *The Voice,* 3(4) December, London, Federation of Deaf People.

Feldman, M. (1994) *Strategies for interpreting qualitative data*, Volume 33, London, Sage.

Fielding, N. (2001) 'Ethnography', in Gilbert, N. (ed), *Researching Social Life*, London, Sage.

Fine, B. (2010) 'Social Capital' in Cornwall, A. and Eade, D. (eds), *Deconstructing Development Discourse: Buzzwords and Fuzzwords*, Rugby, Practical Action Publishing/ Oxfam.

Fine, G. A. (2001) 'Normative troubles: Social expectations as cultural productions', in Denzin, N. (ed), *Studies in Symbolic Interaction*, Vol 24, London, JAI.

Fine, M. (1994) 'Working the Hyphens: Reinventing Self and Other in Qualitative Research', in Denzin, N. and Lincoln, Y. (eds), *Handbook of Qualitative Research*, London, Sage.

Fitzpatrick, T. (2001) *Welfare Theory an Introduction*, Hampshire, Palgrave Macmillan.

Fitzpatrick, T. (2005) *New Theories of Welfare*, Hampshire, Palgrave Macmillan.

Foster, S. (1994) 'Outsider in the Deaf World: Reflections of an Ethnographic researcher', *Journal of the American Deafness Rehabilitation Association*, 27(3) pp. 1 -11.

Fox, M. (2009) 'The Human Fertilisation and Embryology Act 2008: Tinkering at the Margins' *Feminist Legal Studies,* December, 17(3) pp.333 -344.

Fraser, N. (2009) 'Social justice in the age of identity politics: redistribution, recognition and participation', in Henderson, G. and Waterstone, M. (eds), *Geographic thought: a praxis perspective*, Oxon, Routledge.

Freidman, S. (2002) 'Democracy, inequality and the reconstitution of politics', in Tulchin, J. (ed), *Democratic governance and social inequality,* Boulder, Lynne Rienner.

Gabriel, J. (2000) 'Whiteness: endangered knowledges, endangered species' in Tre-Week, G. and Linkogle, S. (eds), *Danger in the Field: Risk and Ethics in Social Research*, London, Routledge.

Garot, R. (2007) '"Where You From!" Gang Identity as Performance', *Journal of Contemporary Ethnography*, 36(1) pp. 50 – 84.

Geertz, G. (1994) 'Ideology as a cultural system', in Eagleton, T. (ed), *Ideology*, London, Longman.

Gergen, K. J. (2000) *An Invitation to Social Construction*, London, Sage.

Gergen, M. (2004) ''Once upon a time' a narratologist's tale', in Daiute, C. and Lightfoot, C. (eds), *Narrative Analysis Studying the Development of Individuals in Society*, London, Sage.

Gibbins, J. (1998) 'Post modernism, post structuralism and social policy', in Carter, J. (ed), *Postmodernity, and the Fragmentation of the Welfare State*, London, Routledge.

Gold, S. J. (1995) 'Gender and Social Capital among Israeli Immigrants in Los Angeles', *Diaspora: A Journal of Transnational Studies*, Winter, 4(3) pp. 267-301.

Goldstein, K. (2002) 'Getting in the Door: Sampling and Completing Elite Interviews', *PS Online* www.aspanet.org, December, pp. 669 – 672.

Gone, J. P., Miller, P. J. and Rappaport, J. (1999) 'Conceptual Self as Normatively Oriented: The suitability of past personal narrative for the study of cultural identity', *Culture & Psychology*, 5(4) pp. 371 – 398.

Grosjean, F. (1996) 'Living with Two Languages and Two Cultures' in Parasnis, I. (ed), *Cultural and Language Diversity and the Deaf Experience*, Cambridge, Cambridge University Press.

Gutt, E. (2005) 'Translation as an interlingual interpretive use' in Venuti, L. (ed), *The Translation Studies Reader*, London, Routledge.

Gwilym, H. (2007) 'Social Services for Adults', in Williams, C. (ed), *Social Policy for Social Welfare Practice in a Devolved Wales*, Birmingham, Venture Press.

Halfpenny, P. and Reid, M. (2002) 'Research on the Voluntary Sector: an overview', *Policy and Politics*, October, 30(4) pp. 533 – 550.

Hallowell, A. I. (1955) *Culture and Experience*, Philadelphia, University of Pennsylvania Press.

Hammersley, M. and Atkinson, P. (2007) *Ethnography: Principles in Practice*, London, Routledge.

Hansard 672 - 675, (2007) HMSO, (accessed September 2008) www.publications. parliament.uk.

Hardesty, M. (2001) 'Biracial lived experience: From encapsulated to constructive self', *Studies in Symbolic Interaction*, vol 24, pp. 113 – 143.

Hartman, A. (1994) 'Setting the Theme: Many Ways of Knowing', in Sherman, E. and Reid, W. (eds), *Qualitative Research in Social Work*, New York, Columbia University Press.

Harris, J. (1997) *Deafness and the Hearing*, London, Venture Press.

Harriss, J. (2001) *Depoliticizing Development: the World Bank and Social Capital*, London, Anthem Press.

Hayden, K. (2000) 'Stigma and Place: Space, Community, and the Politics of Reputation', in Denzin, N. (ed), *Studies in Symbolic Interaction*,Vol 23, Stamford, JAI Press Inc.

Heath, C. (2006) 'Analysing face-to-face interaction: video, the visual and material', in Silverman, D. (ed), *Qualitative Research: Theory, Method and Practice*, London, Sage.

Heinrich, S. (2010) 'Facing the 'dark side' of deregulation? The politics of two-tier labour markets in Germany and Japan after the financial global crisis', in Greener, I., Holden, C. and Kilkey, M. (eds), *Social Policy Review 22 Analysis and Debate in Social Policy 2010*, Bristol, The Policy Press.

Hermans, D. (2008) 'The relationship between the reading and signing skills of deaf children in bilingual education programs', *Journal of Deaf Studies and Deaf Education,* Fall, 13(4) pp. 518 – 530.

Hollway, W. and Jefferson, T. (2000) *Doing Qualitative Research Differently, Free Association, Narrative and the Interview Method*, London, Sage.

Hull, D. H. and Ruse, M. (2007) (eds), *The Cambridge Companion to the Philosophy of Biology*, Cambridge, Cambridge University Press.

Human Fertilisation and Embryology Authority, (2008) 'Code of Practice 8th Edition (consultation draft)' (accessed January 2009) www.hfea.gov.uk.

Humphries, B. (2003) 'What *else* counts as evidence in evidence-based social work?', *Social Work Education,* 22(1) pp. 81 – 91.

Humphries, B. (1994) 'Empowerment and social research: elements for an analytic framework', in Humphries, B. and Truman, C. (eds), *Re-thinking Social Research*, Avebury, Aldershot.

Huspeck, M. (1994) 'Critical ethnography and subjective experience', *Human Studies*, 17(1) pp. 45 – 63.

Isham, W. (1996) 'The Role of Message Analysis in Interpretation', in McIntire, M. (ed), *Interpreting: The Art of Cross Cultural Mediation*, Silver Spring, MD, RID Publications.

Jackson, P. (1990) *Britain's Deaf Heritage*, Haddington, British Deaf History Society and Pentland Press.

Jackson, P. (2001) *A Pictorial History of Deaf Britain*, Winsford, Cheshire, Deafprint.

Jacobs, L. (1992) *A Deaf Adult Speaks Out*, Washington D.C., Gallaudet University Press.

Jenkins, R. (1996) *Social Identity*, London, Routledge.

Jenkins, R. (2006) *Pierre Bourdieu*, London, Routledge.

Jenson, J. M. (2005) 'Connecting science to intervention: Advances, challenges and the promise of evidence-based practice', *Social Work Research*, September 29(3) pp. 131 – 135.

Johnston, H. and Klanermans, B. (1995) (eds), *Social Movements and Culture*, London, UCL Press Ltd.

Jones, S. (2006) 'Structure and Agency in Deafness Discourse: Binaries of Power', *Deaf Worlds International Journal of Deaf Studies*, (22)2 pp. 59 – 72.

Kannapell, B. (1994) 'Deaf Identity: An American Perspective', in Erting, C. J., Johnson, R. C., Smith, D. L. and Snider, B. D. (eds), *The Deaf Way: Perspectives from the International Conference on Deaf Culture*, Washington D.C., Gallaudet University Press.

Keating, M. (2009) 'Spatial rescalling, devolution and the future of social welfare', in Rummery, K., Greener, I. and Holden, H. (eds), *Social Policy Review 21 Analysis and Debate in Social Policy*, Bristol, Policy Press.

Kerijwal, A. K. (2006) 'Successful Entrepreneurship in Third World Countries', in Goodstein, H. (ed), *The Deaf Way II Reader*, Washington D.C., Gallaudet University Press.

Kincaid, H. and Bright, M. (1957) 'Interviewing the Business Elite', *The American Journal of Sociology*, 63(3) pp. 304 – 311.

King, D. (2009) *The Deaf Genes Fiasco: The Human Fertilisation and Embryology Bill 2008 A Commentary*, UK, Human Genetics Alert.

Kooiman, J. (2006) *Governing as Governance*, London, Sage.

Kyle, J. and Woll, B. (1983) *Language in Sign: an International Perspective on Sign Language'*, London, Taylor and Francis.

Ladd, P. (1992a) 'National Union of the Deaf' in Lee, R. (ed), *Deaf Liberation*, Feltham, National Union of the Deaf.

Ladd, P. (1992b) '1976 – 1986: 'Ten years burning down the road'' in Lee, R. (ed), *Deaf Liberation*, Feltham, National Union of the Deaf.

Ladd, P. (2003) *Understanding Deaf Culture In Search of Deafhood*, Clevedon, Multilingual Matters.

Ladd, P. (2006a) 'What is Deafhood and why is it important? in Goodstein, H. (ed), *The Deaf Way II Reader*, Washington D.C., Gallaudet University Press.

Ladd, P. (2006b) 'Deafhood and Deaf history', *DHI paper Berlin, BDHS Journal,* Autumn, pp. 7 – 12.

Ladd, P., Gulliver, M. and Batterbury, S. (2003) 'Reassessing minority language empowerment from a Deaf perspective: The other thirty-two languages', *Deaf Worlds International Journal of Deaf Studies*, 19(2) pp. 6 – 32.

Lane, H. (1984) *The Mask of Benevolence: disabling the Deaf community*, New York, DawnSignPress.

Lane, H. (1995) 'The Education of Deaf Children: Drowning in the Mainstream and the Sidestream', in Kauffman, J. and Hallaghan, D. (eds), *The Illusion of Full Inclusion: A Comprehensive Critique of a Current Special Education Bandwagon*, California, DawnSignPress.

Lane, H. (1996) 'On Language, Power, and the Deaf', in McIntire, M. (ed), *Interpreting: The Art of Cross Cultural Mediation*, Silver Spring, MD, RID.

Lane, H. (2002) 'Do Deaf people have a disability?', *Sign language Studies*, 2(4) pp. 356 – 379.

Lane, H. (2005) 'Ethnicity, Ethics and the Deaf-world', *Journal of Deaf Studies and Deaf Education*, 10(3) Summer, pp. 291 – 310.

Lane, H., Hoffmeister, R. and Bahan, B. (1996) *A Journey into the Deaf-World*, California, DawnSignPress.

Lane, H. and Bahan, B. (1998) 'Ethics of cochlear implantation in young children: A review and reply from a Deaf-World perspective', *Otolaryngology – Head and Neck Surgery*, 119(4) pp. 297 – 313.

Law, J. (2004) *After Method: Mess in social science research*, Oxon, Routledge.

Lawson, L. (1981) 'The role of sign in the structure of the Deaf community', in Woll, B., Kyle, J. and Deuchar, M. (eds), *Perspectives on British Sign Language and Deafness*, London, Croom Helm.

Lee, R. (2004) (ed), *A Beginner's Introduction to Deaf History*, Feltham, British Deaf History Publications.

Levy, N. (2002) 'Reconsidering Cochlear Implants: The Lessons of Martha's Vineyard', *Bioethics*, 16(2) pp. 134 – 153.

Lieblich, A., Tuval, R. and Zilber, T. (1998) *Narrative Research: Reading, Analysis and Interpretation*, London, Sage.

Lilleker, D. G. (2003) 'Doing Politics Interviewing the Political Elite: Navigating a political minefield', *Politics*, 23(3) pp. 207 – 214.

Lister, C. (1997) *Citizenship: feminist perspectives*, Basingstoke, Macmillan.

Littig, B. (2009) 'Interviewing the Elite – Interviewing Experts: Is there a Difference?' in Bogner, A., Littig, B. and Menz, W. (eds), *Interviewing Experts*, Hampshire, Palgrave Macmillan.

Lomax, H. and Casey, N. (1998) 'Recording Social Life: Reflexivity and Video Methodology', *Sociological Research Online,* 3(2) www.socresonline.org.uk.

Lucas, C. (2001) (ed), *The Sociolinguistics of Sign Languages*, Cambridge, Cambridge University Press.

Lyon, D. (2000) *Post-modernity*, Buckingham, Open University Press.

Lysons, K. (1977) 'The Development of Training for Work with Adult Deaf Persons', *British Deaf News,* London, British Deaf Association.

McMillen, J., Proctor, E., Megivern, D., Woodstock Striley, C., Cabassa, L., Munson, M. and Dickey, B. (2005) 'Quality of Care in the Social Services: Research Agenda and Methods', *National Association of Social Workers*, 29(3) pp. 181 – 191.

McRobbie, A. (1996) *PostModernism and Popular Culture*, London, Routledge.

Maines, D. (2001) 'Musing and Thrashing Around at the Intersection of Symbolic Interactionism and Communication Studies', *Studies in Symbolic Interaction*, vol 24, pp. 51 – 62.

Maines, D. and Palenski, J. (1986) 'Reconstructive legitimacy in final reports of contract research', *The Sociological Review*, vol 34 pp. 573 – 589.

Mallinson, R. (2004) 'Deaf culture: When "positive" is a good thing', *Journal of the Association of Nurses in Care*, 15(4) pp. 21 – 22.

Marschark, M., Peterson, R. and Winston, E. (2005) (eds), *Sign language Interpreting and Interpreter Education: Directions for Research and Practice*, Oxford, Oxford University Press.

Maher, J. (2002) *Seeing Language in Sign*, Washington D.C., Gallaudet University Press.

Mehan, H. (1986) 'The role of language and the language of role in institutional decision making', in Fisher, S. and Todd, A. D. (eds), *Discourse and Institutional Authority: Medicine, Education and Law*, New Jersey, Ablex Publishing.

Metzger, M. (1999) *Sign Language Interpreting: Deconstructing the Myth of Neutrality*, Washington D.C., Gallaudet University Press.

Mitchell, W. (2006) 'Utopian gestures' in Bauman H-D., Nelson, J. and Rose, H. (eds), *Signing the Body Poetic: Essays on American Sign Language*, Berkeley, University of California Press.

Miller, G. and Dingwall, R. (1997) (eds), *Context and Method in Qualitative Research*, London, Sage.

Miller, J. and Glassner, B. (2004) 'The "inside" and the "outside": finding realities in interviews' in Silverman, D. (ed), *Qualitative Research, Theory, Method and Practice*, London, Sage.

Mindess, A. (2006) *Reading Between the Signs*, Boston, MA, Intercultural Press.

Mishler, E. (1984) *The Discourse of Medicine Dialectics of Medical Interviews*, Norwood, NJ, Ablex Publishing Corp.

Monaghan, L. (2004) 'Blossoming: Clayton Valli and the power of sign language', *Deaf Worlds International Journal of Deaf Studies*, 20(3) pp. 274 - 280.

Morning, S. (2006) 'Social Science Research Council Web Forum 'Is race real?'' *On Distinction*, ssrc.org (accessed May 2009).

Morse, J. (1994) *Emerging from the Data, the Cognitive Process of Analysis*, Thousand Oaks, Sage.

Muhs, J. (2002) 'Deaf people as eyewitnesses of national socialism', in Ryan, D. and Schuchman, J. (eds), *Deaf people in Hitler's Europe*, Washington D.C., Gallaudet University Press.

Nagel, J. and Mahr, A. (1999) *Democracy and Democratization*, London, Sage.

Neath Port Talbot County Borough Council Social Services (accessed February 2012) www. npt.gov.uk › Home Page › Health & Social Care.

(NHSCCA) National Health Service and Community Care Act (1990) London, HMSO, www.legislation.gov.uk/ukpga.

Nicholson, L. and Seidman, S. (1995) (eds), *Social Post-Modernism: Beyond identity politics*, Cambridge, Cambridge University Press.

Norris, P. (2002) *Democratic Phoenix Reinventing Political Activism*, Cambridge, Cambridge University Press.

O'Brien, M. and Penna, S. (1998) 'Oppositional postmodern theory and welfare analysis: Anti-oppressive practice in a post modern frame', in Carter, J. (ed), *Postmodernity and the Fragmentation of the Welfare State*, London, Routledge.

Ogunjirin, A. (2006) 'How we can better the lives of Deaf people in developing countries through business investment', in Goodstein, H. (ed), *The Deaf Way II Reader*, Washington D.C., Gallaudet University Press.

Padden, C. and Humphries, T. (2005) *Inside Deaf Culture*, Cambridge, Mass: Harvard University Press.

Padden, C. (1996) 'From the cultural to the bicultural: The modern Deaf community', in Parasnis, I. (ed), *Cultural and Language Diversity and the Deaf Experience*, Cambridge, Cambridge University Press.

Padden, C. (1994) 'The Deaf Community and the Culture of Deaf People', in Gregory, S. and Hartley, G. (eds), *Constructing Deafness*, London, Printer Publishers Limited.

Padden-Duncan, T. (2007) 'On Deaf professionals in management: Exploring the implications of the glass ceiling', *Deaf Worlds International Journal of Deaf Studies,* (23) 2 and 3, pp. s135 – s160.

Padgett, D. (1998) *Qualitative Methods in Social Work Research*, London, Sage.

Parasnis, I. (1996) 'On interpreting the Deaf experience within the context of cultural and language diversity', in Parasnis, I. (ed), *Cultural and Language Diversity and the Deaf Experience*, Cambridge, Cambridge University Press.

Patchett, K., Jones, J. B. and Balsom, D. (2000) *The New Welsh Constitution: The Government of Wales Act 1998*, Cardiff, University of Wales Press Cardiff.

Perry, P. (2001) 'White means never having to say you're ethnic: white youth and the construction of "cultureless" identities', *Journal of Contemporary Ethnography,* 30(56) pp. 56 – 91.

Pestello, F. and Saxton, S. (2000) 'Renewing the promise of pragmatism: towards a sociology of difference' in Denzin, N. (ed), *Studies in Symbolic Interaction*, Vol 23, London, JAI.

Personal communication a: 2010, a hearing member of teaching staff at a college in Wales.

Personal communication b: 2012, a hearing social work academic colleague from Cardiff University.

Personal communication c: 2007, a hearing sociologist from Bristol University.

Personal communication d: 2007, a hearing linguist from Cardiff University.

Personal communication e: 2009, a Deaf colleague from South Wales.

Personal communication f: 2012, a Deaf colleague from Southern England

Personal communication g: 2012, a hearing senior social work practitioner colleague from South Wales

Personal communication h: 2011, a Deaf associate from South Wales

Pickersgill, M. (1998) 'Bilingualism – current policy and practice', in Gregory, S., Knight, P., McCracken, W., Powers, S. and Watson, L. (eds), *Issues in Deaf Education*, London, David Fulton Publishers.

Pinker, S. (1994) *The Language Instinct*, London, Penguin.

Pokorny, D. (1996) 'Cultural and Psychological Dynamics in Court Interpreting', in McIntire, M. (ed), *Interpreting: The Art of Cross Cultural Mediation*, RID, Silver Spring, MD.

Portes, A. (1985) 'Social Capital: Its origins and applications in modern society', in Lesser, E. (ed), *Knowledge and Social capital Foundations and Applications*, Woburn, MA, Butterworth-Heinmann.

Portes, A. (1998) 'Social Capital: Its origins and applications in modern sociology', *Annual Review Sociology,* vol 24, pp. 1 – 24.

Powell, F. and Geoghegan, M. (2004) *The Politics of Community Development*, Dublin, A. & Farmar, A.

Priestly, M. (1999) *Disability Politics and Community Care*, East Sussex, The Gildredge Press.

Prior, S. and Conway, M. (2008) ''All the doors are closing': National Deaf Service Users' Thoughts and Views on Being Deaf, Mental Health and Employment', *British Journal of Occupational Therapy*, March, pp. 95 – 102.

Proctor, R. (2002) 'Eugenics in Hitler's Germany', in Ryan, D. and Schuchman, J. (eds), *Deaf People in Hitler's Europe*, Gallaudet University Press, Washington D.C..

Putnam, R. (2000), *Bowling Alone: The Collapse and Revival of American Community*, New York, Simon Schuster.

Qureshi, H. (2004) 'Evidence in Policy and Practice: What Kinds of Research Designs?', *Journal of Social Work*, 4(1) pp. 7 – 23.

Reagan, T. (2002) 'Toward an 'archaeology of deafness': Etic and Emic constructions of identity in conflict', *Journal of Language, Identity and Communication,* 1(1) pp. 41 – 66.

Reed, M. (1992) *The Sociology of Organisations: Themes, Perspectives and Prospects*, New York, Harvester Wheatsheaf.

Rodda, M., Abel, R. A., Skelton, U., Eldrige, R. W., Warren, F. and Gordon, A. (1979) *A word in deaf ears - A study of communication and behaviour in a sample of 75 deaf adolescents*, London: Royal National Institute for the Deaf (RNID).

Rogers, K., Coyne, S. and Bale, C. (2007) 'The Effect of Early Communication on the Self-Esteem of Deaf People', *Deaf Worlds International Journal of Deaf Studies*, 23(1) pp. 44 – 65.

Roots, J. (1999) *The Politics of Visual Language: Deafness, Language Choice, and Political Socialisation*, Ottawa, Canada, Carleton University Press.

Rosaldo, R. (1989) 'Imperialist Nostalgia', *Representations*, *Special Issue: Memory and Counter-Memory*, Spring, 26, pp. 107 – 122.

Rosenau, P. (1992) *Post-modernism and the Social Sciences: Insights, Inroads, and Intrusions*, Princeton, NJ, Princeton University Press.

Rossman, G. and Rallis, S. (1998) *Learning in the Field*, London, Sage.

Rothman, B. K. (1998) *Genetic Maps and Human Imaginations*, New York, WH Norton.

Royal National Institute for the Deaf, (1999) *Best Practice Standards: Social Services for Deaf and Hard of Hearing People*, London, RNID.

Rubin, H. and Rubin, I. (1995) *Qualitative Interviewing the Art of Hearing Data*, London, SAGE.

Rutherford, S. (1996) 'Funny in Deaf - Not in Hearing', in McIntire, M. (ed), *Interpreting: The Art of Cross Cultural Mediation*, Silver Spring MD, RID Publications.

Ryan, L., Sales, R., Tilki, M. and Siarra, B. (2008) 'Social networks, social support and social capital: The experiences of recent Polish migrants in London', *Sociology*, 42(4) pp. 672 - 690.

Sabatier, P. A. (1993) 'Policy change over a decade or more' in Sabatier, P. A. and Jenkins-Smith, H. (eds), *Policy Change and Learning an Advocacy Coalition Approach*, Boulder, Westview Press.

Sainsbury, S. (1986) *Deaf Worlds: A Study of Integration, Segregation and Disability*, London, Hutchinson.

Sandstrom, K., Martin, D. and Fine, G. A. (2006) *Symbols, Selves and Social Reality*, Los Angeles, Roxbury Publishing Co.

Seidman, I. (1998) *Interviewing as Qualitative Research*, London, Teachers College Press.

Seligson, S. *Should the Deaf be considered an ethnic group?*, www.bu.edu/today/2011 (accessed October 2012)

Shklar, J. (1990) *The Faces of Injustice*, London, Yale University Press.

Silverman, D. (1981) *The Theory of Organisations*, London, Heineman.

Silverman, D. (2001) *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*, London, Sage.

Skinner, D. (2006) 'Racialized futures: biologism and the changing politics of identity', *Social Studies of Science,* 36(3) pp. 459 – 488.

Smith, J. and Sutton-Spence, R. (2007) 'What is the Deaflore of the British Deaf community?', *Deaf Worlds International Journal of Deaf Studies,* (23)1 pp. 18-43.

Sorenson, E. and Torfing, J. (2009) 'The politics of self-governance in meso level theories' in Sorensen, E. and Triantafillou, P. (eds), *The Politics of Self-Governance*, Ashgate, Surrey.

Sorenson, E. and Triantafillou, P. (2009) 'The politics of self-governance: an introduction', in Sorensen, E. and Triantafillou, P. (eds), *The Politics of Self-Governance*, Surrey, Ashgate.

Soukup, B. (2006) 'Changing the World – together', in Goodstein, H. (ed), *The Deaf Way II Reader Perspectives from the Second International Conference on Deaf culture*, Washington D.C., Gallaudet University Press.

Sparrow, R. (2005) 'Defending Deaf Culture: The Case of Cochlear Implants', *The Journal of Political Philosophy,* 13(2) pp. 135 – 152.

Spicker, P. V. (2006) *Policy analysis for practice: applying social policy,* Bristol, Policy.

Stanley, M. (1999) 'The Irish Deaf Society's political developments', *Deaf Worlds International Journal of Deaf Studies,* 15(1) pp. 38 – 46.

(SSIW) Social Services Inspectorate for Wales (2004) *Inspection of services for people with a physical or sensory impairment*, London, Social Services Inspectorate for Wales.

Stokoe, W. (1980) *Sign and Culture*, Silver Spring MD, Linstok Press.

Sutton-Spence, R. (2005) *Analysing Sign Language Poetry*, Hampshire, Palgrave Macmillan.

Sutton-Spence, R. and Woll, B. (1999) *The Linguistics of British Sign Language*, Cambridge University Press, Cambridge.

Taylor, G. (1986) 'Deaf People, Ethnic Minorities and Social Policy', in Gregory, S. and Hartley, G. (eds), *Constructing Deafness,* London, Pinter Publishers.

Tervoort, B. (1983) 'The Status of Sign Language in Education in Europe', in Kyle, J. and Woll, B. (eds), *Language in Sign*, London, Croom Helm.

Tibbets, P. (2000) 'How relevant is the concept of the 'biologic individual' to sociology?', in Denzin, N. (ed), *Studies in Symbolic Interaction*, Vol 23, London, JAI.

Thompson, N. (2001) *Anti-discriminatory Practice*, Basingstoke, Palgrave.

Thompson, R. (2008) *Soil and Slaves: An Environmental History of Northeastern North Carolina 1584 – 1860*, Doctoral Thesis, Cardiff University.

Thoutenhoofd, E. D. (2000) 'Philosophy's real-world consequences for Deaf people: Thoughts on iconicity, sign language and being Deaf', *Human Studies*, 23(3) pp. 261 – 279.

Tucker, B. (1994) 'Deafness – disability or subculture: the emerging conflict', *Third Wave of Disability Movement*, (on-line, accessed October 2012).

Turner, G. (2003) 'Government recognition and £1 million boost for British Sign Language', *Deaf Worlds International Journal of Deaf Studies,* 19(1) pp. s74 - s78.

Turner, G. (2005) 'Toward real interpreting', in Marschark, M., Peterson, R. and Winston, E. (eds), *Sign Language Interpreting and Interpreter Education*, Oxford, Oxford University Press.

Turner, G. (2007) ''I'll tell you later': On institutional audism', *Deaf Worlds International Journal of Deaf Studies,* 22(3) pp. 50 – 70.

Turner, G. H. and Alker, D. (2007) 'Partnership in British Sign Language research and policy development', *Deaf Worlds International Journal of Deaf Studies*, 19(2) pp. 47 – 65.

Vale of Glamorgan Local Education Authority policies (accessed February 2009) www.valeof glamorgan.gov.uk

van Manen, (1990) *Researching lived experience*, London: New York University Press.

Venuti, L. (2005) (ed), *The Translation Studies Reader*, London, Routledge.

Wade, P. (2002) *Race, nature and culture: an anthropological perspective*, London, Pluto Press.

(WAG) Welsh Assembly Government (1998) *A research and development strategy for social care in Wales,* February, Cardiff, WAG.

(WAG) Welsh Assembly Government (2004) *Making the connections: delivering better services for Wales*, October, Cardiff, WAG.

(WAG) Welsh Assembly Government (2003) *The review of health and social care in Wales*, June, Cardiff, WAG.

(WAG) Welsh Assembly Government (1999) *An education & training action plan for Wales*, March, Cardiff, WAG.

Wakeling, P. (2007) 'White Faces, Black Faces: Is British Sociology a White Discipline?', *Sociology*, October, 41(5) pp. 945 – 960.

Wales Gene Park (2008) Information meeting on the Human Fertilisation and Embryology Bill, at Techniquest, Cardiff www.wgp.cf.ac.uk/ProfessionalEducationEvents.

Wallace, A. (2009) 'Governing at a distance? The turn to the local in UK social policy' in Rummery, K., Greener, I. and Holden, H. (eds), Social Policy Review 21 Analysis and Debate in Social Policy, Bristol, Policy Press.

(WCVA) Wales Council for Voluntary Action, (1998) *Building Communities*, September, Caerphilly, WCVA.

(WCVA) Wales Council for Voluntary Action, (2011) *The Third Sector in Wales: State of the Sector Survey Results*, January, Rhyl, WCVA.

Webb, J. (2006) *Organisations, Identities and the Self*, Hampshire, Palgrave Macmillan.

Williams, C. (2007) (ed), *Social Policy for Social Welfare Practice in a Devolved Wales*, Venture Press, Birmingham.

Williams, M. and May, T. (1996) *Introduction to the Philosophy of Social Research*, London, UCL Press.

Wilson, E. (1975) *Socio-biology: The New Synthesis*, Cambridge, Mass, Belknap Press of Harvard University Press.

Wodak, R., de Cillia, R., Reisigl, M. and Leibhart, K. (1999) *The Discursive Construction of National Identity*, Edinburgh, Edinburgh University Press.

Woll, B., Sutton-Spence, R. and Elton, F. (2001) 'Multilingualism: The global approach to sign languages', in Lucas, C. (ed), *The Sociolinguistics of Sign Languages*, Cambridge, Cambridge University Press.

World Federation of the Deaf, www.wfdeaf.org (accessed October 2012).

www.bbc.co.uk/voices/multilingual/bsl today 2008 (accessed June 2008).

www.bda.org.uk (accessed June 2008).

www.bda.org.uk (accessed September 2012).

www.cymdeithas.org/deddfiaith 2008 (accessed June 2008).

www.deaflinx.com (accessed October 2012).

www.guardian.co.uk/society/2012/jun/14/social-care-funding-cuts (accessed June 2012).

www.justice.gov.uk/lawcommission/areas/adult-social-care (accessed August 2012).

www.timebanking.org (accessed December 2008).

www.tutorcare.co.uk/NVQ-Training/Level-5-Diploma-in-Health-and-Social-Care   (accessed
October 2012).

www.wales.gov.uk/topics/equality policy unit (accessed September 2012).

Young, A. and Ackerman, J. (2001) 'Reflections on validity and epistemology in a study of
working relations between Deaf and hearing professionals', *Qualitative Health Research*,
11(2) pp. 179 – 189.

Young, A., Ackerman, J. and Kyle, J. (1998), *Looking on – Deaf People and the Organisation
of Services*, Bristol, The Policy Press.

Young, A., Hunt, R., Loosemore-Reppen, G., McLaughlin, H. and Mello-Baron, S. (2004) 'A
profile of 15 social work services with deaf and hard of hearing people in England', *Research
Policy and Planning*, 22(1) pp. 31 – 45.

Young, I. M. (1990) *Justice and the Politics of Difference*, New Jersey, Princeton University Press.

Young, I. M. (1995) 'Gender as Seriality: thinking about women as a social collective', in Nicholson, L. and Seidman, S. (eds), *Social Postmodernism*, Cambridge, Cambridge University Press.

Appendix A

Samples summary

Phase	Number of respondents	Description
Phase one Deaf chief executives / chairs in England and Wales: 1st interview [Chapter 5]	13 3 as against 10 8 (3 or 5) OR 5 3 or 4 or 6	Total Division of group characteristics according to critical personal history factors of: Parent type – Deaf or hearing School type – residential (with Deaf parents or hearing parents) OR mainstream hearing school with a unit for hearing impaired children Age individual learned BSL, (affected by parent type, school type, or post-school discovery)
Phase one Deaf chief executives /chairs in England and Wales: 2nd interview [Chapter 6]	13	Total Division of group characteristics according to organisational realities, aims and ambitions shaped by financial factors of:

	7	Organisational arrangements of 'self-sufficiency' in income receipt
	4	Organisations holding Service Level Agreements with adult social services
	2	Organisations holding financial partnerships /merger agreements where they also have medically deaf service users
Phase two hearing elites holding public sector office in Wales: 3rd interview [Chapter 7]	9	Total Division of groups according to sector of employment and role:
	2	Politicians of the Welsh Government
	2	Officers of the National Assembly for Wales (includes both the political and administrative arms of the Welsh Government)
	3	Senior officers in adult social services from local authorities in Wales
	2	Third sector policy and engagement facilitator leaders

Appendix B

Interview schedules

Interview 1 (phase one, chapter 5)

What identity did you grow up with?

Has it changed and why?

When did you become culturally Deaf?

How are other parts of your identity significant, compared to your Deaf identity?

Does the BSL language have culture? What is your experience of this?

What type of education did you receive?

What do you believe should be the form of Deaf education?

What is your view on whether Deaf people are disabled?

What is your view on cochlear implants?

What is your view on the Human Fertilisation and Embryology Bill and research into the 'Deaf gene'?

How have you felt socially included or excluded in your life?

What do you believe is the extent of Deaf social inclusion or exclusion in society?

Is there a Deaf ethnicity?

What inspired you to be ambitious in your career?

Interview 2 (phase one, chapter 6)

What alternative to social work do you provide? What is the difference?

Where does the idea come from? What models have influenced the service?

What are you trying to change in the Deaf collective, and in society?

How do you evaluate your provision?

What are the core values of your provision? Is there any conflict in organisational provision and philosophy?

How has your organisation changed?

How does your organisation address needs of members' other identities?

How is your organisational provision and philosophy understood by funders and policy makers?

How do the different funding system sectors work in relation to Deaf people?

What are your networks and communication structures?

Is there any sense of political mobilisation of Deaf organisations? How does this work, and has it changed over time?

What are the levels of organisational training, skills and expertise? How are these acquired and developed?

What is your structure of line management and accountability in provision?

What are your organisation's foremost challenges and priorities for the future?

Interview 3 (phase two, chapter 7): example interview schedule

Interview questions with a senior civil servant

What is the rationale of statutory funding to Deaf people through sensory impairment services? Is this the way forward?

Do you think there are alternative ways that Deaf people could be treated and invested in, in government policy – i.e. other than 'disability'?

Would you say that one purpose of providing social care to Deaf people is to compensate for their lack of social and political opportunities, or is it to fund 'naturally' vulnerable individuals?

From a government perspective, could Deaf people be seen as a purposeful collective under statutory funding conditions?

Could the label of individual need according to sensory impairment conflict with the label of culture and language minority?

How are government policies for Deaf people developed in your department?
Where does the evidence and research come from that you base your policies on?

Is up to date guidance helpful where assumptions of Deaf people's position is of sensory impairment and individual need?

Are Deaf people's organisations proactive in engaging with government on public policy?

How are the needs of the Deaf community commissioned in policy, within local government and third sector frameworks?

How can you consider including Deaf citizens in your policy making, when improving your public services?