

# **One of society's most vulnerable groups? A systematically conducted literature review exploring the vulnerability of deafblind people**

**Peter Simcock**  
**PhD Student, King's College London**  
**Senior Lecturer, Staffordshire University**

## **Abstract**

The vulnerability of deafblind people is considered axiomatic; they are seen not only as a vulnerable group, but as one of the *most* vulnerable. This paper aims to synthesise existing knowledge to determine what is known about such vulnerability. A comprehensive literature search was undertaken between April 2013 and May 2014. The review method was *informed* by systematic review principles, an approach based on a 'hierarchy of evidence' would have reduced the amount of literature reviewed significantly, to the point where synthesis would not be possible. Included material was appraised and an interpretative rather than aggregative approach to synthesis adopted. Drawing on principles of critical interpretive synthesis, rather than being a determiner of whether material should be included or excluded, a critique of the literature is offered *within* the synthesis. 28 references were identified for inclusion, originating from the UK, USA, Australia, Continental Europe and the Nordic Countries. No empirical studies specifically examining the experience of vulnerability of deafblind people were found. However, deafblind people describe feelings of vulnerability in studies exploring their experiences more generally, and in personal accounts of living with the impairment. Literature produced by practitioners and specialist organisations also explores the topic. Deafblind people are identified as a population 'at risk' of various adverse outcomes, particularly when compared to the non-deafblind majority, and deafblind people describe being and feeling vulnerable in various situations. The literature largely relates to negative outcomes and includes significantly less exploration of positive risk taking, coping capacity and resilience. Deafblind people do not appear to describe themselves as being vulnerable as a permanent state, suggesting a need for greater exploration of the experience amongst all sections of this heterogeneous population, with consideration of the concepts of resilience and coping capacity.

### ***What is known about this topic:***

- Deafblindness is a complex impairment and deafblind people are considered a vulnerable population

- Vulnerability is a contested concept, yet one which health and social care practitioners need to understand
- A salutogenesis perspective is lacking in the literature on deafblindness

***What this paper adds:***

- Both etic and emic perspectives of vulnerability are evident in the literature on deafblindness
- The perception of *all* deafblind people as vulnerable is questionable
- Future studies of the lived experience of vulnerability amongst this population should explore coping, resilience, and the potential of positive outcomes when one is vulnerable.

**Keywords:** deafblind; dual sensory impairment; vulnerability; critical interpretive synthesis

**Introduction**

Deafblind people are described as ‘some of the most vulnerable members of our community’ (Hutton 2000:3). However, there is limited research on the experience of this vulnerability amongst the deafblind population. Whilst it may appear ‘intuitively obvious’ who is vulnerable (Mandelstam 2013), vulnerability itself is a contested and complex concept (Grundy 2006, Parley 2010). Limited understanding of vulnerability may result in risks of harm being overlooked, a possible contributing factor to the death in 1989 of British deafblind woman Beverley Lewis (author), or in practice that is over-protective, adversely impacting on individuals’ human rights, particularly their right to respect for private and family life (Dunn et al. 2008). Intrinsicly linked to the notions of risk and the need for protection, it is essential for health and social care practitioners to understand the concept. The aim of this review is to synthesise existing knowledge about the relationship between deafblindness and vulnerability, in order to answer the following: *what is known about the vulnerability of deafblind people?*

**Definitions**

Deafblindness is a severe and complex impairment (Langer 2008, Bodsworth et al. 2011). This complexity becomes apparent when attempts are made to define and describe the condition (Alley and Keeler 2009, Dammeyer 2010). Various terms for the impairment have emerged (Mar 1993, Enerstvedt 1996, Wittich et al. 2013) and these reflect the broad spectrum of people who can be considered 'deafblind' (Smith 1993, Alley and Keeler 2009). What deafblind people have in common is deprivation in use of the distance senses (McInnes 1999), resulting in difficulties with communication, accessing information and mobility (Department of Health 1997). However, variations in, *inter alia*, aetiology, age, age of onset, interval between impairment in each sense, cognitive function, primary communication method or language use (for example, tactile sign language, visual sign language, deafblind manual or oral communication) and cultural background (Langer 2008, Dalby et al. 2009, Bodsworth et al. 2011) all impact on a person's experience of deafblindness. Such is the variation amongst deafblind people, that Smith (1993) argues that use of the single term 'deafblind' to describe the population as a whole is 'meaningless'.

In addition to the broad categories of congenital and acquired deafblindness, four distinct groups of deafblind people have been identified (Deafblind Services Liaison Group 1988, Department of Health 2009):

1. Those deafblind from birth or early childhood
2. Those visually impaired from birth or early childhood who subsequently acquire a hearing impairment
3. Those Deaf or hearing impaired from birth or early childhood who subsequently acquire a visual impairment
4. Those who acquire visual and hearing impairment in later life.

The majority of deafblind people fall into the fourth group, which is predicted to expand considerably (Robertson and Emerson 2010b).

Lewin-Leigh (2000) observes that deafblind people have unique needs and face unique challenges. A defining feature of deafblindness as a unique impairment is

the notion of synergy: the sum (deafblindness) is greater than the parts (hearing and vision impairment) (Brabyn et al. 2007, Deafblind UK 2006). The combined vision and hearing impairment has a multiplying effect: it prevents the deafblind person from using one sense to compensate for the impairment in the other and from functioning as a single sensory impaired person (Deafblind UK 2006, Roberts et al. 2007).

In England, the impact of this unique challenge is acknowledged in social care law: local authorities have specific duties towards deafblind people, in addition to those for single sensory impaired people, including the provision of specialist social care assessment and services (Department of Health 2014a). However, this unique nature is also reflected in the recognition of deafblindness as a third separate sensory impairment, alongside deafness and blindness, at European level (European Parliament 2004). There is evidence of consensus at an international level over use of the unhyphenated term 'deafblind' (rather than 'deaf-blind') in recognition that the impairment is a third distinct entity (Lagati 1995).

## **Method**

A preliminary scoping search of bibliographic databases identified a very limited number of topic relevant empirical studies; what emerged was a highly diverse body of material, reflecting Pawson et al's (2003) classification of the types and quality of knowledge in social care: organisational knowledge; practitioner knowledge; user knowledge; research knowledge; and policy community knowledge. Such a diverse collection of material problematised two aspects of the systematic review process: quality appraisal and synthesis. The review was therefore systematically conducted and *informed* by the principles of rigour, comprehensive search strategies, and transparency. An approach based on a 'hierarchy of evidence' was rejected, as this would have reduced the amount of literature reviewed to the point where synthesis would not be possible. Furthermore, such an approach would have resulted in the loss of much material considered to be practitioner knowledge and 'user' testimony. Whilst the knowledge gained from users is often undervalued as evidence (Pawson et al.

2003), there is increasing recognition of its importance in systematic reviews (Rutter et al. 2010, Gough et al. 2012).

A comprehensive literature search was undertaken between April 2013 and May 2014. Twelve electronic bibliographic databases (See Box 1) were searched. Search terms were based on key concepts drawn from the review question and its context (See Box 2). Searching was an iterative process, with terms being refined and developed as a result of the findings of the initial scoping searches. To identify grey literature and relevant but unpublished material, websites were searched and Internet search engines used (See Box 3).

*Deafblind Review* (publication of Deafblind International) and *Talking Sense* (publication of the Charitable Organisation *Sense*) were hand searched. The *Deafblind Bibliography* (constructed by James Gallagher, a British deafblind man, as part of his Deafblindness Web Resource) and ‘*Selected readings on sensory loss in older age*’ produced by the Centre for Policy on Ageing were also searched. Visits were made to the *Sense* library and discussions held with *Sense* practitioners. Finally, citation tracking, reference harvesting, author searching and personal contact with named authors enhanced the search (Barroso et al. 2003, Fisher et al. 2006, Rutter et al. 2010).

#### *Applying the Criteria*

Certain references were excluded on the basis of the title alone. Those references appearing relevant were stored in bibliographic software (EndNote) and the criteria were applied following reading of the title and abstract, where available, by the author. Those appearing relevant were retrieved and the criteria applied a further time. Details on identification, screening, eligibility and inclusion can be found in the PRISMA diagram (Figure 1) (PRISMA from Moher et al. (2009)):

***Insert Figure 1 Here***

#### *Appraisal, Analysis and Synthesis*

Included material was initially appraised by the author using the TAPUPAS standards devised by Pawson et al. (2003) as guidelines. This framework involves asking the following of any type of knowledge: Transparency – is it open to scrutiny? Accuracy – is it well grounded? Purposivity – is it fit for purpose? Utility – is it fit for use? Propriety – is it legal and ethical? Accessibility – is it intelligible? Specificity – does it meet source-specific standards? The source specific standards are outlined in the ‘Types and Quality of Knowledge in Social Care’ knowledge review (Pawson et al., 2003). However, owing to the limited amount of material identified, priority was given to relevance over type or quality; Killick and Taylor (2009) and Ploeg et al. (2009) report that it is often necessary to ‘relax’ quality criteria, in order to incorporate the material that has been found. An interpretative rather than aggregative approach to synthesis was adopted, owing to the nature of the review question and the diversity of material (Bryman 2008). The limited number of empirical studies and variety of reporting conventions and definitions of deafblindness used, rendered data extraction problematic. Therefore, whilst data relating to the deafblind population concerned in the source material were extracted (See Table 1), the interpretative approach adopted by the author involved reading and re-reading the material selected in order to identify dominant themes, related concepts, similarities and incongruities (Fisher et al. 2006). Drawing on principles of *critical interpretive synthesis* (Dixon-Woods et al. 2006), rather than being a determiner of whether material should be included or excluded, critique of the literature is offered *within* the synthesis.

## **Findings**

28 references met the criteria. Eleven are considered research knowledge, using a variety of methods and approaches. None of these focus specifically on the experience of vulnerability amongst deafblind people; however, the topics of these studies (such as learned helplessness; ontological security; psychological distress; and fear of falling) were considered relevant to the review question. Furthermore, in four studies, participants discuss and describe experiences of feeling vulnerable (Heine and Browning 2004, Göransson 2008, Pavey et al. 2009, LeJeune 2010); in three studies, vulnerability is emphasized and

considered a key theme emerging from the data (Gullacksen et al. 2011, Kyle and Barnett 2012, Hersh 2013). Four references are considered 'user' testimony; this includes personal accounts of living with deafblindness. Whilst these accounts do not focus specifically on vulnerability, they include descriptions of experiences of fear, insecurity and feeling vulnerable. Ten references are 'practitioner knowledge'. This material is written by practitioners from a range of disciplines. The references draw predominantly on the authors' practice experience, but also refer to other literature and interviews with colleagues in the field, deafblind people and their families. None of these papers focus solely on vulnerability, though one includes a chapter on vulnerability to sexual abuse (Moss and Blaha 2001). However, all include consideration of issues of vulnerability, in a variety of contexts. The final three references are organisational knowledge. All are produced and published, or presented, by the two major UK charities for deafblind people: *Sense* (Kiekopf 2007, Sense 2012) and Deafblind UK (Deafblind UK 2007). Table 1 summarises the 28 references.

### **Findings and Synthesis**

Dammeyer (2015) highlights that research in deafblindness is still in its infancy, and calls for greater interest in the field amongst researchers. Lack of a 'research infrastructure' for studies with deafblind people (Brennan and Bally 2007:282) is apparent when reviewing the literature exploring vulnerability amongst this population. No common definition of deafblindness is evident across the 28 references, as similarly identified by Wittich et al. (2013) in their systematic review of terms and definitions of deafblindness across clinical and research literature. For example, whilst Sauerberger (1993) and Danermark and Möller (2008) adopt a functional definition, Hersh (2013:1) makes no reference to functional limitations in her definition, referring simply to 'some degree of combined hearing and visual impairment'. In the Viljanen et al. (2012) study, whilst some participants are clearly deafblind, this is recorded as separate visual and hearing impairments, which are self-defined.

It is also important to note that the material relates to different 'sections' of the deafblind population; this includes congenitally deafblind people, those with

Usher Syndrome (Type I and II), and people acquiring deafblindness in later life. These 'sub-populations' have very different experiences and needs (Moss and Blaha 2001, Department of Health 2009). Whilst the material notes the population concerned, not all authors provide sufficiently nuanced information about the chosen 'sub-population' but rather refer to the broad categories 'congenital' or 'acquired'. Deafblind people in these categories are highly diverse in relation to, *inter alia*, age and manner of onset, additional cognitive and physical impairment, primary communication method or language preference, severity of impairment and cultural affinity. Smith (1993:24) maintains that it is essential to be 'overly clear' about these differences and argues that it is 'not enough to state the population clearly at the beginning of a paper or discourse and then use the shortened term 'deafblind' throughout'. Across the literature reviewed, this diversity and its implications are not always made explicit. Some authors provide limited details on these characteristics and in the literature concerning more than one 'sub-population' of deafblind people, even where details are provided earlier in the paper, these are not always made explicit in relation to direct participant quotations or references to practice experiences. Furthermore, it is not always possible for the reader to cross-reference data related to age, age of onset, communication methods and other characteristics. These limitations impact on the synthesis of material included.

Despite being the largest 'sub-population' of deafblind people (Robertson and Emerson 2010a), older adults acquiring deafblindness in later life have traditionally received less attention in research than congenitally deafblind children. However, a range of literature has emerged; this explores issues such as communication (Heine and Browning 2004), social care needs (Pavey et al. 2009), prevalence (Brennan 2003), and cognitive impairment and later life acquired deafblindness (Lin et al. 2004). Despite increased policy attention on vulnerability amongst older people generally (Brocklehurst and Laurenson 2008), the literature search identified few studies exploring the experience of vulnerability amongst this group in any detail. In one paper, this group were specifically excluded (Danermark and Möller 2008). Whilst Roberts et al. (2007)



make brief reference to vulnerability in their briefing for health and social care practitioners, it was not considered sufficient for inclusion in the review.

The challenge posed by interpretation and translation in qualitative research is evident across studies, particularly in Hersh's (2013) research. Hersh (2013) acknowledges that non-verbal behaviours of those using tactile communication were not noted; this may impact on interpretation of the responses of these participants, as such behaviours are important elements of meaning in tactual communication methods (Hart 2006). Hersh (2013) also states that family members were used to interpret; this raises both methodological and ethical issues (Young and Hunt 2011).

Further limitations are apparent across the research knowledge. In the majority of the empirical studies included, participants were known to and recruited via specialist organisations of and for deafblind people. The potential for bias that this engenders (Padgett 2008) is acknowledged by most, but not all, authors. The two literature review papers (Marks 1998, Danermark and Möller 2008) provide no information on how the literature used was found, selected and appraised. Furthermore, Marks (1998: 200) relates the literature used to 'best practices in teaching children who are deaf-blind'; however, there is no indication in the paper detailing how these best practices were identified or validated.

Relatively low response rates to surveys and completion by proxies (Deafblind UK 2007, Sense 2012), a lack of information on professional backgrounds (Butler 2009), missing full citations for references (Volden and Saltnes 2010) and lack of clarity in relation to where the knowledge originates (Moss and Blaha 2001), all impact on the rigor of the practitioner and organisational knowledge. Consideration must also be given to the potential for bias owing to the fact that the producers of the organisational knowledge (and funder of one of the empirical studies (Pavey et al. 2009)) are campaigning charitable bodies for sensory impaired people (Salkind 2014). The personal accounts are limited in detail and depth, offering only a 'snapshot' of the authors' life experiences. They

are also not representative of the experiences of all deafblind people. In particular, the account from Steve (Surname not identified) (2012) offers very limited biographical information and largely focuses on a single issue, namely the use of social care services.

*Why and which deafblind people are considered vulnerable?*

The identification of deafblind people as a 'vulnerable group' is evident across the literature. Moss and Blaha (2001) and Kiekopf (2007), writing in the context of vulnerability to abuse, focus *specifically* on the reasons why deafblind people are considered vulnerable. Noting that such reasons are complex and interlinked, Kiekopf (2007) suggests that vulnerability is heightened by the main difficulties associated with the impairment: communication, mobility and access to information.

The communication challenges posed by deafblindness, particularly, though not limited to, those congenitally deafblind (Hart 2008) may result in deafblind individuals being unable to disclose abuse, thus increasing their vulnerability (Moss and Blaha 2001; Kiekopf 2007). Such communication challenges and consequent vulnerability are not solely related to the impairment. Deafblind people may find that channels for communicating about abuse are inaccessible, or have a limited network of people who are appropriately skilled in their communication method. Congenitally deafblind individuals may lack the necessary language and vocabulary to describe or disclose abuse, particularly sexual abuse (Moss and Blaha 2001, Kiekopf 2007). This is not necessarily because the language itself lacks the appropriate vocabulary, but because parents, educators and communication support workers lack language skills or because necessary terminology has not been developed with deafblind individuals (Ridgeway 1993, Swinbourne 2012). As a result of these challenges, potential abusers may view deafblind people as safe victims (Kiekopf 2007) and criminal justice professionals may view them as unreliable witnesses (Moss and Blaha 2001). Kiekopf (2007) highlights that data taken from the Sense Abuse

Database for a five-year period (2000-2005) reveal that in just 9.5% of cases ( $n = 94$ ) was the abuse disclosed by the victim.

Arguing that an inability to explore one's environment, anticipate attack and move away quickly to defend oneself all increase vulnerability, Kiekopf (2007) is the only author to comment on the contribution of mobility difficulties to the vulnerability of deafblind people. Limited access to information as a contributing factor to deafblind people's vulnerability is reported more widely across the literature. Low levels of information about sexuality and 'sexual rules' (Moss and Blaha 2001), the environment (Marks 1998), and the sequence of events, including those related to care and support (Kiekopf 2007, Göransson 2008, Kyle and Barnett 2012) may result in deafblind people being confused about what is acceptable and non-acceptable behaviour towards them (Kiekopf 2007). In some situations, deafblind individuals may tolerate abusive behaviours, perceiving them as 'normal' or as sensory experiences (Moss and Blaha 2001, Kiekopf 2007). A lack of information and dependence on others for information (particularly where communication is received tactually on a one-to-one basis) may also result in low levels of assertiveness and independent decision-making (Sauerberger 1993, Hersh 2013). Marks (1998) argues that such passivity, particularly if developed in early life, results in a situation of learned helplessness amongst deafblind children. This has been linked to deafblind children's lack of resistance to sexual abuse (Moss and Blaha 2001) and an increased risk of sexual assault and domestic violence for deafblind women (Merkin and Smith 1995).

In addition to those factors related to communication, mobility and access to information difficulties, Kiekopf (2007) suggests that the interactions and relationships between deafblind people and health and social care practitioners may impact on levels of vulnerability. Numerous professionals may be involved in providing care and support to deafblind people (Kiekopf 2007, Danermark and Möller 2008) and, whilst many achieve a significant level of independence (Alley and Keeler 2009, Kyle and Barnett 2012), high levels of dependence on others are noted in the literature (Sauerberger 1993, Moss and Blaha 2001,

Kiekopf 2007, Danermark and Möller 2008, Bodsworth et al. 2011, Gullacksen et al. 2011); in relation to congenitally deafblind children, this can include what Marks (1998:208) identifies as 'extreme dependence' owing to one-to-one support needs. Such high levels of dependence on others have been linked to increased vulnerability to abuse (Calderbank 2000, Association of Directors of Social Services 2005, Hague et al. 2011). Kiekopf (2007), Danermark and Möller (2008) and Butler (2009) all observe that deafblind people may learn that those providing support are 'safe'. Sauerberger (1993) describes working with deafblind people who are very surprised to learn that the public are unclear about deafblindness and deafblind people's needs. Such perceptions of deafblind people, combined with public and professional misperceptions that disabled children, including deafblind children, are not abused (Moss and Blaha 2001, Stalker and McArthur 2012), contribute to their vulnerability.

As an accessible sense, touch is essential when communicating with deafblind people (Kiekopf 2007, Göransson 2008). However, the literature suggests that touch is an issue associated with increased vulnerability. For deafblind children with additional developmental delay, Moss and Blaha (2001:11) identify touch as 'one of the primary teaching and learning tools'. They add that deafblind children receive more touch than their peers and as a result are more comfortable with it. Kiekopf (2007) observes that deafblind people therefore learn that it is acceptable to be touched. This could be by numerous people, including family members, peers, and health and social care practitioners (Moss and Blaha 2001; Kiekopf 2007); it also includes people not close to nor 'chosen' by the deafblind person (Göransson 2008). Some of this touch may be of a more intimate nature than would be considered appropriate between non-intimate partners according to normative standards (Sauerberger 1993, Moss and Blaha 2001). As such, Smith (1993) suggests that deafblind people receive mixed messages about appropriate touch. She also notes, as does Göransson (2008), that deafblind people may lack awareness of the social and cultural 'rules' of touch and personal space. Moss and Blaha (2001) highlight that this includes lack of awareness of the private areas of the body. Whilst these factors may heighten deafblind people's vulnerability, it is also evident that the issue of touch

may increase a practitioner's sense of vulnerability within a professional relationship. Sauerberger (1993) describes situations where deafblind service-users have expressed a desire for a hug when she has arrived or when departing and Moss and Blaha (2001:52) note that deafblind adolescents may 'respond sexually to touch', albeit non-sexual touch. Therefore, close physical contact is both necessary in interaction, but also a potential source of vulnerability for both deafblind people and practitioners.

It is important to acknowledge that the material with a particular focus on the reasons why deafblind people are considered to be vulnerable is related to certain sub-sections of the deafblind population: deafblind children with significant developmental delay and congenitally deafblind people. Kiekopf's (2007) paper contains a short section on the vulnerability of those with acquired deafblindness, but this is not the main focus. Whilst Moss and Blaha (2001:95) state that it is the needs associated with deafblindness that make those with intellectual impairments 'a very vulnerable group', generalisations cannot be made across the deafblind population, which as already noted, is a highly heterogeneous group of people with very different needs and circumstances. The causes of heightened vulnerability identified within the literature do not always, therefore, relate to *all* deafblind people. Ironically, Smith (1993:28) argues that the tendency for all deafblind children to be 'lumped together as a category' may itself increase the vulnerability of those children who are "just" deafblind, as their needs can be overlooked.

#### *Vulnerable or 'at risk'?*

Health and social care professionals are often involved in determining which individuals and groups are at higher risk and therefore considered 'vulnerable' (Spiers 2000). Risk is intrinsically linked to vulnerability, and assessment of the level of risk of harm is determined by 'external judgements of endangerment' and 'functional capacity' to cope (Spiers 2000:718). Risk factors are located within the individual (for example, communication difficulties, learned helplessness or lack of independence), but the determination of the level of risk

is made by comparison to normative standards. This external identification of individuals and groups, who are at greater risk of health or social problems, or harm, reflects an etic perspective of vulnerability (Spiers 2000). Such a perspective is evident in the literature: deafblind people are identified as being 'at risk' of various dangers or harms when compared to the non-deafblind population.

Both Moss and Blaha (2001) and Kiekopf (2007) consider the risk of abuse. Whilst Moss and Blaha (2001:107) focus on sexual abuse, noting a 'very great risk' for deafblind children with developmental delay compared to 'their typical peers', Kiekopf (2007:23) suggests deafblind people are 'potentially [at] greater risk' of all forms of abuse. These comments relate specifically to deafblind children with significant developmental delay and congenitally deafblind people, and cannot therefore be generalised. Merkin and Smith (1995) identify deafblind women as being at risk of long-term sexual assault and domestic violence, partly as a result of early life passivity and learned helplessness; however, this is based on their experience of supporting only 28 deafblind women, in contact with a domestic violence service. Passivity and lack of information in relation to decision-making are also linked to 'unusual' financial decisions, which Pavey et al. (2009) argue may place older deafblind people at greater risk of financial abuse.

Practitioners identify deafblind people as being at risk of specific dangers associated with daily living and physical harm (Sauerberger 1993, Luey 1994). This includes accidents within the home, whilst travelling and when crossing roads. Luey (1994) describes such risk as stressful and linked to feelings of vulnerability for older people with acquired dual sensory loss.

Linked to difficulties with communication and independent travel, is the risk of social isolation. High levels of social isolation are not only identified as something to which deafblind people are at risk, but also a contributor to increased risk of abuse, psychological distress, heightened emotional states and mental health difficulties (Bodsworth et al. 2011, Butler 2009, Göransson 2008,

Mar 1993, Moss and Blaha 2001, Volden and Saltnes 2010). High levels of social isolation were not described by participants in Kyle and Barnett's (2012) study. However, the authors acknowledge that the participants in this study were 'more confident', 'already in contact with organisations' and 'those who have friends who were also Deafblind' (ibid.:42).

Deafblind people experience ongoing change and necessary adaptation in their lives, owing to the interaction between a fluctuating impairment and the environment. Therefore, it is unsurprising that deafblind people are identified as being at greater risk of ontological insecurity: reduced confidence in the continuity and constancy of one's self-identity and environment (Danermark and Möller 2008). Marks (1998), Deafblind UK (2007), Danermark and Möller (2008), Göransson (2008) and Kyle and Barnett (2012) all refer to the link between constantly changing routines, uncertain events, unfamiliar environments, lack of control, and increased risk of stress and insecurity. Göransson (2008:52) observes that deafblind people face uncertainty 'perhaps on a daily basis', and unfamiliar environments and an inability to predict events are considered particularly problematic. Kyle and Barnett (2012:82) found that:

[i]nsecurity arose in unknown environments or where the layout had been changed. In situations of change, insecurity becomes a real problem and we begin to *enter the domain of vulnerability* (emphasis added).

Miner (1997) suggests that a lack of ontological security amongst deafblind people may be linked to increased risk of mental health problems. Whilst studies recognise deafblind people as being at risk of further physical health problems, in part owing to late manifestations of their conditions (Gullacksen et al. 2011), the identification of deafblind people as a group at greater risk than non-deafblind people of emotional and mental health difficulties is particularly evident across the literature; this includes psychological distress, depression and major psychiatric illness (Bodsworth et al. 2011, Wickham 2011). Whether deafblind people are at greater risk than the general population is difficult to determine; Hersh (2013) refers to mixed results from the research relating to depression amongst sensory impaired people, and Volden and Saltnes (2010)

note that depressive illness amongst deafblind people may result from a number of complex, inter-related factors. Furthermore, Mar (1993), Bodsworth et al. (2011) and Wickham (2011) all note that the risk of mental health difficulties faced by deafblind people is exacerbated by a lack of specialist and appropriate services. Owing to communication difficulties resulting from such a lack of specialist services (Mar 1993, Deafblind UK 2007, Hersh 2013) and misinterpretation of the effects of sensory impairment (Sauerberger 1993, Miner 1997, Wickham 2011) deafblind people are identified as a group at risk of misdiagnosis of mental health conditions.

Spiers (2000) notes that the identification of an individual or group as being 'at risk' operates as 'social sanction' for intervention by health and social care professionals. Kyle and Barnett (2012:59) observe that the risk of insecurity, social isolation and associated vulnerability are considered by care and support services as 'justification for intervention'. However, Sauerberger (1993) and Kyle and Barnett (2012) identify that for many deafblind people, it is more important to feel in control of one's life, rather than be 'protected' by the intervention of others. There is therefore a risk of over-protection when the perspectives of deafblind people themselves are not considered. Some of these perspectives are evident in the literature.

#### *What do deafblind people say they feel vulnerable about?*

Experiences of feeling vulnerable are described and discussed by deafblind people across the literature. Gullacksen et al. (2011:30) note that vulnerability is one of the 'topics emphasized by the focus groups', participants of which had progressive acquired impairment. Some deafblind people express an overall feeling of vulnerability; this is often associated with being alone. A participant in LeJeune's (2010:7) focus groups describes feeling 'very alone and often frightened' and Henderson (2000:S18), a 17 year-old girl with Usher Syndrome, describes feeling 'scared and alone' following diagnosis. For some deafblind people, it is going out alone which results in feelings of vulnerability; however, others report feeling vulnerable both outdoors and inside their own homes.



Sauerberger (1993) notes that some deafblind people worry that they will always be alone; furthermore, with reference to the experiences of one of her service-users, she highlights that not being alone is associated with no longer being vulnerable. The perception of oneself as being exposed to potential harm when alone, yet being able to withstand such harm when no longer alone, reflects an emic perspective of vulnerability. This perspective is informed by the lived experience of the subject, rather than objective risk assessment based on normative standards (etic) (Spiers 2000). Whilst deafblind people may acknowledge their own inherent risk factors, it is the challenge to self of being alone combined with the perception that being alone renders one unable to respond to the potential for harm that leads to feelings of vulnerability.

Some deafblind people, particularly those who are older, describe feeling vulnerable about specific physical harms or dangers. This includes fear of falling (Pavey et al. 2009, Viljanen et al. 2012), fear of being a victim of crime (Pavey et al. 2009, Kyle and Barnett 2012) and of accidents in the home (Sense 2012). Lack of control over the environment appears central to these specific fears. For example, in the context of fear of crime, a participant in Kyle and Barnett's (2012) study relates this to being unaware, when alone, about who is coming into the home. Similarly, a respondent to the Sense (2012) survey relates her fear of falling to a lack of control in the home environment when alone. Kyle and Barnett (2012) also observe that fear of specific dangers or harms is intrinsically linked to being unable to access the environment by touch, thus resulting in a lack of control.

Lack of control appears to be more significant to deafblind people in their discussions of vulnerability, than identifying specific dangers. Participants in research by Göransson (2008), LeJeune (2010), Gullacksen et al. (2011), and Kyle and Barnett (2012) all describe feeling insecure, frightened and vulnerable as a result of perceiving themselves to be losing control over the environment or events happening around them. Participants in Göransson's (2008) study describe feeling insecure in relation to events not 'turning out' as planned;

specific examples are given of situations that increase insecurity owing to a lack of control, such as a bus not taking a usual route or an interpreter failing to arrive. Lack of control and consequent feelings of vulnerability are particularly evident for deafblind people when they are in unfamiliar environments (Stiefel 1991, Deafblind UK 2007, Göransson 2008, LeJeune 2010, Kyle and Barnett 2012). However, it is not just control of the physical environment that results in vulnerability, but also loss of control in relation to events occurring and an ability to interpret these.

Whilst a lack of control and being alone are features of deafblind people's experiences of vulnerability, some deafblind people feel vulnerable to overprotection (Sauerberger 1993, LeJeune 2010, Hersh 2013). Such overprotection can take active forms (for example, restricting activities) or passive forms (for example, withholding certain information) (Hersh 2013). Deafblind people describe feeling overprotected by both family members (LeJeune 2010) and health and social care professionals (Sauerberger 1993, Hersh 2013).

Those with progressive conditions, such as Usher syndrome, describe feeling vulnerable about the future. For some, their fears are related to further sensory loss (Miner 1997, Henderson 2000) and the ability to cope with this (Gullacksen et al. 2011). LeJeune (2010:6) describes the fear of the effects of further sensory loss expressed by participants in her focus groups as 'overwhelming for many'. Older deafblind people in Pavey et al's (2009) study describe anxiety about future deterioration of health generally and the health and social care services that will be available to them. Deafblind people's relationship with health and social care services is not just a future concern but also related to present feelings of vulnerability.

An attribute of the emic perspective on vulnerability is the person's 'perceived ability to withstand, integrate or cope with ... challenge' (Spiers 2000:719). For deafblind participants in Kyle and Barnett's (2012) study, social care services, such as communicator-guides, are perceived as an important resource in

responding to challenge. Butler (2009) also refers to service-users reporting feeling safe when with professional staff with whom they have a close relationship. Participants in Göransson's (2008) and Gullacksen et al's (2011) studies, and Pollington (2008) in her personal account, describe feeling frustrated and fearful about services being unavailable or inaccessible, both now and in the future. Such unavailability is associated with feeling vulnerable. Those already in receipt of services express feelings of particular vulnerability in relation to these services being reduced or stopped (LeJeune 2010, Sense 2012, Steve (surname not identified) 2012). Göransson (2008) observes that some deafblind people feel particularly unsafe when accessing health care services; this is largely linked to fears that communication difficulties will result in their needs being misunderstood. Respondents to Sense's (2012) survey of social care experiences report concerns about their needs not being appropriately recognised in the assessment process. Health and social care surveys by Deafblind UK (2007) and Sense (2014) and research by Bodsworth et al. (2011) highlight several negative experiences for deafblind people using such services in the UK, suggesting that their feelings of vulnerability in this context are not without foundation.

Smith (1993:23) argues that intellectual impairment and deafblindness 'have become inappropriately combined in the minds of... [health and social care] staff'. However, whilst deafblindness poses a number of challenges, a deafblind participant in Gullacksen et al's (2011:21) study observes that 'losing one's abilities is not the same as losing one's competence'. Many deafblind people report feeling vulnerable about being perceived as 'incompetent' (Miner 1997), 'chronically confused' or 'mentally deficient' (Stiefel 1991), 'pathetic' (Pollington 2008) or 'mentally ill' (LeJeune 2010). This challenge to one's self-perception, by the public (LeJeune 2010) and by professionals (Deafblind UK 2007), is considered to have a negative impact on life experiences. As a result of both these misperceptions and communication difficulties, some deafblind people describe feeling vulnerable in social situations. Feelings of embarrassment, fear, anxiety and distress in social situations are described by deafblind people across the literature (Stiefel 1991, Sauerberger 1993, Göransson 2008, Gullacksen et al.

2011, Kyle and Barnett 2012). Participants in Heine and Browning's (2004:123) study are described as 'fearing' such situations and report that communication difficulties cause 'immense anxiety'. It is important to note, however, that only four participants in this study had *dual* sensory impairment.

## **Discussion**

A common approach to vulnerability involves the objective identification, description and categorisation of people with particular needs as a 'vulnerable' or 'at risk' group (Satz 2008, Fawcett 2009). Arguably, the vulnerability of deafblind people is considered axiomatic; statements appear in the literature identifying deafblind people not only as a vulnerable group but as one of the 'most vulnerable'. Reflecting an etic perspective (Spiers 2000), deafblind people are identified as a population 'at risk' of a range of harms or adverse outcomes, particularly when compared to the non-deafblind majority. Whilst such categorisation can offer 'useful preliminary sorting' (Schröder-Butterfill and Marianti 2006:15), the identification of deafblind people as a vulnerable group is problematic. Resembling other groups attributed the label 'vulnerable' (Fawcett 2009), deafblind people, as previously noted, are highly heterogeneous; as Schröder-Butterfill and Marianti (2006:15) observe, the experience of vulnerability 'is not invariable even among narrowly-defined risk groups'. Whilst some practitioner authored material and organisational knowledge considers the factors contributing to deafblind people's vulnerability, this material is largely focused on congenitally deafblind people, and those with additional intellectual impairment; it cannot be generalised across the highly diverse deafblind population.

The disability movement has been critical of this approach to vulnerability, arguing that it contributes to the 'othering' and dehumanisation of disabled people (Fawcett 2009, Wiles 2011, Crowther 2015). Rejecting the dominant construction of vulnerability as pertaining to particular groups, many have maintained that vulnerability is universal, and argue that all human beings are vulnerable at some points in their lives (Grundy 2006, Hoffmaster 2006, Harrison 2008, Satz 2008, Wiles 2011). The universality of vulnerability is a

core assumption of an emic perspective (Spiers 2000) and also a key premise of the theory of vulnerability developed by legal scholar Martha Fineman (2008). Fineman (2008:12) argues that ‘all individuals are vulnerable, in the sense that they have the potential to become dependent’. Whilst such an approach is useful in challenging stigma and processes that ‘other’ particular groups (Fineman 2008), Kohn (2014) argues that it cannot offer suggestions for social welfare policy to address the challenge of allocating limited resources. Consideration of the particular vulnerabilities of specific groups, including deafblind people, therefore has value.

A further premise of Fineman’s (2008) theory is that vulnerability is constant. Applying this theory to the experiences of people with impairments, Satz (2008:532) observes that ‘vulnerability does not end when one leaves a movie theatre, a workplace, or a commuter train’. Gerontological and intellectual impairment research suggests that some health and social care practitioners conceptualise vulnerability in older and learning disabled people as constant, or as a permanent and fixed state (Grenier 2004, Parley 2010, Abley et al. 2011). However, older and disabled people themselves reject this notion of being ‘vulnerable in general’, and refer to feeling vulnerable in specific, time-limited situations (Parley 2010, Abley et al. 2011, Wiles 2011). Comparably, deafblind people do not appear to describe themselves as being at risk, or feeling vulnerable, as a permanent state: ‘I feel vulnerable because I am deafblind’. Instead, they refer to particular situations, such as social occasions, being alone or being in contact with health services. As such, like other groups, deafblind people may more accurately ‘be classified and declassified as vulnerable throughout their lifespan’ (Fanning and Dalrymple 2011:175).

Former constructions of vulnerability have focused on the ‘status’ or inherent characteristics of individuals, including sensory impairment (Greenfields et al. 2011). McCormick (2011) observes that these have informed social welfare law and policy. For example, the first statutory guidance on adult safeguarding in England, *No Secrets* (Department of Health 2000:2.3), defined a ‘vulnerable adult’ as someone ‘who is or may be in need of community care services by reason of

mental or other disability, age or illness'. In extending the inherent jurisdiction of the high court to protect vulnerable adults in certain circumstances, Dunn et al. (2008:239) note that Munby LJ, 'situate[d] vulnerability as being, first and foremost, inherent to that adult. Inherent vulnerability resides in a person's individual characteristics, defined by.... the presence of illness or disability'; this description included explicit reference to being deaf or blind.

Whilst such an approach has been rejected by the disability movement (Smith et al. 2010, Crowther 2015), a link between the impairment characteristics of deafblindness and vulnerability is evident in the literature, with attention paid to the relationship between difficulties communicating, accessing information and mobilising, and vulnerability. However, vulnerability is also associated with situational and external factors, such as social isolation, inaccessible services, inadequate communication support and misdiagnosis. This reflects more contemporary conceptualisations of vulnerability, which have highlighted not only the complex and multiplicity of environmental factors that can contribute to vulnerability (Schröder-Butterfill and Marianti 2006, Fineman 2008, Kohn 2014), but also its social construction (Gill 2006, Brocklehurst and Laurenson 2008). Deafblind people, particularly older deafblind people, describe feeling vulnerable as a result of unavailable, inaccessible and inappropriate care and support services. Dodds (2014) terms such vulnerability as 'pathogenic': vulnerability is exacerbated because of failures in policy and social support. The experience of vulnerability is actively constructed through the failure of society and the environment to respond adequately to both the inherent and the situational.

Such contemporary approaches to vulnerability have informed social welfare law and policy. For example, UK legislation has shifted from the notion of 'vulnerable adults' to 'adults at risk', and accompanying statutory guidance acknowledges that circumstances beyond inherent characteristics can render adults vulnerable (Department of Health 2014b:14.55). However, Dunn et al. (2008) and Fawcett (2009) argue that this construction of vulnerability remains too narrow: whilst inherent characteristics and wider environmental and situational factors are

considered, the subjective, lived experience of 'being vulnerable' (the emic perspective) is absent. In this review, no empirical studies specifically examining the lived experience of vulnerability of deafblind people were identified, albeit that deafblind participants describe feelings of vulnerability in studies exploring their experiences more generally. Furthermore, whilst the personal accounts describe lived experience, these are limited in detail and depth.

Dunn et al. (2008) and Fawcett (2009) maintain that an understanding of the subjective lived experience of vulnerability is essential for health and social care practitioners. Failure to consider these subjective experiences, they argue, risks disempowering individuals, and leads to interventions that may override their wishes and priorities; physical safety may also be privileged over other desired outcomes. Parley (2010:267) observes that in health and social care settings, vulnerability 'generally means open to exposure to harm'; therefore interventions focus on preventing harm (Fawcett 2009). However, Kohn (2014) notes that some people may place greater priority on maintaining independence than safety. Whilst deafblind people describe feeling vulnerable to specific harms, this review highlights that they are also concerned about lack of control, being perceived as incompetent or pathetic, being in social situations where communication is difficult, and being overprotected. In increasingly personalised health and social care systems, Abley et al. (2011) argue that practitioners must be alert to these concerns, using them to guide intervention, in order to promote person-centred care and support.

The literature considering the vulnerability of deafblind people largely relates to negative outcomes. This includes being at risk of abuse, poor physical health outcomes, mental ill health, ontological insecurity and social isolation. As a result, it may perpetuate 'pervasive social norms that vulnerability is weakness' (Wiles 2011:579). Highlighting that people are rarely 'passively subject to threat', Schröder-Butterfill and Marianti (2006:10) developed a systematic framework for approaching vulnerability, that gives 'coping capacity' (in addition to outcomes, threats and exposure) equal weight as a constituent part of the concept. Coping capacities are defined as 'the set of assets and relationships that

allow people to protect themselves from a bad end or recover from a crisis' (Schröder-Butterfill and Marianti 2006:15). Grundy (2006) suggests that this includes family relationships, social networks, coping strategies, and financial assets. There are examples, in the literature, of deafblind people describing their coping capacity, with reference made to their ability to adapt to changes in impairment, family support, peer support and specialist services such as interpreters and communicator-guides. Awareness of these coping capacities can inform health and social care intervention, as services can be targeted at 'bolstering people's defences' (Schröder-Butterfill and Marianti 2006:11). However, there is significantly less exploration of capacity to cope and resilience in the deafblind literature than the attention to negative outcomes, reflecting Danermark and Möller's (2008:S121) assertion that what is absent:

in the scientific literature on deafblindness is a salutogenesis perspective, i.e. research demonstrating the potentiality among people with deafblindness.

Kyle and Barnett (2012) argue that a focus on risk, insecurity and vulnerability to unfavourable outcomes may continue to support a stereotyped view of deafblind people as a dependent population.

Sauerberger (1993) reports that many of her deafblind service-users showed great courage in facing various challenges over the life course; according to Brown (2013) it is the willingness to be vulnerable that acts as the basis and catalyst for such courage. Nakashima and Canda (2005) suggest that much can be learned about resilience 'from those who have the courage to engage with their vulnerability' (Wiles 2011:574) and Wiles (2011) highlights that vulnerability itself is not inherently negative.

## **Conclusion**

This paper offers a review of relevant literature in order to determine what is known about the vulnerability of deafblind people. Owing to the limited material found, relevance was given priority over quality in determining inclusion; therefore this literature review has its own limitations and the findings must be



interpreted with caution. Deafblind people are identified by health and social care professionals, as a group more 'at risk' than the non-deafblind majority to a range of harms. However, the limited literature focusing specifically on the reasons for this vulnerability largely concerns particular sub-sections of the deafblind population. Deafblind people across the population do however describe their lived experiences of feeling vulnerable. What appears particularly limited in the literature is research adopting a salutogenesis perspective, in which consideration is given to the coping capacities of deafblind people. Further exploration of the lived experiences of the range of people who can be considered deafblind needs to consider the potential positive outcomes of being vulnerable and move away from a sole focus on risk and harm. This may serve to dispel the notion that *all* deafblind people are permanently vulnerable.

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**Box 1: Databases Searched**

Applied Social Sciences Index and Abstracts (ASSIA)  
 British Nursing Index (ProQuest)  
 Cumulative Index to Nursing and Allied Health Literature (CINAHL)  
 Education Resources Information Centre (ERIC)  
 International Bibliography of the Social Sciences (IBSS)  
 PsycINFO  
 Social Policy and Practice (via OVID)  
 PubMed  
 Social Services Abstracts  
 Sociological Abstracts  
 SCOPUS  
 Web of Knowledge (v.5.8)

**Box 2: Search Terms**

Deafblind OR deaf-blind OR “dual sensory loss” or “dual sensory impair\*” OR ‘hearing and sight loss’ OR ‘hearing and sight impair\*’ OR ‘hearing and visual loss’ OR ‘hearing and visual impair\*’ OR ‘deafness and sight loss’ OR ‘deafness and sight impair\*’ OR ‘deafness and visual loss’ OR ‘deafness and visual impair\*’ OR ‘blindness and hearing loss’ OR ‘blindness and hearing impair\*’ OR ‘vision and hearing difficulties’ OR ‘deafness and blindness’ OR ‘deafness and vision difficulties’ OR ‘sight and hearing difficulties’ OR ‘usher syndrome’ OR ‘charge syndrome’ OR ‘congenital rubella syndrome’

AND

vulnerab\* OR maltreatment OR harm OR ‘adult protection’ OR abuse OR ‘at risk’ OR protect\* OR safeguard\*

**Box 3:****Internet Search Engines**

BASE (Bielefeld Academic Search Engine)  
 Google Scholar  
 JSTOR (Digital Library produced by ITHAKA)  
 Open Grey  
 Social Care Online (SCIE Database)  
 Social Welfare at the British Library Portal  
 SUMMON (Staffordshire University Search Tool)

**Websites**

Action on Elder Abuse  
 Action on Hearing Loss  
 Age UK  
 Amazon  
 Beth Johnson Foundation  
 Brunel Institute for Ageing Studies  
 Centre for Ageing Research,  
 Lancaster  
 Deafblind UK

	Department for Health Information Center for Acquired Deafblindness (Copenhagen) International Longevity Centre Joseph Rowntree Foundation Centre for Social Gerontology, Keele National Consortium on Deafblindness Royal National Institute for Blind People (RNIB) Sense Skills for Care Thomas Pocklington Trust
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<b>Inclusion and Exclusion Criteria</b>	
<p>Included references which:</p> <ul style="list-style-type: none"> <li>• Related to deafblind people. This included people of any age, congenitally deafblind children and adults, and people with acquired deafblindness, irrespective of age of onset.</li> <li>• Explored the issue of vulnerability or being vulnerable or feeling vulnerable.</li> <li>• Were qualitative and quantitative studies, literature reviews, personal accounts and biographical material by deafblind people, health and social care practitioner authored materials and material produced by specialist organisations.</li> <li>• Were peer-reviewed and non-peer reviewed publications, conference proceedings, grey literature and material produced online; published and unpublished material.</li> </ul>	<p>Excluded references which:</p> <ul style="list-style-type: none"> <li>• Related only to those with single sensory impairment.</li> <li>• Lacked any clarity in relation to the deafblind population concerned: i.e. no indication at all if concerned children, adults, congenitally deafblind people, those with additional impairments, or those with acquired deafblindness.</li> <li>• Offered no consideration of the concept of vulnerability or deafblind people's experiences of feeling or being vulnerable</li> <li>• Focused solely on medical treatments or medical interventions</li> <li>• Were produced before 1970</li> <li>• Were not available in the English language</li> <li>• Could not be retrieved in full by the author</li> </ul>

<ul style="list-style-type: none"><li>• Were produced from 1970 to date (1970 was the year deafblindness was first mentioned in a UK Act of Parliament).</li><li>• Contained international and national material but only if available in the English Language.</li></ul>	
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Author(s) & Title	Type of Knowledge	Description	Deafblind Population Concerned	Limitations
<p>Marks (1998) <i>Understanding and Preventing Learned Helplessness in Children who are Congenitally Deaf-blind.</i></p>	<p>Research Knowledge</p>	<p>A literature review linking the literature on learned helplessness with that on best practices in teaching deafblind children. The paper's aim is to explore how practitioners in education and care can prevent or reduce learned helplessness in deafblind children.</p> <p>In addition to drawing on the literature, the author, a deafblind specialist from the Department of Special Education, Michigan State University, East Lansing, also draws on her own experience teaching and consulting in the field.</p> <p>The paper is published in the international peer-reviewed journal, <i>Journal of Visual Impairment &amp; Blindness</i>.</p>	<p>Congenitally Deafblind Children</p>	<p>No information on how literature reviewed was found, selected or appraised.</p> <p>Literature used related to 'best practice'; no indication in the paper detailing how these best practices have been validated or identified.</p>
<p>Heine &amp; Browning (2004) <i>The communication and psychosocial perceptions of older adults with sensory loss: a qualitative study.</i></p>	<p>Research Knowledge</p>	<p>An Australian qualitative research study exploring the communication and psychosocial perceptions of older adults with single or dual sensory loss, acquired in later life.</p> <p>Research participants were all known to the Vision Australia Foundation (a not for profit organisation providing services to visually impaired people).</p> <p>Data were gathered from individual and group interviews. The interviews were recorded (video or audio) and transcribed verbatim. Data were analysed using content and thematic analysis, with</p>	<p>Older Adults (all aged over 60) with single or dual sensory loss, acquired in later life (n=10; 4 with dual sensory loss: 1 man and 3 women).</p> <p>All legally blind (Snellen 6/60 or worse).</p> <p>All speech users.</p>	<p>No further details on age or age of onset of deafblindness for participants</p> <p>Participants recruited via specialist organisations of and for deafblind people: potential for bias.</p>

		<p>a focus on participants' meanings, motives, feelings and ideas. Feelings of anxiety and fear were evident in the data.</p> <p>The research is published in the international, interdisciplinary and peer-reviewed journal <i>Ageing and Society</i>.</p>		
<p>Danermark &amp; Möller (2008) <i>Deafblindness, Ontological Security and Social Recognition</i>.</p>	<p>Research Knowledge</p>	<p>A discussion paper, which explores deafblindness in relation to trust, ontological security, social recognition and self-identity.</p> <p>The paper draws on the literature related to ontological security and research with deafblind people to explore how the deafblind population experiences the phenomenon.</p> <p>Both authors are from the Swedish Institute for Disability Research, Orebro University, Sweden. The paper is published in the peer-reviewed <i>International Journal of Audiology</i> (a merger of three former journals: <i>Audiology</i>, <i>British Journal of Audiology</i> and <i>Scandinavian Audiology</i>).</p>	<p>Specific focus on adults with acquired deafblindness, excluding older people acquiring deafblindness in later life.</p> <p>Authors note that people with acquired deafblindness are 'a very heterogeneous group'.</p>	<p>No information on how the literature reviewed was found, selected and appraised.</p>
<p>Göransson (2008) <i>Deafblindness in a Life Perspective</i></p>	<p>Research Knowledge</p>	<p>A four-year Swedish research project aimed at examining what life looks like for deafblind people in different age groups.</p> <p>The data were gathered from other research, eight in-depth qualitative interviews, eight interviews based on the World Health Organisation's International Classification of Functioning, Disability and Health, and two focus groups.</p>	<p>Reports on deafblind people of all age groups and different types of deafblindness. Authors acknowledge the differences between congenital and acquired deafblindness, the impact of age of onset, the impact of progressive dual sensory loss, and the</p>	<p>Participants recruited via specialist organisations of and for deafblind people: potential for bias.</p> <p>Focus groups not organized for sign language users, those using tactile communication and older people reducing data available for these groups.</p>

		<p>Experiences and issues related to vulnerability are evident in the data.</p> <p>The data were analysed using a life adjustment model and the research is presented in a book published by Swedish Publisher Mo Gårds Förlag.</p>	<p>differences in language use and language acquisition.</p> <p>Uses Nordic definition of deafblindness: “ a combined vision and hearing disability. It limits activities of a person and restricts full participation in society to such a degree that society is required to facilitate specific services, environmental alterations and/or technology”</p> <p>The two focus groups included:</p> <p>(a) Five people (3 men and 2 women), all working age, all using spoken language.</p> <p>(b) Thirteen parents of children and adolescents with deafblindness.</p>	<p>When direct quotations from participants are used, information relating to age, age of onset and communication method of the participant is not always made explicit.</p> <p>Study involved multiple interpretation and translation activity.</p>
<p>Pavey et al. (2009) <i>The needs of older people with acquired hearing and sight loss.</i></p>	<p>Research Knowledge</p>	<p>A research study, funded by the UK visual impairment charity Thomas Pocklington Trust, which explores the needs of older people with acquired dual sensory impairment.</p> <p>The research had two phases. First, analysis of two pre-existing datasets (Network 1000 dataset and the Cambridge Dataset) relating to 609 older deafblind people and second, analysis of 20 case studies of older deafblind people. At the end of</p>	<p>Older people who have acquired hearing and sight loss in later life.</p> <p>Secondary data sources: relate to people over 50 with later life acquired dual sensory loss.</p> <p>20 Case Studies:</p>	<p>Participants recruited via specialist organisations of and for deafblind people: potential for bias.</p> <p>Study funded by charitable organisation for visually impaired people.</p> <p>Network 1000 dataset only included those registered with sight loss. Deafblind people may choose not to</p>

		<p>these phases, the researchers (from the University of Birmingham and the University of Cambridge) met with group of professionals in the deafblind field to discuss and validate the findings.</p> <p>Qualitative methods were used to analyse the data from both sources, supported by use of the computer software programme <i>NVivo</i>. Experiences of vulnerability were evident in the datasets.</p> <p>The research is published by the Thomas Pocklington Trust.</p>	<p>Older people with later life acquired dual sensory loss. Age range: 58-92 years old; the majority (n=14) in 80s. 11 women and 9 men. 18 White British, 2 Indian. All but 1 had additional health problems or impairments.</p>	<p>register or have a sight impairment that is not eligible for registration.</p>
<p>Lejeune (2010) <i>Aging with a Dual Sensory Loss: Thoughts from Focus Groups</i></p>	<p>Research Knowledge</p>	<p>A USA based pilot study to inform the development of survey instruments for a larger research project: the Persons Aging with Hearing and Vision Loss (PAHVL Project). The PAHVL project is yet to report (mid 2014).</p> <p>Data were gathered from nine focus groups of 68 participants, exploring issues related to persons ageing with both hearing and vision impairment. Feelings of fear and vulnerability were discussed during the focus groups.</p> <p>Research is published in an online journal published by the Association for Education and Rehabilitation of the Blind and Visually Impaired.</p>	<p>Older People ageing with hearing and vision loss.</p> <p>Focus on those with single sensory impairment, acquiring a second sensory impairment in later life.</p> <p>Nine Focus Groups, total of 68 participants.</p> <p>7 Focus groups concerned those who were visually impaired first and subsequently acquire a hearing impairment.</p> <p>2 Focus groups concerned people who were deaf/hearing impaired first and subsequently acquired a sight loss.</p>	<p>Participants recruited via specialist organisations of and for deafblind people: potential for bias.</p> <p>In-depth analysis not undertaken.</p> <p>Demographic information not collected from all participants.</p> <p>No information on length of time between onset of first and second impairment.</p>



			<p>All but 1 participant aged over 55 (1 was soon to be 55). The majority of participants over 62.</p> <p>All individuals self-identified as having dual sensory impairment.</p> <p>All participants were members of consumer or support groups.</p> <p>Further demographic information collected from 39 participants:  20% African American; 80% White American  64% women; 36% men  31% blind, 69% visually impaired; 26% Deaf American Sign Language Users; 74% Hearing impaired speech users.</p> <p>3 participants had a cochlear implant.</p> <p>2 participants were in paid employment.</p>	
Bodsworth et al. (2011)	Research Knowledge	A UK based research study using the General Health Questionnaire (GHQ-12) to explore	539 participants. All members of the UK Charitable	No age of onset information

<p><i>Deafblindness and mental health. Psychological distress and unmet need among adults with dual sensory impairment.</i></p>		<p>psychological distress amongst deafblind adults. The research also had a secondary aim of exploring unmet need amongst deafblind adults, by comparing reported levels of support with desired support.</p> <p>The Deafblind charity <i>Deafblind UK</i> supported recruitment by sending a self-report survey to all 2717 of their members; survey format was adapted depending on the communication needs of the members. 539 analysable surveys were returned.</p> <p>Data were analysed using SPSS (version 13.0).</p> <p>The research is published in the interdisciplinary, peer-reviewed <i>British Journal of Visual Impairment</i>.</p>	<p>organisation Deafblind UK.</p> <p>All aged 18 or over. Age range: 18-104 years old. The mean age of the participants was 72 years old.</p> <p>404 participants were over 50 years of age, and acquired deafblindness in later life.</p> <p>36.2% were male, 61.3% female.</p>	<p>Participants recruited via a specialist organisation of and for deafblind people: potential for bias.</p> <p>Relatively low response rate</p> <p>Social work support identified as practical help rather than specialist support.</p> <p>In relation to care and support services, the extent of support offered to participants was not asked about.</p>
<p>Gullacksen et al. (2011) <i>Life Adjustment and Combined Visual and Hearing Disability /Deafblindness – an Internal Process over Time</i></p>	<p>Research Knowledge</p>	<p>A Swedish follow up study to Göransson (2008). The aim of this research was to use a life adjustment model to analyse the experiences of living with combined visual and hearing disability / deafblindness.</p> <p>Data were gathered via focus groups. A topic emphasized in the focus groups was vulnerability.</p> <p>The results and analysis of the research are published in an online text by the Nordic Centre for Welfare and Social Issues.</p>	<p>Focus on acquired deafblindness and the authors use the term deafblind as a generic word for “acquired combined visual and hearing disability, according to the Nordic definition of deafblindness”</p> <p>15 participants in total; three focus groups: Swedish, Danish and Norwegian.</p> <p>4 men and 11 women. Aged between 25-65; majority aged between 35-50.</p> <p>11 were congenitally</p>	<p>Participants recruited via specialist organisations of and for deafblind people: potential for bias.</p> <p>Age of participants given when direct quotations used, but not always age of onset.</p> <p>Interpreters used in data collection, but no acknowledgement that they are not neutral – lacks exploration and acknowledgement.</p> <p>Difficult to cross-reference data on age, age of onset and communication preferences.</p>

			<p>Deaf/Hearing impaired and subsequently acquired sight loss. 4 were visually impaired from birth or childhood, and subsequently acquired hearing impairment.</p> <p>All had progressive impairment; majority (n=11) had Usher Syndrome.</p> <p>9 participants used spoken language (supported by hearing aids and assistive technology). 6 participants used sign language: 4 visual sign and 3 tactile sign. 1 participant had a cochlear implant.</p> <p>Swedish Focus Group: all women communicating with sign language. Danish Focus Group: 3 women, 1 man, all communicating via spoken Danish. Norwegian Focus Group: equal number of men and women, using mix of communication methods.</p>	
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<p>Kyle &amp; Barnett (2012) <i>Deafblind Worlds</i></p>	<p>Research Knowledge</p>	<p>A UK based research project, completed wholly in British Sign Language (and its deafblind variants). The aim of this study was to examine the experience of being Deafblind, to determine if this was similar to Deaf people's experience and to establish if Deaf and Deafblind people could work together.</p> <p>Qualitative data were gathered via interviews and group meetings. Interviewers were deafblind themselves. The themes of insecurity and vulnerability emerge from the data.</p> <p>Quantitative data were also gathered on the characteristics of the participants.</p> <p>The research has not yet been formally published, but the full report was retrieved directly from the first author.</p>	<p>21 participants.</p> <p>All used British Sign Language (and/or deafblind variants e.g. hands on or tactile sign language).</p> <p>Included congenitally deafblind people and people born Deaf, using British Sign language and identifying as a member of the Deaf community, subsequently acquiring a visual impairment.</p> <p>85% of participants had hearing loss before the age of 5 years old. 41% acquired sight loss by the age of 10 years old.</p> <p>6 men and 15 women.</p> <p>Age Range: 21-66 years old. 41% aged 21-35 years old. Six of the participants were aged between 51-65 years old.</p> <p>77% used visual BSL by preference.</p>	<p>Age and age of onset of deafblindness not always made clear against participant direct quotations.</p> <p>Direct quotations presented in written English, but whole study completed in different modality (BSL).</p>
<p>Viljanen et al. (2012) <i>Fear of falling and coexisting sensory</i></p>	<p>Research Knowledge</p>	<p>A Finnish research study examining the combined effect of fear of falling and coexisting sensory difficulties on mobility.</p>	<p>All participants were women and were aged between 63-76 years of age. 28% (n=122) of participants had two sensory</p>	<p>Age of onset not made completely explicit.</p> <p>Hearing impairment and visual</p>

<p><i>difficulties as predictors of mobility decline in older women.</i></p>		<p>434 participants were recruited from the Finnish Twin Study on Ageing (FITSA) cohort.</p> <p>Data were gathered from a structured questionnaire and logistic regression was used to analyse the data.</p> <p>The research is published in the peer-reviewed <i>Journals of Gerontology: Medical Sciences</i>.</p>	<p>impairments (a combination of hearing impairment and/or vision impairment and/or balance difficulties); 10% (n=42) had three (hearing impairment, vision impairment and balance difficulties).</p>	<p>impairment presented as separate entities.</p> <p>Reference made to two sensory impairments not always indicative of deafblindness; in this study, this may refer to hearing loss and balance difficulties, or sight loss and balance difficulties.</p> <p>All participants were women and twins.</p>
<p>Hersh (2013) <i>Deafblind People, Communication, Independence, and Isolation.</i></p>	<p>Research Knowledge</p>	<p>A research study exploring the experiences of deafblind people in six different countries (France, Poland, England, Italy, Spain and Czech Republic). The aim of this study was to explore issues related to communication, independence and isolation for deafblind people; it forms part of a larger research project, which explores travel issues for blind, visually impaired and deafblind people.</p> <p>Qualitative data were gathered from semi-structured interviews, based on a list of topics/themes, which were modified as the study progressed. Participants were interviewed by the author, who is from the Department of Biomedical Engineering, University of Glasgow. The data were analysed using qualitative methods; however, computer software was not used for analysis owing to the multi-lingual nature of the data. The themes of vulnerability and overprotection emerged from the data.</p> <p>The research is published in the peer-reviewed</p>	<p>The term deafblind is used by the author to mean ‘people with some degree of combined hearing and visual impairment’. She acknowledges that the ‘deafblind people interviewed were very varied’.</p> <p>28 participants from six different countries: 27 deafblind people and the mother of a deafblind woman with autism.</p> <p>Participants’ ages ranged from below 16 years of age (n=1), to over 70 years (n=4). Age of onset of hearing impairment/deafness and visual impairment is noted separately; ranges from birth</p>	<p>Difficult to cross reference data on age, age of onset, communication method and severity of impairment.</p> <p>Limitations associated with interpretation and translation:</p> <ul style="list-style-type: none"> <li>• Whilst data analysis was undertaken in the language of the participants, direct quotations are presented in written English.</li> <li>• Non-verbal behaviours of those using tactile communication were not noted; this may impact on interpretation of participant responses, as such behaviours are important elements of meaning in tactual communication methods (Hart 2006).</li> <li>• Family members were used to</li> </ul>

		<i>Journal of Deaf Studies and Deaf Education.</i>	<p>to later life (60+).</p> <p>14 women and 14 men.</p> <p>68% participants used speech; 7% used speech and writing; 11% used visual sign language; 7% used tactile sign language; 7% used tactile alphabet and sign.</p> <p>75% participants noted as blind, 17% as partially sighted; 36% participants noted as Deaf, 64% as Hard of Hearing.</p> <p>7 participants had additional impairments.</p>	<p>interpret. Such family members are non-neutral constructors of knowledge (Temple 2002), who may, albeit unintentionally, omit or embellish information from the participant (Regmi et al. 2010). Furthermore, they do not necessarily have the skill level, professional status or registration (including commitment to a code of ethics) of qualified interpreters.</p> <p>Participants recruited via specialist organisations of and for deafblind people: potential for bias.</p>
<p>Stiefel (1991) <i>The Madness of Usher's. Coping with Vision and Hearing Loss (Usher Syndrome Type II.</i></p>	User Testimony	<p>A personal account of living with Usher Type II written by a 60-year-old American woman, self-defined as ' now in her fifth decade of deafblindness'.</p> <p>The account is presented in book published by The Business of Living Publications, Texas.</p>	<p>A 60-year-old American woman (at time of publication), self-defined as ' now in her fifth decade of deafblindness'.</p> <p>Author has Usher Type II; born with hearing impairment and has experienced considerable depreciation of sight in last 25 years.</p> <p>She is a speech user.</p>	<p>Detailed account but based on personal experience.</p> <p>Author has particular background, not representative of all deafblind people – includes private education.</p> <p>Has contact with organisations of and for deafblind people.</p>

<p>Henderson (2000) <i>Coping with Usher Syndrome.</i></p>	<p>User Testimony</p>	<p>A personal account of coping with Usher Syndrome, written by a 17-year-old girl with Usher Type I living in the UK. In the account, the author discusses her feelings about her diagnosis, the difficulties she encounters and her thoughts about the future.</p> <p>The account is published in <i>The Lancet</i>.</p>	<p>17-year-old young women diagnosed at 15 with Usher Type I.</p> <p>She experienced difficulties with hearing from birth and used hearing aids up to the age of 13. Then refused hearing aids and used British Sign Language to communicate.</p>	<p>Based solely on personal experience.</p> <p>Limited detail and depth.</p>
<p>Pollington (2008) <i>Always change – the transitions experience by an older woman with declining sight and hearing.</i></p>	<p>User Testimony</p>	<p>A personal account of living and ageing with deafblindness, published in charitable organisation’s (Sense) periodical.</p> <p>The author is a 68-year-old English woman who has been deafblind since her teenage years as a result of Usher Type II.</p>	<p>A 68-year-old English woman who has been deafblind since her teenage years as a result of Usher Type II.</p> <p>Born with hearing impairment and began to experience sight changes in childhood. Significant deterioration in sight in mid-40s.</p> <p>Communicates using speech and now uses braille to access printed material.</p>	<p>Based solely on personal experience.</p>
<p>Steve (Surname anonymous) (2012) <i>Is this social care enough?</i></p>	<p>User Testimony</p>	<p>An opinion piece and personal reflection authored by a man deafblind and physically impaired as a result of Alström Syndrome. There are limited biographical details about the writer.</p> <p>The piece is published online, by the UK charity Sense.</p>	<p>An adult man, deafblind and physically impaired (wheelchair user) as a result of Alström Syndrome.</p> <p>Experienced progressive visual impairment from birth (nystagmus and photophobia). Hearing impairment acquired</p>	<p>Limited biographical information about the author.</p> <p>Focus on single issue: use of social care services.</p> <p>Presented as an online blog, so difficult to verify authorship.</p>

			subsequently (no details when).  Hearing aid user and communicates using speech.	
Mar (1993) <i>Psychosocial Services: Presentation</i>	Practitioner Knowledge	<p>A paper presented at the 1993 <i>National Symposium on Children and Youth who are Deaf-blind</i> in Monmouth, Oregon, USA. The paper was presented by H.H. Mar, a developmental psychologist who has worked as a counselor for deafblind people.</p> <p>The paper reviews current practices in the delivery of psychosocial services for deafblind people and explores how effective they are, particularly in meeting needs related to social and emotional well-being.</p> <p>The author draws predominantly on his own practice experiences, with some reference to other literature</p>	<p>Paper has a stated focus on 'children, adolescents and young adults who are deafblind'.</p> <p>The author 'sets the scene' to the paper by referring to a man in his 30s, congenitally deafblind as a result of Congenital Rubella Syndrome, and 'mildly mentally retarded' (sic). He goes on to acknowledge that his personal experience, on which the paper is largely based, is biased towards deafblind young people with cognitive disabilities.</p>	<p>Professional background of the author not made clear in the paper (this information was sourced elsewhere).</p> <p>The author acknowledges a bias toward deafblind young people with cognitive disabilities, but suggest the paper will also cover the psychosocial concerns of all deafblind individuals. It is not clear throughout the paper where this occurs as the author largely uses the single term 'deafblind' in much of the discussion.</p>
Sauerburger (1993) <i>Independence without sight or sound. Suggestions for Practitioners Working with Deaf-Blind Adults.</i>	Practitioner Knowledge	<p>A textbook published by the American Foundation for the Blind, New York and authored by an Orientation and Mobility (O&amp;M) specialist/instructor who has worked with deafblind people at state rehabilitation agencies, private agencies and schools for over twenty years.</p> <p>The author predominantly draws on her own experiences, supported by reference to other published material, to offer practical suggestions,</p>	<p>The author uses a functional definition of deafblind: 'a person is deafblind if he or she has a combination of vision and hearing losses that together create a unique set of circumstances requiring adaptive techniques to function' (p1).</p>	<p>Focus of the text is on practice and strategies for best practice, rather than the experiences of deafblind people.</p> <p>Whilst heterogeneity amongst deafblind people is acknowledged, details of the characteristics of deafblind clients discussed in the text are not always made explicit.</p>



		<p>strategies and techniques for those working with deafblind adults.</p>	<p>The text draws on the author’s experience of working with a range of deafblind people, including:</p> <p>Those profoundly deafblind; those with residual hearing and/or vision; those with additional health problems or impairments (including learning disability); those with Usher Type I and II; those with congenital deafblindness, including those with with congenital rubella syndrome; those born with visual impairment who subsequently acquire hearing loss; and those acquiring dual sensory loss in later life.</p> <p>The text focuses on deafblind adults not children.</p>	
<p>Smith (1993) <i>Psychosocial Services: Reaction</i></p>	<p>Practitioner Knowledge</p>	<p>A paper presented at the 1993 <i>National Symposium on Children and Youth who are Deaf-blind</i> in Monmouth, Oregon, USA. The paper was presented by T. Smith, former director of the American Sign Language and Interpreting School of Seattle (1989-2007) and author of <i>Practical Tips for Working and Socializing with Deafblind People</i>.</p> <p>The paper is a reaction paper to that presented by H.H. Mar (1993). Smith draws on her experiences of working with deafblind people. She argues for</p>	<p>The author draws on her experiences of working with deafblind people. She acknowledges that the majority of this experience is work with adults who are “just” deafblind: those with no additional intellectual impairment/learning disability; most of those she has worked with have Usher</p>	<p>The author is Director of the ASL and Interpreting School of Seattle. However, no information is provided on her professional background – this is problematic for a paper drawing on experiences.</p> <p>The paper contains no references to other literature, but it is not made clear if the author intends to draw solely from her knowledge from practice</p>

		the development of deafblind communities for this population.	Syndrome.  The paper discusses both deafblind children and deafblind adults.	experience. She is the author of textbooks concerning with professional practice with deafblind people and has a PhD in the field. It is not clear if she is also drawing on this material.
Luey (1994) <i>Sensory Loss: A neglected issue in social work.</i>	Practitioner Knowledge	<p>A practitioner paper describing the 'Hearing-Vision Project', in which the author co-ordinated the work of specialists in two agencies (one for hearing impaired people and one for visually impaired people), provided direct support and identified ways in which social workers might support the acquired deafblind population.</p> <p>The paper draws on the experiences of the author during the project, and an earlier exploratory study in which she interviewed 30 deafblind people.</p> <p>The author is a social worker at the Hearing Society for the Bay Area, Inc. San Francisco, California, USA.</p> <p>The paper is published in the peer-reviewed <i>Journal of Gerontological Social Work.</i></p>	<p>Older people with later life acquired deafblindness.</p> <p>All clients of the 'project' were over 60 years of age (except 4 people with rare disorders). The median age is 87 years old.</p> <p>Just over 50% clients were women.</p> <p>45% had a moderate hearing impairment; 10% severe hearing impairment</p> <p>19% had total sight loss.</p> <p>More than 50% clients had an additional physical illness or impairment (e.g. arthritis, heart problems, diabetes).</p>	<p>The paper offers more description than analysis, and the focus is on service organisation rather than deafblind people's experiences.</p> <p>Limited information is given on the exploratory study. No information is given on the 30 deafblind people interviewed for that study.</p>
Merkin & Smith (1995) <i>A community based model providing services for Deaf and Deaf-blind victims of sexual assault and</i>	Practitioner Knowledge	<p>A report by the Education coordinator (Merkin) and Executive Director (Smith) of the Abused Deaf Women's Advocacy Services (ADWAS) in Seattle, Washington, USA. The paper describes the experiences of the authors in establishing a Deaf run agency providing services to Deaf and deafblind women experiencing sexual assault and</p>	<p>Focuses on deafblind 'victims' of sexual assault and Domestic Violence.</p> <p>28 deafblind people supported by the agency described in the article, with an age range</p>	<p>No further details on the 28-deafblind people supported (e.g. congenital or acquired deafblindness, age, age of onset, interval between sensory losses) are provided.</p> <p>Authors refer to 'various</p>

<p><i>domestic violence.</i></p>		<p>domestic violence.</p> <p>At the time of publication, the agency was the only domestic violence service specifically for Deaf and deafblind women in the USA and had supported 28 deafblind adults.</p> <p>The paper is published in the international, interdisciplinary and peer-reviewed journal <i>Sexuality and Disability</i>.</p>	<p>between 4-76 (though this refers to both Deaf and deafblind users).</p> <p>Includes deafblind people using 'various communication techniques'.</p>	<p>communication techniques', but no further detail is given.</p> <p>It is not always clear in the paper if the points being raised relate to Deaf and deafblind people, just Deaf people or just deafblind people.</p>
<p>Miner (1997) <i>People with Usher Syndrome Type 2: Issues and Adaptations</i></p>	<p>Practitioner Knowledge</p>	<p>A practitioner paper drawing on practice experience, other literature and interviews with adults with Usher Syndrome Type II over a four-year period.</p> <p>The author is a clinical social worker based in New York, USA at the time of publication, but now based in Los Angeles.</p> <p>The paper is published in the international peer-reviewed journal, <i>Journal of Visual Impairment &amp; Blindness</i>.</p>	<p>Adults with Usher Syndrome Type II.</p> <p>The author interviewed 32 people over a four-year period.</p> <p>Author acknowledges that 'people with Type II are not an homogeneous group', with differences in language use and cultural affiliation.</p> <p>The age of some (not all) of the participants is given, and ranges between 24 and 45 years of age.</p>	<p>The demographic details of all the participants, including age, are not given.</p> <p>Nine of the 32 participants were clients or acquaintances of the author. The potential impact of this pre-existing relationship is not acknowledged or explored.</p>
<p>Moss &amp; Blaha (2001) <i>Introduction to Sexuality Education for Individuals who are Deafblind and</i></p>	<p>Practitioner Knowledge</p>	<p>A textbook published by the National Information Clearinghouse on Children Who Are Deaf-Blind and authored by a Family Support Specialist (Moss) and Teacher Trainer (Blaha) both from Texas Deafblind Outreach, Austin, Texas, USA.</p>	<p>Focuses on deafblind children with additional significant developmental delay, defined as follows: 'a child with very rudimentary communication skills, is inwardly focused, and</p>	<p>Lack of clarity in relation to the origin of some of the knowledge referred to.</p> <p>This is a textbook, and focuses predominantly on service issues and best practice, rather than the detailed</p>

<p><i>Significantly Developmentally Delayed.</i></p>		<p>The book is aimed at parents, professionals, and others working with school-aged deafblind children with significant developmental delay.</p> <p>The book draws on literature related to sexuality education and deafblindness, conversations the authors had with parents and colleagues, and the authors' own practices experiences whilst working at the Texas School for the Blind and Visually Impaired, and Texas Deafblind Outreach.</p>	<p>is not likely to seek out other people to engage in typical social interactions. The child often has additional physical disabilities and may be considered to be cognitively impaired'.</p>	<p>experiences of deafblind people.</p>
<p>Butler (2009) <i>Personal – Professional Relationships.</i></p>	<p>Practitioner Knowledge</p>	<p>A practitioner authored piece describing the relationships between practitioners and deafblind people, and the potential for vulnerability within these relationships.</p> <p>The author draws on her own experiences, other research in the field and contact with other professionals and deafblind practitioners.</p> <p>The paper is published in the online version of <i>Talking Sense</i>, the magazine of the UK deafblind charity Sense.</p>	<p>The author largely focuses on acquired deafblindness, but includes deafblind children and adults. She draws some distinctions between deafblind people with learning disabilities, congenitally deafblind people and young deafblind people.</p> <p>The author illustrates some of her points with reference to a woman, now in her 50s, with progressive sight and hearing impairment since the age of 3.</p>	<p>Lack of detail in relation to the professional background of the author.</p> <p>Detail missing from the references.</p> <p>Largely draws on experiences with deafblind people known to the particular service.</p>
<p>Volden &amp; Saltnes (2010) <i>Norway's new ways with mental health.</i></p>	<p>Practitioner Knowledge</p>	<p>A short report by a Specialist Psychologist (Volden) and Senior Psychiatrist (Saltnes) from the National Centre for Hearing Impairment and Mental Health, which is part of Oslo University Hospital, Oslo, Norway.</p> <p>The report draws on the experiences of the work of the authors with a broad range of deafblind people;</p>	<p>Focuses on deafblind people with mental health difficulties, including depression and psychosis.</p> <p>The report considers both congenitally deafblind people and those with acquired</p>	<p>Full citations for references are missing.</p> <p>Lack of detail in general presentation.</p> <p>Greater focus on description of service and need for services, rather than the lived experiences of deafblind people.</p>

		<p>it also includes reference to other studies, though full citations for these are not offered.</p> <p>The report is published in the online version of <i>Talking Sense</i>, the publication of the UK deafblind charity Sense.</p>	<p>deafblindness, and acknowledges the range of differing communication needs amongst these populations.</p> <p>The paper specifically comments on issues for people with a profound loss of hearing and vision, and people with Usher Syndrome.</p>	
<p>Wickham (2011) <i>Depression in the Deafblind Community: Working from a Social Work Perspective.</i></p>	<p>Practitioner Knowledge</p>	<p>A practitioner paper drawing on practice experience and other literature to explore depression in the deafblind community, from a social work perspective. The author is a social worker for the Senses Foundation, Australia.</p> <p>The paper is published in the biannual publication of Deafblind International.</p>	<p>The author states that the paper is 'mainly related to adults with acquired deafblindness'.</p> <p>The paper considers those with progressive or sudden dual sensory loss and refers to a study of those living with deafblindness over a period of time.</p>	<p>Limited detail on the literature drawn upon. Insufficient information provided in order to locate study referred to.</p> <p>Refers to those with 'acquired deafblindness' but offers little further information in relation to age, age of onset and other characteristics.</p>
<p>Deafblind UK (2007) <i>Cause and Cure. Deafblind People's experience of the NHS.</i></p>	<p>Organisational Knowledge</p>	<p>A report produced and published by the UK charity Deafblind UK, based on their health survey of deafblind people's experiences of the NHS in 2006 and the results of the first national survey of deafblind people and healthcare experiences in 2001 (Who Cares? Access to Health Care for Deafblind People)</p> <p>The 2006 survey was sent to all 2717 members of the organisation; 486 surveys were completed and returned. Some participants' surveys were</p>	<p>486 surveys returned.</p> <p>All members of Deafblind UK. All deafblind adults.</p> <p>Reader can imply from the findings, that the participants use a range of communication methods, though this is not made explicit.</p>	<p>The method of analysis is not made explicit.</p> <p>No further information on participants (age of onset, age, congenital or acquired) is provided.</p> <p>Some of the surveys are completed with support or by proxies; difficult to determine impact of this.</p>

		completed with support.		Produced by a campaigning charitable organisation for deafblind people.
Kiekopf (2007) <i>Reasons why deafblind individuals are vulnerable to abuse.</i>	Organisational Knowledge	<p>A paper presented at the 2007 Deafblind International World Conference in Perth, Australia. The lead presenter and named author is Steve Kiekopf, Policy and Quality Officer at the UK based deafblind charity Sense.</p> <p>The paper explores why deafblind individuals are vulnerable to abuse.</p> <p>The paper predominantly draws on data from the Sense Abuse Database over a five-year period (2000-2005) to contextualize the discussion. The Sense abuse database stores information on allegations and incidences of abuse amongst deafblind people using Sense services. In the period concerned, 94 incidences of abuse are recorded; this includes physical abuse, financial abuse, sexual abuse, psychological abuse and neglect.</p> <p>The paper also draws on some literature authored by practitioners in the fields of deafblindness and learning disability/intellectual impairment.</p>	<p>Main focus of the paper is congenitally deafblind people, children and adults. There is some separate comment on individuals with acquired deafblindness.</p> <p>Of the 94 incidences of abuse reported in the Sense Database between 2000-2005:</p> <p>86 concerned congenitally deafblind people in residential or day service settings.</p> <p>8 concerned older people with later life acquired deafblindness.</p>	<p>Data relates specifically to deafblind people using the services of the organisation only.</p> <p>Produced by a campaigning charitable organisation for deafblind people.</p> <p>Some literature drawn upon relates to learning disability / intellectual impairment; this does not relate to all congenitally deafblind people.</p> <p>Details missing in the reference list.</p>
Sense (2012) <i>Fair Care for the Future. Why social care matters for deafblind people.</i>	Organisational Knowledge	A report produced and published by the UK deafblind charity Sense, based on its survey of 89 deafblind people's experiences of social care in England and Wales.	<p>89 deafblind adults, including those with congenital deafblindness and acquired deafblindness.</p> <p>Age Range: 18-80+ years Age of onset Range: Birth -</p>	<p>The report includes limited information on recruitment processes and survey tools; direct quotations within the report are stated to be verbatim</p> <p>46% (n=41) of returned surveys had been completed on behalf of the</p>

			<p>80+ years</p> <p>67% (n=60) had other conditions in addition to deafblindness.</p> <p>Report includes 5 'case studies':</p> <ol style="list-style-type: none"> <li>1. 50-year-old woman, born profoundly Deaf, subsequent sight loss (registered blind), uses tactile BSL to communicate.</li> <li>2. 22-year-old woman, congenitally deafblind, with additional impairments including epilepsy and learning disability. Uses own version of signed supported English to communicate.</li> <li>3. 72-year-old man, dual sensory loss acquired in later adulthood, speech and hearing aid user.</li> <li>4. 21-year-old woman, congenitally deafblind with additional physical impairment, learning disability (intellectual</li> </ol>	<p>deafblind person.</p> <p>Cannot link the age and age of onset information.</p> <p>Relatively low response rate.</p> <p>Produced by a campaigning charitable organisation for deafblind people.</p>
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			<p>impairment); learning Makaton to communicate.</p> <p>5. 24-year-old man with Wolfram Syndrome (DIDMOADS). Acquired deafblindness, with progressive sight loss and profound bilateral deafness.</p>	
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TABLE 1: SUMMARY OF MATERIAL INCLUDED IN THE REVIEW



