

School for Social Care Research



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Research with d/Deaf people

Alys Young
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Methods Review 9

Improving the evidence base for
adult social care practice



The School for Social Care Research

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ABSTRACT

This review specifically concerns social care research with, or in contexts that concern, d/Deaf adults. It addresses: (i) key background knowledge concerning the diversity of what it is to be d/Deaf including the essentially contested nature of the term 'deaf' and its implications; (ii) how the special or additional considerations surrounding what it is to be d/Deaf influence research design (including what happens when these are ignored); (iii) specific issues of innovative or adaptive research practice in research with d/Deaf people or in d/Deaf contexts; and (iv) ethical considerations in carrying out research with d/Deaf people.

RECOMMENDATIONS FOR RESEARCH ON ADULT SOCIAL CARE PRACTICE

Adult social care practice involving d/Deaf people is significantly under-researched and the complexity of these populations rarely recognised. We recommend that:

- A comprehensive review of good social care practice should be undertaken which can evidence appropriate, effective and model approaches which have not been documented from a research perspective.
- Any research which involves the complex populations we might term d/Deaf people must fundamentally recognise the implications of the diversity of the population for the design, practice and validity of social care research.
- The engagement of d/Deaf professionals and service users should be central to the identification of future research priorities and best practice.

KEYWORDS

Deaf, sign language, deafness, hearing loss, Deaf Culture, research methods

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INTRODUCTION

There are many ways to 'be deaf' (Taylor and Darby 2003). Compare for a moment the newborn child, screened for hearing in the first hours of life and diagnosed deaf at two months, with the older person coming to terms with the loss of hearing that accompanies the ageing process. The challenges of acquiring a spoken language in the context of deafness from birth (Stokes 1999) and the challenges of coping with the loss of access to language in the context of sound (Hogan 2001; Morgan-Jones 2001) are barely comparable (Young 2006). Consider the Deaf adult who grew up in a Deaf family, where everyone uses sign language. Deafness was not a barrier to acquiring a full and fluent language because their first language was an entirely visual-spatial one (Sutton-Spence and Woll 2000). They pride themselves on their Deaf heritage and value the culture into which they were born (Padden and Humphries 1988). Their experience is poles apart from the young adult who uses hearing aids and lip-reading to support their preferred use of spoken language. S/he prides themselves on being like everyone else who can hear. In all four of these examples, the individuals might be equally 'deaf' in audiological terms. On a hearing test, each might have a similar degree of deafness. Yet their experiences of the world and their identities are very different. Each has a different relationship with 'not hearing' and a different understanding of what it is to 'be deaf'.

In conventional terms we acknowledge this diversity and the ways in which deafness might be physiological condition and/or identity through the use of lower case 'd' and upper case 'D' (Woodward 1972). Lower case 'd' is generally used to refer to the audiological condition of not hearing and is mostly applied to those who use spoken language. Upper case 'D' is used to mark those who use sign languages such as British Sign Language (BSL) and are members of the Deaf community. In this sense the word 'Deaf' is akin to other markers of cultural-linguistic identity such as French or Polish. As such it is possible for a hearing person to be Deaf (for example, if they grew up in a culturally Deaf family with BSL as a first language). One's hearing status is not the fundamental defining feature of what it is to be Deaf. It is also possible for a culturally Deaf person to be referred to as 'hearing' if they are behaving out of cultural character. Sometimes the inclusive term 'd/Deaf' is used to indicate all, from whatever perspective. We follow these conventions throughout this review while simultaneously unpacking why it might not be straightforward to maintain the distinctions the terminology acknowledges.

In what follows we will consider in detail the implications of how deafness is understood and experienced for the practice of research in general, and social care research in particular. We will analyse the challenges and threats to good quality research with d/Deaf people, consider innovative research practices and adaptations to methods in this context, and discuss ethical practice in research with and about d/Deaf people. The review is confined to research concerning adults but links to d/Deaf childhoods are made as appropriate. The review does not include considerations associated with research with deafblind people or d/Deaf people with disabilities, which encompass additional or specialist issues in their own right.

UNDERSTANDING DEAFNESS

One in seven people in the UK is deaf, if by that we mean people with any degree of hearing that is less than that usually considered the norm for the majority of the population. Around one per thousand children will be deaf in the 0 to 3 age group, with the number doubling to two per thousand in the 9 to 16 age group. Forty-two per cent people aged over 50 and 71 per cent people aged over 70 will experience hearing loss (RNID 2006). BSL is formally recognised as an indigenous language by the UK government (Turner 2003) and is first or preferred language of over 50,000 Deaf people (<http://www.bda.org.uk>). Depending on one's perspective, therefore, deafness is a low-incidence condition affecting few children (DfES 2006); a commonly acquired disability with a significant impact on the health and mental health of older people (Hogan *et al.* 2009); and a defining characteristic of a minority and minoritised community (Ladd 2003). However, the diversity of deafness and d/Deaf people as understood by population, age of onset, degree of deafness, service user group, social context and so forth is in many respects not the most fundamental variable when considering research with d/Deaf people. While they require accounting for, as we discuss later, a greater concern is whether, and how, attention is being paid to the model(s) of deafness that underpin the research and the consequences of these.

In basic terms, we talk about the medical, cultural and social models of deafness (Corker 1998). The first is defined not just by an interest in the physiology of (not) hearing, but rather in the way in which it focuses on deafness as impairment and a deviation from normal functioning. As such deafness is something to be remedied; the goal being to restore hearing in such a way as to enable the individual to function in as unimpaired manner as possible. In the cultural model the emphasis on deafness as loss and deviation is directly challenged by focusing on *being* Deaf as a variety of naturally occurring human identity. This identity is manifest through the existence of Deaf people's own languages (sign languages of each country) and through the cultural ways of being that accompany those language-using groups; for example, norms of behaviour, cultural perspectives, conventions and shared histories (Lane *et al.* 1996; Padden and Humphries 1988). There is an increasing emphasis on the derivation of Deaf identity through the collective/the community (Ladd 2003), rather than in terms of the individual. In the social model of deafness, attention turns to the ways in which society disables those who are deaf, a phenomenon famously termed the phonocentric nature of societies (Corker 1998; Derrida 1976). For example, a deaf person is disabled by a loud speaker announcement at a railway station not because they are deaf, but because that announcement is not accessible in a visual form also. The roots of disability do not lie in impairment *per se*, but/and in the ways in which the social context fails to adapt to enable the participation of its citizens (Oliver 1990; World Health Organization (WHO) 2001).

However, in setting out these differing models in a definitional kind of way, one is apt to create three false impressions. First, that each model is equally accepted and respected in its own right and own terms. Second, that each is mutually exclusive; and third, that their

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co-existence is regarded as benign. None of these impressions is quite correct. The problem is that when one moves from the abstract to the personal (not deafness but d/Deaf people) then the complex interactions between how we see ourselves and how others see us, become manifest. Indeed, as has been pointed out in a different context, the more clearly we define the limits and boundaries of something then the more seriously we start to think about the possibility of transgressing them (Cupitt 1998).

Consider for a moment the culturally Deaf social work professional (first language British Sign Language) who demands the most sophisticated digital hearing aids to assist in accessing the casual conversation of their hearing office colleagues, but who in formal meetings would prefer to make their point in their own first language and would want an interpreter. In their use of audiological equipment s/he acknowledges, be it tacitly, the medical (impairment) model of deafness. The social model of deafness places the responsibility on their employer to provide access through the interpreter provision, without which they will be disabled by them. S/he asserts their cultural-linguistic identity through their preferred means of communication. Seen from this perspective, their life and social actions defy any singular model of deafness. In social research studies concerning d/Deaf people, how individuals have made transitions from deaf to Deaf identity, hearing to deaf identities, and the presentation of self within the cross-currents of Deaf, deaf and disabled attributed identities, have all been legitimate foci of concern (Hogan 1998; Najarian 2008; Valentine and Skelton 2007). Indeed, acknowledging the multiplicity of identity and its fluidity in context is a recurring theme in this field of study (Corker 1998; Davis 1995).

However, recognising the non-essentialist nature of these models is not the same as suggesting that these different understandings of what it is to be d/Deaf command equal acceptance and that they are somehow benign in their manifestations. As has been and continues to be argued, the cultural model is still struggling to be accepted and the cultural identities of Deaf people(s) are ones that have often been denied, diminished and oppressed (Ladd 2003; Lane 1992). It was only in 2003 that the UK government formally recognised BSL as an indigenous language but it still has no legal protection (<http://www.bda.org.uk>). The cruel punishment of children who signed in school is well within living memory (Channel 4 Productions 1999). Recent proposed amendments to the Human Fertilisation and Embryology Act 1990 included a clause that said

that people or embryos known to have a gene, chromosome or mitochondrial abnormality that confers a significant risk of serious physical or mental disability, serious illness or other serious medical condition, must not be preferred over those not known to have an abnormality (Emery *et al.* 2008).

Deafness was given as an example. The subsequent international debate and campaign drew attention to whether and why being Deaf (or indeed deaf) should be regarded as a serious medical condition and the failure to regard d/Deaf and hearing lives as of equivalent worth (Stop Eugenics II 2008).

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So understanding deafness is complex and it is a constructed and contested phenomenon, but why should this matter when thinking about research methods and methodologies? The most basic answer is because what you see is what you get; and failure to recognise this effect introduces error both in the design of research studies and in the interpretation of their findings.

THE INFLUENCE OF MODELS OF DEAFNESS ON RESEARCH DESIGN

At its simplest level, different models of deafness will lead the researcher to focus on different concerns within the same constituency of interest. Take for example, quality of life for older d/Deaf people in care homes. From a medical model perspective, one might be interested in studies which examine hearing aid benefit; from a social model perspective, studies which consider the dynamics of social exclusion; from a cultural model perspective studies which examine the influence of a hearing cultural environment (Young *et al.* 2010). But what if in designing a study of quality of life for older d/Deaf people in care homes, there was little awareness of the various ways to understand what it is to be d/Deaf and their implications, and no acknowledgement of where the study might be situated in relation to them?

In terms of hearing aid benefit, for example, we know that many older people do not wear their prescribed hearing aids (Smeeth *et al.* 2002). However the reasons why an older deaf person might not do so and the reasons why an older Deaf person chooses not to are likely to be very different. For 'deaf' people the transition to hearing impairment is one that is often resisted and thus hearing aids rejected as visible markers of such transition (Jones *et al.* 1987). For 'Deaf' people, hearing aids can represent a view of their identity that they have actively resisted throughout their adult lives – they are not impaired versions of hearing people, they are Deaf people. Consequently they have never worn hearing aids since they were able to exercise a choice about the matter. In terms of social exclusion, the dynamics of uncertain access to spoken conversation might have very different roots depending on one's d/Deaf history(ies). The realignment of social identity to one at the margins of group interactions is a particular challenge to those who lose their hearing (Hogan 2001). Older Deaf adults who sign may have grown up through an education system that compelled them to speak. For them the loneliness of 'the edge of the conversation' (Ladd 1991) is not a new but lifelong experience of social exclusion. From a cultural perspective, the influence of a hearing residential environment is not confined to the lack of access through the spoken word, but encompasses also the influence of cultural oppression it can recreate. As a Deaf research participant commented in a study of older people's care, 'I want to be a name not a number until I die' because for her a hearing care home brought back memories of her residential education in an age when deaf children were known by numbers, rather than their names (Young *et al.* 2010).

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The key issue in working through these examples is that it is not enough to say that different models of deafness might direct the researcher to different concerns. Failure to appreciate and take into account the conceptual differences in how being d/Deaf is constructed and experienced can lead to research designs that are not sensitised enough to the diversity of experience and thus unwittingly produce partial and/or biased results. The history of mental health research with d/Deaf people is a key example in this respect. Failure to account for culturally determined norms amongst Deaf signers has consistently resulted in Deaf people being labelled as deficient and psychologically aberrant (Lane 1992).

THE IMPACT OF UNDERSTANDING d/DEAF PEOPLE ON CHARACTERISING RESEARCH POPULATIONS

Whether carrying out large-scale survey research, or more modestly seeking to record the demographics of a participating sample, there is a requirement to capture the identity/self definition/personal characteristics of those involved. Given our earlier discussion about the different meanings of what it is to be d/Deaf and how deafness as physiological condition and d/Deafness as identity/identities might intersect, such classifications can prove particularly problematic. Unless handled well they may also prove at best misleading and at worst discriminatory.

Ethnicity, deafness and disability

Categories relating to ethnicity and disability appear commonly on questionnaires. From a culturally Deaf perspective, a research participant is unlikely to tick a category marked 'disabled' but might tick an ethnicity category labelled 'other' (i.e. Deaf). Indeed it could be argued that good practice would dictate that Deaf as an ethnic category should be offered when engaging in research that might include Deaf people. However doing so would not enable any easy comparisons to be made with larger national data sets, if one were seeking to establish, for example, the representativeness of the sample. A recent review of all major UK surveys/data sets concerning disabled people with respect to equality does not record or acknowledge any distinction between Deaf people who may be sign language users from all those with hearing impairments, while at the same time drawing attention to differences found with respect to disabled people from ethnic minorities (Purdam *et al.* 2008). It is also important to realise that even if one regards being Deaf as an ethnicity/culture there are still further layers of diversity that require recognition and exert influence, for example being Black and Deaf or LGBT and Deaf, or indeed all three (Harris *et al.* 2009; Luczak 1993).

Disability remains the pre-eminent category of classification in matters of social policy, health and social care practice in relation to d/Deaf people. However there is little consistency. The UK government official definition of disability within the 1995 Disability Discrimination Act (DDA) (revised 2005) includes all impairments to speech and hearing.

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Yet the Office for National Statistics has, for the first time, included a question in the test census about sign language use (ONS 2007) and has subsequently introduced a BSL guide to the 2011 census (ONS 2009) to ensure its accessibility in the same way as they have done for Welsh, thus reinforcing the formal cultural-linguistic status of Deaf people.

It is also common to see distinctions made in datasets on grounds that bear little relationship with an individual's self identity. A common example is data collected on people who are distinguished by 'deaf with speech' or 'deaf without speech'. This categorisation first arose in the National Assistance Act 1948, parts of which remain in current law. Although intended as a functional distinction with respect to communication, it is highly unreliable and rather meaningless. Someone who has experienced a traumatic sudden hearing loss, such as the former MP, later Lord, Jack Ashley might retain excellent speech but have significant problems with receptive language (Ashley 1973). Similarly to classify someone as deaf without speech says little about their communication abilities if they are, for example, a fluent sign language user. The category both discriminates against their preferred language use and fails to recognise inherent abilities. Similar kinds of potential errors and indirect discrimination appear in questionnaire categories where 'deaf' and 'speech impaired' appear as alternatives.

Thinking carefully about even the most basic labels and categories by which to classify research participants is not a matter of political correctness; it is of vital importance if errors are to be avoided in how samples are described and inferences drawn (some guidance on this is given in the section below). Also, as a user of data, being alert to the inherent problems associated with how d/Deaf people are described in datasets is important for evaluating the validity and reliability of any secondary data analysis that might be undertaken.

Asking about communication and language

In research involving d/Deaf people it is often important to find out about how individuals communicate, either for purposes of characterisation of a sample (as above) or in its own right as a research concern. However, asking about communication and language is not straightforward.

Consider the question 'What is your preferred means of communication?', followed by a series of alternatives from which one is instructed to 'tick one'. The alternatives given are: speech; speech with sign; British Sign Language; other, please specify. The first problem is the confusion between 'means of communication' and language. BSL is a language; speech is a means of communication but could relate to any spoken language (for example, spoken English, spoken Hindi, spoken Polish etc.). The second problem is the universal nature of preferred communication implied by the question; namely, that the same means is used in all situations with all people. In fact the opposite is more commonly the case. Deaf children are particularly adroit at matching their chosen communication method and complexity of communication to their interlocutor, for example signing with other Deaf friends, speaking and signing at home, speaking only in the classroom

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(Sutherland and Young 2007). Deaf professionals regularly report the accommodations they have to make with the communication limitations of those around them (Young *et al.* 2000; 2002). Thirdly, such a question fails to distinguish between expressive language and receptive language. A deaf person may speak well but be a poor lip-reader, for example. An older deaf person may indeed prefer speech but to tick that box says little about how their preference is poorly reflected in how much they actually understand of what is spoken to them. It is therefore important to ensure that even the most basic demographic questionnaire distinguishes between expressive and receptive communication and allows a participant enough flexibility in how they reply to indicate situational and contextual differences in both preference and ability.

In summary, characterising a population that includes d/Deaf people is very difficult to achieve with any degree of reliability. Interpretation of data which includes d/Deaf people should be treated with caution unless there is a satisfactory description of how and why the sample is described as it is.

MATCHING LANGUAGE PREFERENCES IN DATA COLLECTION

Given the diversity of what it is to be d/Deaf, ensuring that data collection matches preferences in language and communication is vital for quality research in this field. However, it is not a standard that is necessarily easy to achieve.

Access

In research studies that involve data collection in person (interviews, focus groups, participatory research methods) making the research process accessible is a central concern. For hearing aid users (whether researcher or researched) this means ensuring that the physical environment in which the data are collected is suitable, for example, avoiding reverberant locations. For those for whom lip-reading is a significant part of their communication profile, paying attention to light is important. For example, avoiding situations where light is dim and avoiding situations where light is behind the speaker – both make lip-reading more difficult. Also, it is a common misconception that deaf people are all good lip readers. Only around 30 to 40 per cent of speech is lip-readable and individuals' skills and abilities as lip-readers vary considerably (ALTA undated). For sign language users, ensuring visual accessibility and the avoidance of visual distractions are important. For example, in focus groups, everyone has to be able to see everyone else clearly to follow conversations. Rooms with busy walls, or researchers who sign wearing patterned tops, both create difficult backgrounds against which to 'read' a visual language.

In situations of data collection with Deaf people where the researcher does not sign or does not sign well enough, it is common practice to use an interpreter. What is often not appreciated is that an interpreter does not solve the access problem necessarily and their presence can create additional effects within the research process. In this respect timing is

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crucial. Interview-based data collection methods, in particular, require the development of a good rapport between interviewer and interviewee. Tuning in to the nuances of what an interviewee is seeking to express is not just a matter of content but sensitivity also to affect. A good interviewer will use their awareness of sub-texts (what is hinted but not expressed) and the skills of active listening to help direct the course of the interview and what is covered. However, once an interpreter is used, then the interviewer will always be about a sentence and half behind what the interviewee has said. Consequently, what someone says and how they appear when they say it (for example through body language, facial expression and other kinaesthetic markers) are out of sync. This disjunction can make it more difficult for a non-signing interviewer to pick up on the full range of clues that support empathic and quality interviewing (Hindley *et al.* 1993).

While these kinds of effect might be true of any spoken language research situation in which interpreters are involved, there is an added complication when one of those languages is a signed language: an interpreter has to face the person signing to be able to 'see' what is being said. Consequently their 'voice over' as they interpret will come from a different direction from where an interviewee may be positioned. The hearing/non-signing interviewer is thus faced with the disorientating experience of not being able to look in the direction of where the spoken language message is coming from if they are to maintain eye contact with the person they are interviewing. From a culturally Deaf perspective, the maintenance of eye contact (even from those who may not directly understand what is being signed) is of paramount importance because the person with whom they are communicating is primarily 'visually known'. For that person to look away or to look down is tantamount to indicating they are not interested in the Deaf person with whom they are communicating. A correlate amongst hearing people would be how one might feel if the person you were talking to put their fingers in their ears.

The written word

Paper or electronic based written data collection methods such as questionnaires and surveys are often wrongly perceived to present no barriers to d/Deaf people. It is assumed that the written word is accessible as it is not dependent on aural access. However, deafness can, and for some groups commonly does, interfere with the development of literacy.

For those who acquire a hearing loss in adulthood one would not expect the barriers to literacy to be different from those in the general population. There will be a spread of reading abilities, and failing eyesight, particularly with older age, can make reading more troublesome. Good research practices promoting plain English and clear typefaces/fonts will apply as in other contexts.

However, for those who might have been deaf in childhood the crucial variable is the extent to which childhood deafness interfered with their acquisition of a spoken language. Phonetic awareness is a vital component in our ability to learn to read, and deafness, in many different ways and to different extents, will make access to sound

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unreliable, or partial, or more difficult to interpret correctly. Hearing aids and cochlear implants do not restore hearing; they make the best of what might be accessible for the individual. Consequently deafness interferes significantly in the development of literacy (Mayer 2007; Paul 1998).

Traxler (2000) reports that 50 per cent of deaf students graduate from secondary school with a reading level of fourth grade or less (equivalent to 9 or 10 years old), and furthermore that 30 per cent leave school functionally illiterate (Marshark *et al.* 2002). For deaf children who grow up with BSL as a first language the literacy challenge has an added component: English is tackled as a second language using the resources of their first (which has no written form) alongside varying degrees of phonetic awareness. Consequently, paper or electronic written data collection methods are not an easy fix for making a research project accessible to d/Deaf populations for whom the written word may present varying degrees of difficulty.

Beyond access

Beyond the issues of literacy and access, there are also additional considerations of language *preference*. Just because someone might be able to participate in a research project in one language does not mean it is necessarily their preferred language. This is a consideration in many research projects, not just in those that might involve d/Deaf people. The issue is usually managed by studies being specific about their exclusion criteria (for example, anyone unable to provide data in English is excluded); making their data collection methods available in a variety of languages; or ignoring/not acknowledging the issue. In relation to research studies involving d/Deaf people there are particular problems with all of these strategies.

As we have reiterated throughout this review, d/Deaf people are not just highly heterogeneous in terms of identity, communication and language use, but imposed attempts at differentiation or categorical distinction may be irrelevant to individual realities. Describing someone as profoundly deaf and another as moderately deaf does not define their relative communication strengths and language preferences. Saying a deaf child grew up using spoken language does not predict their adult cultural identity. Describing someone as partially hearing says nothing about their lip-reading ability. Identifying an individual as culturally Deaf does not establish their relationship with the spoken or written word. Consequently, how any individual deaf or Deaf person might respond to a data collection strategy that either ignores the issue of language preference (for example, in just assuming people will participate if they can use English) or makes the use of particular language (such as English) an explicit inclusion category, will have a variety of effects.

For example, to a deaf adult who has acquired their hearing loss with the ageing process, English may be their first language, or may not be for reasons that have anything to do with being deaf. Offering the possibility of completing a questionnaire in their 'preferred' language may result in requests for it in Urdu, for instance. For a culturally Deaf adult

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completing a questionnaire in English may pose few barriers if they are a fluent bilingual. To another it may create misunderstandings. To both it may be politically unacceptable not to be offered the opportunity to participate on equal terms with others for whom English is their first language. For a researcher who makes no distinctions other than 'can the individual provide data in English?', potential differences in the quality of those data and whether they are reliable are not seen, unaccounted for or ignored.

However, until recently, it has not been possible with paper or electronic data collection methods to respond to language preferences if that preference was for a signed language. The advent of web-based technologies, faster broadband speeds and higher resolution web cams has made it possible not only to construct questionnaires in BSL that can be watched rather than read, but also to capture responses in BSL. Participants can sign their replies using web cams and their responses can be remotely securely captured for later analysis (Belk 2010). Web-based applications also enable the possibility of hosting a questionnaire in both English and BSL simultaneously, offering the respondent ultimate flexibility to choose their language of preference, use both, or indeed mix and match the languages of their responses. As any bilingual knows, there are just some concepts better expressed in one language than another. Finally technology has caught up with the flexible and creative language use of many Deaf people.

INSIDERS/OUTSIDERS

Thus far, we have largely focused on issues of identity and language and their implications for research design, data collection and the interpretation of findings. A related concern, particularly with respect to interpretative research methodologies, is the influence of the insider and/or outsider status of researchers and participants. The basis from which we know a situation or experience (our lens, our perspective, our standpoint) is important for what we see, how we tell what we see and how we interpret what is told.

For example, a hearing researcher, however experienced and skilled, has not had the personal experience of growing up as a deaf child. Their resources for interpreting data involving Deaf adults will be very different from those of their Deaf colleague who has been a deaf child. That fact will always be relevant; whether and how it might be significant will depend largely on how the research is conducted. A lack of personal experience of deafness is unlikely to be influential in the mechanics of statistical analysis, but may well be in the development of the questions that have generated the data in the first place (whether they are pertinent and relevant, and whether they demonstrate understanding). It might also be highly relevant to making sense of the data produced, particularly within interpretative methodologies.

A hearing person might understand from a linguistic perspective what is being said or signed, but could they correctly interpret it from a cultural perspective? For example, in a study of the working relations of Deaf and hearing staff in educational and health

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settings by Young *et al.* (2002) the Deaf and hearing researchers both relied on each others' cultural knowledge to make sense of the data and were surprised by what each saw (Young and Ackerman 2001). The hearing staff's lack of confidence in their own professional abilities when faced with Deaf colleagues 'who could sign as if there were no tomorrow' was immediately graspable to the hearing researcher who knew exactly how that felt. The extent of Deaf staff's *personal* hurt when hearing colleagues who could sign chose not to do so around them was missed. The Deaf researcher's immediate identification of the connection Deaf participants made between 'rubbish my language and you rubbish me' was only superficially recognised by the hearing researcher; its origins, resonances and consequences had to be explained.

However, insider or outsider status is not just defined by the sharing or absence of subjective characteristics and experiences (are you Deaf or hearing? Were you deaf from birth or did you lose your hearing?). Nor is it solely attributable to ascribed identities – the way we might be made insiders by others' recognition of what it is we share with them (black and deaf; gay and Deaf). Insider/outsider status is also something that is constructed. Political ideologies, social forces, historical practices and ethical frameworks can all serve to construct some as outsiders, not just because they are 'other', but in how that 'otherness' is portrayed.

For example, well within living memory, sign languages were described to hearing parents of deaf children as akin to the rudimentary communication of animals (Van Uden 1968). Although the grammatical status and linguistic properties of sign languages are well established, their status as equal languages with those which are spoken remains largely socially determined. From a different perspective, hearing habilitation is itself influenced by a kind of historical determinism that has privileged attention to the acoustic properties of sound and the mechanisms of hearing, rather than the ecological experience of the ways in which the world imposes its audibility:

...[because] physicists and anatomists were able to develop their accounts of reality before psychologists and social scientists established independent models of human behaviour... The answer to the question, what does it mean to hear gets literally translated into the mechanical-biological model (Noble 1983 p.327).

In social research with d/Deaf people, considerations of insider/outsider status have become increasingly important in critical analysis of the quality and validity of research studies. In this respect, the objectification of deafness and d/Deaf people and the exclusion of d/Deaf people within research production are key concerns.

The objectification of deafness and d/Deaf people

Consider the difference between a study whose focus is 'the impact of deafness on access to mental health services' and another whose focus is 'the accessibility of mental health services for d/Deaf people'. In the first formulation, the condition of deafness and its consequences (for hearing, sound, communication, understanding and so forth) are

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emphasised and accrue an explanatory authority (be it one to be analysed and documented) in questions of access. The person disappears from view. In the second, *being* d/Deaf (which encompasses issues of identity and subjective experience) is given priority. The ability to respond to the needs and preferences of the person – how accessible are mental health services to d/Deaf people – becomes a guiding consideration (not how does deafness interfere with accessibility). But are such differences only a matter of choice of words and emphasis and therefore of little import?

It could be argued that the two formulations of the focus of the study in this example are quite legitimately constructed to emphasise different sets of considerations. The problem is that the first, in making deafness rather than d/Deaf people its subject, reinforces an approach that defines people by their condition. It makes the consequences of that condition a primary explanatory variable in understanding barriers to access (rather than locating that responsibility with the service that might be inaccessible). Also, from a Deaf perspective, the impact of deafness on accessibility fails to acknowledge the ways in which the person must come first, because being Deaf is an identity not a condition.

What unites all these varied perspectives is a rejection, be it for different reasons, of the objectification of experience through making 'deafness' the focus, rather than engaging with the subjective experience of being deaf or Deaf. Deafness is treated as the object of enquiry and d/Deaf people fail to be visible in comparison with the condition and consequences of deafness. It was partly in response to these kinds of subtle dynamics of exclusion, which construct the person as attached to the deafness, and deafness as the 'lens' through which to understand the person, that the Deaf scholar Paddy Ladd coined the term 'Deafhood' (Ladd 2003). It stands as a Deaf variety of personhood within the spectrum of human diversity. This construction has become its own paradigm informing, amongst other things, research focus, design and practice. (A Google search for 'Deafhood' will reveal around 37,000 hits.)

Exclusion from the process of research production

Whether from a culturally Deaf perspective or more broadly from a disability perspective, d/Deaf people have also been consistently treated as outsiders in research through their construction as the subjects of research – they are the sample, they provide the data. Research is done 'on' them, or 'for' them, but rarely 'with' them, or from and by 'us'. As Oliver (1992) famously remarked, disabled people (a label which in his usage would also refer to deaf people) have been excluded from the 'social relations of research production'. This exclusion is significant because without insider status, d/Deaf people have less opportunity to set the agenda for what should be researched in the first place and how research should be carried out. There are few opportunities for d/Deaf people's experiences to be the interpretative framework through which to understand the data produced and their implications. Consequently the power of research, particularly in the sphere of social research, to influence policy and practice remains within the control of those who are not d/Deaf.

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That said, and with reference to the opening remark of this paper, there are many ways to be deaf. For some deaf people, these considerations of exclusion will be regarded as of little relevance. They do not regard themselves as disabled, they are hearing people with a hearing loss which may not be central to their self-identity and may be regarded as posing few barriers to full participation. For some Deaf people, the disability movement's critique of exclusion from research production does not go far enough. It fails to acknowledge the unequal power differential between languages (the signed and the spoken/written) as a source of academic exclusion and a means of its perpetuation.

The written word remains *the* dominant means of research knowledge production and dissemination. Whether through conference proceedings, journal articles, books, or monographs like this, one's scholarship becomes communicated and enshrined. Once written down, it is searchable by an international community, it is reproducible by electronic means and it is, to a large extent, the currency by which an academic's quality and status is measured. But, for Deaf academics in particular, the written word can pose considerable barriers. These might arise, in part, from the literacy challenges experienced by many d/Deaf people and/or the use of a second language, as previously discussed. However, the barriers are also structural, institutional and political.

It is perfectly possible in this technological era to produce academic scholarship in a signed language and for it to be archive-able, reproducible, searchable and transmittable to others. An academic journal exists, the Deaf Studies Digital Journal, that 'publishes' papers in ASL (American Sign Language) and is accessible through web-based media (<http://dsdj.gallaudet.edu/>). Press releases announcing research findings have been posted in BSL on University websites (for example, the University of Manchester, February 2010). Conference proceedings can be on DVD for those papers given in sign language (see Rogers 2008). However, the overwhelming majority of research scholarship and what comes to be identified as 'evidence' is in written form. Therefore any Deaf academic will in the course of their career be required to carry out the vast majority of their research in that form. Equal status is not afforded to the written and the signed academic paper. Although PhD programmes can be made accessible through the use of interpreters and/or supervisors who sign, the thesis usually requires submission in the written word (although the viva can happen in BSL as a reasonable adjustment allowable under the Disability Discrimination Act 1995).

Also because, until recent times, very few Deaf people have entered academic life and even fewer have achieved positions of seniority, a research lexicon is yet to be firmly established (Jones 2004). For example, in the UK today there are numerous signs emerging for 'quantitative' and 'qualitative' research, but specific terms such as phenomenology or linear regression are yet to be clearly marked in BSL rather than fingerspelled in English. As more and more Deaf academics progress, they will set the signs for the terms which will become standardised (see <http://www.deafacademics.org/>). In sign language, the sign used will be related to the underlying concept of the technical term (not the word in the spoken language). At the moment interpreters, who in many cases are not as academically

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able as the Deaf people for whom they are interpreting, struggle to make sense of the academic concepts for which they seek signs, which can result in a highly unreliable transmission of the source message.

Finally, in terms of the implications of the exclusion of sign language from the academic milieu, a key problem arises when a study may be carried out almost exclusively in one language (sign language) but to gain legitimacy and status within the academic world requires reporting in another (the written word). Here the potential loss is not simply that of meaning (when translation occurs between languages), but also the loss which arises from denial. In reporting the work in a language other than that of its production, one is in a very concrete sense writing out and making invisible one's own language (Temple and Young 2004). For many Deaf researchers this is a particularly difficult issue in that it comes close to contributing to the linguistic and cultural oppression that they would see has been perpetuated on their own communities, at the same time as trying to illuminate to others the concerns of those communities (Young and Ackerman 2001). Hearing academics being prepared to present their work themselves in sign language and the rise of peer-reviewed journals that publish in signed languages are two ways in which the structural inequities between signed and spoken languages within academic research can be practically and symbolically challenged.

ETHICAL ISSUES IN SOCIAL RESEARCH WITH D/DEAF PEOPLE

Standards of ethical conduct in research with d/Deaf people are no different from standards of ethical conduct in research with any population. However the *achievement* and *execution* of appropriate ethical research practice with, and within, these populations may require specific awareness and adaptations to usual practice. Such special considerations are more acute in research involving Deaf people which, for the reasons we have discussed, will fundamentally encompass concerns of cross-cultural ethical research practice (Pollard 1994). However, there are also a range of implications that arise associated with the implications of hearing, the visual-ness of communication and the social constructions of what it is to 'be deaf', that have ethical consequences for the conduct of research. A brief selection of some of the most commonly occurring considerations is set out below.

Is the topic, research study or research question ethical in the first place?

In this era of highly scrutinised research ethics and governance procedures for the approval and formal adoption of research studies, this question of whether a study might be ethical in the first place may seem redundant. If not ethical, then there are plenty of safeguards which will detect it and prevent its execution. However, what is ethical research, particularly in relation to Deaf people, is a hot topic of debate. Beyond issues of whether Deaf cultural-linguistic identity is recognised and afforded equal status and rights, there is significant concern that society is seeking to eradicate Deaf people, either

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directly or indirectly through the consequences of some kinds of research activity.

For example, medical and genetic research is increasingly enabling the detection of deafness pre-birth. Approximately 50 genes as well as over 100 gene loci have been identified so far and the number of distinct syndromes that include deafness as one feature suggest there may be several hundred genes involved in the ear and hearing in total (Hereditary Hearing Loss Homepage 2009; Morton and Nance 2006). The problem in this respect is not the science *per se* but how its implications are being constructed. It is becoming increasingly common to find people talking about the prevention of babies being born deaf. Assumptions are made that futures in which there are no Deaf people are desirable ones, and therefore an appropriate rationale for research activity. For some Deaf people the pursuance of such research endeavours is tantamount to genocide (Ladd 2003).

The debates around genetics research may seem an extreme example and one not immediately relevant to considerations of social care research with d/Deaf people. However it is one example of many kinds of research study that are perceived to reinforce the less desirable status of signing Deaf people, or which structurally reinforce the priority given to other ways to be deaf (Blume 1999). The disparity in funding between cochlear implant research in comparison with sign language/Deaf communities-related research is another often cited example. Funding directed at what is perceived to be a cure and reinforcement of the desirability of speech is not necessarily regarded as ethical by Deaf communities (Ladd 2003). Deaf people's resistance to research in this field which is perceived to represent scientific advance can also, from the opposite perspective, be regarded as unethical (Hagan 2004).

Our point in discussing these examples is that some kinds of research studies which may 'pass' ethical safeguard procedures will not necessarily be regarded as ethical by those whom the research seeks to benefit. Researchers face their own ethical dilemmas about the extent to which a study they are pursuing and their decision about from whom they accept funding, may tacitly support values that are at odds with the values of Deaf peoples and communities.

Informed consent

Many of the considerations we have previously discussed concerning literacy, access and preferred language are highly pertinent to informed consent. Language and communication are key to ensuring maximal understanding and, therefore, optimal conditions in which to arrive at a decision about research participation. However, particularly for signing Deaf people, there are some additional considerations associated with ensuring good processes of consent, beyond those of providing letters of invitation, information materials and consent forms in sign language (see, for example, 'Deaf Approach to Life' project: <http://www.nursing.manchester.ac.uk/deafapproachtolife/>).

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Even if language preferences are fully met, concepts such as 'consent' may be highly unfamiliar. Deaf people commonly are subject to what has been described as a low 'fund of information' (Pollard 2002). Fund of information refers to the accumulated knowledge we all have which has nothing to do with intelligence, but much more to do with those facts we pick up, or that common sense understanding of ideas that we accumulate through exposure to casual conversation and access to media. Think for a moment how much one's understanding of an unfamiliar illness might be shaped by a character in weekly soap opera acquiring and living with it as part of the plot; or how one's geography of the world is picked up through listening to radio programmes over the years, that might not actually be about geography but in which the correspondent is broadcasting from somewhere else. The un-deliberate acquisition of facts, lay understandings and working knowledge is far harder for d/Deaf people to acquire, whether sign language users or not. As the deaf poet David Wright (1969) remarked on going up to Oxford, what he missed was not hearing, but rather 'overhearing', as that was a route by which others were making sense of their new environment and those within it.

Consequently, common sense understandings of important concepts associated with informed consent (including consent itself) cannot be assumed. Delivery of information in BSL does not ensure understanding unless the implications of a participant's fund of information is also taken into consideration. Good practice in this respect includes, for example, checking of understanding and consent through a conversational process that enables the exploration, face-to-face, of the information materials that might have been received. Increasingly, such an approach to consent can be executed remotely through web chat. Broadband speeds are now enabling commonly available applications such as Skype and OoVoo to be effective sign language communication media for research purposes too.

Another important aspect of informed consent when working with and within Deaf communities concerns the small size and closeness of the community. Familial, social and professional networks amongst Deaf people (and some hearing people who might be insiders to different extents) are very tight and overlapping. It is no exaggeration to say everyone knows each other, not just locally or nationally, but also for many people this closeness extends internationally (Ladd 2003). In hearing worlds we may find the 'six degrees of separation' (Guare 1990) maxim quite credible. Amongst Deaf people one can imagine a norm of two degrees of separation at most. For informed consent this connectedness is an important consideration because it is highly likely that a research participant will know, be related to, or have some pre-existing connection with one or more members of a research team, particularly if that team is led by or includes Deaf researchers. The researcher who carries out an interview may in the same week appear in a different guise at a community event or a family party.

Consequently informed consent may involve considerations of who will have access to their data more commonly for Deaf participants than others. Do they want to have their data analysed by people with whom they may have later, ongoing or different forms of

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contact as well? Decisions about whether to be involved in research need to be made in full awareness of the acceptability or not of such implications for an individual (Pollard 2002).

In practical terms, this translates into an approach that ensures all information materials contain very explicit information about who is in the research team and who is likely to see the data (even in an indirect supervisory capacity, for example, in the case of research students). Not only should names be given but it is good practice to include photographs too, so a potential participant is given every opportunity to locate the researcher within their visual memory. To understand the significance of this point it is important to realise that amongst Deaf communities, people are not usually known by their written/spoken name, they are known by a sign name that is given to them (Sutton-Spence and Woll 2000). One may know the face and/or the sign name, but not recognise the written English name, for instance. Small examples like this underline the the primary relevance of cultural competence to ethical research practice with and within Deaf communities and cultures.

Anonymity

Particularly in relation to data collected in sign language, preserving the anonymity of participants can pose complex challenges. Imagine a data set of interviews that have been collected in BSL and the research analysis will be carried out in the source language. The anonymisation of the data set within the process of analysis is more or less impossible. If the data were in a spoken language that is transcribed, then the tone of voice of the interviewee and their visual identity disappear in the transformation of data from sound to orthography.

The visual identity of the Deaf interviewee cannot be covered up through pixelating the face, for example, because a significant part of sign language grammar is conveyed by the face (not the hands). To cover up the face is to render the message unintelligible. Consequently the data source remains entirely recognisable throughout the process of analysis. This lack of anonymity has many practical consequences that are ethical issues; for example, where the data may be viewed. In a shared office of researchers, if the data are viewed on a researcher's computer, others will be able to see who has been a research subject – thus breaking promises of both confidentiality and anonymity. Funding bodies' requests to archive qualitative data for purposes of secondary data analysis by others cannot be fulfilled while preserving anonymity if the data are kept in sign language. The use of 'quotes' from participants is not straightforward. If these quotes are rendered in BSL then they would need to be re-signed by someone else for use in presentations for example. The oft used phrase on consent forms concerning giving consent for anonymised quotations to be used thus carries with it a whole new set of implications.

Attempting to avoid these potential problems by simply translating the data into a language that has a written form is not a resolution, both for reasons of loss of meaning through translation and through the reinforcement of the dominance of spoken/written

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word in the generation of knowledge of Deaf people, as previously discussed. Indeed concerns that Deaf culture, Deaf people and their language should not be rendered invisible by the research process have led some Deaf participants in projects to insist that their real names are used and their rights to anonymity waived (Crasborn 2010).

CONCLUSIONS

This review has not set out to be a 'how to do research with d/Deaf people' manual. It has aimed to uncover a range of important considerations that underpin valid, sensitive, rigorous and ethical research practice with d/Deaf people. In many respects, what has been covered is the tip of the iceberg. Aspects of social care research have been the central concern, but there is a great deal more that would be pertinent to a psychological or educational research focus. However, in summary, the key considerations in the design and execution of social care-related research studies which involve d/Deaf people are:

- There are many ways to *be* deaf, not just a variety of models of *deafness*.
- Research design, including the formulation of research aims or questions as well as the process of research, is influenced by how deafness and being d/Deaf is understood.
- Failure to pay attention to the implications of this heterogeneity, how it is contested and the fluidities of identity that may be encompassed, will undermine the rigour and validity of any piece of research involving d/Deaf people.
- The insider and outsider positioning of both d/Deaf and hearing researchers is an important consideration, particularly with respect to interpretative methodologies.
- Ensuring that data collection matches preferences in language and communication is a vital component of quality research in this field. But issues of access are not the same as issues of preference and should not be treated as such.
- The classification of research participants for purposes of reporting and analysis is particularly problematic.
- Innovations in web-based technologies are opening up new approaches to the involvement of d/Deaf people as research producers as well as research participants.
- Standards of ethical conduct in research with d/Deaf people are no different from standards of ethical conduct in research with any population. However the *achievement* and *execution* of appropriate ethical research practice with and within these populations may require specific awareness and adaptations to usual practice.
- Ethical considerations in research with d/Deaf people may encompass whether some research topics are themselves ethical as well as specific considerations concerning anonymity and identity which are of particular relevance to Deaf signing people.

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