

**Ageing with a unique impairment:  
a systematically conducted review of older deafblind people's experiences.**

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**Abstract**

Little is known about the experiences of people ageing with impairments; social gerontology has largely focused on those ageing *into* disability rather than those ageing *with* disability. This paper synthesises existing knowledge to determine what is known about the experiences of those ageing with deafblindness. A comprehensive literature search was undertaken between April 2013 and May 2014. The review method was *informed* by systematic review principles. A total of 24 references were identified for inclusion. No studies examining deafblind people's experience of ageing and old age specifically were found, suggesting that those ageing with deafblindness are an understudied sub-group within the deafblind population. However, deafblind people describe ageing experiences in studies exploring their lives generally, and in personal accounts of living with the impairment. Practitioner authored material also explores the topic. Similarities in experience were identified between those ageing with deafblindness and those ageing with other impairments: ongoing change and consequent need for adaptation; a particular relationship between ageing and impairment; a sense that whilst one can learn adaptive strategies having lived with impairment for many years, it does not necessarily get easier; and a particular relationship with care and support services. These experiences illustrate the unique nature of ageing with impairment, and

challenge gerontologists to engage in further research and theorising in the field of disability in later life.

## **Keywords**

deafblindness; dual sensory impairment; ageing with disability

## **Introduction**

Whilst there is a body of interdisciplinary research on life transitions (Barroso *et al.* 2003) and a developing interest in those ageing with disability, Jeppsson Grassman *et al.* (2012) observe that little is known about the experiences of people ageing with a range of impairments; social gerontology and gerontological social work research has tended to focus on those ageing *into* disability rather than those ageing *with* disability (Jeppsson Grassman *et al.* 2012; Putnam 2002). Writing as an adult ageing with impairment, Newell (2008:74) argues that:

[t]he ageing of adults with all types of disabilities is an important issue which has not necessarily received the intellectual energy that it should.

However, this population has become more visible (Putnam 2002), as a result of increased life expectancy, and advances in rehabilitation and medical technologies, and a body of literature on the topic is emerging. This literature notes important differences between the 'ageing with disability' and 'ageing into disability' populations, but has largely focused on those with physical impairments (for example, Gilson and Netting; Zarb and Oliver 1993) or intellectual impairment (for example, Bigby and Haveman 2010; Gangadharan *et al.* 2009; Kåhlinet *et al.* 2013) and not sensory impairments, though one of the Jeppsson Grassman *et al.* (2012) studies related to adults ageing with

visual impairment. The aim of this review is to synthesise existing knowledge about those ageing with dual sensory impairment, also known as deafblindness, in order to answer the following: *what is known about the experiences, views and key features of old age and ageing for deafblind people?*

Those who have aged with deafblindness are largely an unrecognised population, in both policy and the literature. Furthermore, in practice, social care services have often overlooked those ageing with impairments (Verbrugge and Yang; Zarb 1993); in the United Kingdom (UK), services for disabled adults have often been targeted at those aged 18-65, whilst those over 65 are regularly transferred to mainstream older people's services. To inform policy and practice, there is a clear need to explore the experiences of those ageing with specific impairments such as deafblindness; such a need has been noted in relation to changing clinical needs (Dalby *et al.* 2009) and also in relation to specific groups (for example, those born with congenital rubella syndrome during the 1960s rubella pandemic (Armstrong and O'Donnell 2004) and those with Usher syndrome (Damen *et al.* 2005)).

## **Definitions**

Deafblindness is a severe and complex impairment (Bodsworth *et al.* 2011; Langer 2008). 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 (Enerstvedt 1996; Mar 1993; Wittich *et al.* 2013), reflecting the broad spectrum of people who can be considered 'deafblind' (Alley and Keeler 2009; Smith 1993). What deafblind people have in common is deprivation in use of the

distance senses (sight and sound) (McInnes 1999), resulting in difficulties with communication, accessing information and mobility (Department of Health 1997). Geenens (1999) observes that deprivation in the distance senses also significantly diminishes information to the brain, impacting on the way in which deafblind people, particularly congenitally deafblind people, make sense of their surrounding environment. Deafblind people may therefore rely on the proximal senses, particularly touch, to explore and engage with their environment. Nicholas (2010:7) notes that deafblind people 'use active touch in ways that no one else does... [and] are generally more experienced in recognising stimuli by active touch'. Variations in, *inter alia*, aetiology, age, age of onset, interval between impairment in each sense, cognitive function, language/communication method and cultural background (Bodsworth *et al.* 2011; Dalby *et al.* 2009; Langer 2008) all impact on a person's experience of deafblindness.

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 2014). In England the Department of Health's (1997) good practice guidelines, *Think Dual Sensory*, extend these classifications and apply them specifically to older deafblind people:

1. Those whose deafblindness has been acquired and developed in old age.
2. Older people who have lived with sight impairment and subsequently acquire hearing loss.

3. Older deafened or hearing impaired people who have used speech to communicate, who subsequently acquire visual impairment.
4. Older culturally Deaf people who use British Sign Language, who subsequently acquire visual impairment.
5. Older people who have been deafblind for all or the majority of their life.

The majority of deafblind people fall into the first of these groups, a population predicted to expand considerably (Robertson and Emerson 2010). Whilst this group has received less attention in research than congenitally deafblind children, and young people with acquired deafblindness (Brennan *et al.* 2005; Roberts *et al.* 2007) a range of literature is now evident. However, much less is known about those older people who have aged or are ageing *with* deafblindness. Whilst these are a much smaller group of deafblind people than those acquiring deafblindness in later life, it is important to note that they remain a heterogeneous population, with factors such as age of onset, previous education, communication method, cultural identity, and social support as key variables.

## **Method**

This paper reports on the findings of the second element of a systematically conducted literature review, the first element of which explored what is known about the vulnerability of deafblind people. The findings of the latter are published elsewhere (Author's own). Whilst the inclusion criteria for the first element differed to those of the second (it did not focus solely on those ageing with deafblindness), the review method adopted was the same. A preliminary scoping search of bibliographic databases

identified 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 problematized two aspects of the systematic review process for both components of the review: 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 any attempt at synthesis would not be possible. Such an approach would also have resulted in the loss of much material considered to be practitioner knowledge and 'user' testimony. There is increasing recognition of the importance of such knowledge in systematic reviews (Gough *et al.* 2012; Rutter *et al.* 2010).

A comprehensive literature search was undertaken between April 2013 and May 2014. Twelve electronic bibliographic databases (See Table 1) were searched. Search terms were based on key concepts drawn from the review question (See Table 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 Table 3). Whilst it is a commercial website, Amazon was also explored, as its usefulness for literature searches has been acknowledged (Bryman 2008). One of the publications in this review (Stoffel 2012) was found solely via Amazon.

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The *Deafblind Bibliography* (constructed by James Gallagher, a deafblind man from the UK, 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 searched. The author also hand searched *Deafblind Review* (publication of Deafblind International) and *Talking Sense* (publication of the Charitable Organisation *Sense*). Visits were made to the *Sense* library and discussions held with *Sense* practitioners. Finally, the search was enhanced through citation tracking, reference harvesting, author searching and personal contact with named authors (as recommended by Barroso *et al.* 2003; Fisher *et al.* 2006; Rutter *et al.* 2010).

Certain references were excluded on the basis of the title alone. Those references appearing relevant were stored in bibliographic software (EndNote) and the criteria (See Table 4) 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 Table 4 about here >

< Insert Figure 1 about here >

The author used the TAPUPAS standards devised by Pawson *et al.* (2003) as provisional guidelines for appraising the literature included. This framework involves assessing the Transparency, Accuracy, Purposivity, Utility, Propriety and Accessibility of the material. It also requires the reviewer to consider source specific standards, relevant to each of the types of knowledge; these are outlined in the Social Care Institute for Excellence 'Types and Quality of Knowledge in Social Care' knowledge review (Pawson *et al.* 2003). However, priority was given to relevance over type or quality, owing to the limited amount of material identified; 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. Owing to the nature of the review question and the diversity of material, an interpretative rather than aggregative approach to synthesis was adopted (Bryman 2008). The diversity of material, variety of reporting conventions and multiple definitions of deafblindness used rendered data extraction problematic. The interpretative approach adopted by the author therefore 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**

### *Description of Literature*

A total of 24 references met the criteria and were therefore included. Eleven are research knowledge, adopting various methods. None of these studies focus specifically



or solely on the experience of ageing with deafblindness; however, the topics and research questions were considered relevant to the review question. Whilst LeJeune's (2010) study is part of a larger research project entitled 'Persons Aging with Hearing and Vision Loss' (PAHVL Project), this title could be considered somewhat misleading. The participants in this study had acquired a second sensory impairment after the age of 55 years, having previously been single sensory impaired (either hearing impaired or sight impaired). Whilst they are now 'ageing with deafblindness', they have not necessarily been deafblind for the majority of their lives. The study was included however, as the experiences of this population are distinct from those older people who have acquired dual sensory impairment in later life (LeJeune 2010).

Ten references are 'user' testimony. These include collections of personal accounts of living with deafblindness published as texts, in specialist organisations' publications or in peer-reviewed journals. Most are written by deafblind people, whilst others have been constructed in response to questions posed by friends and social care practitioners. Two have a particular focus on the experiences of old age and ageing with deafblindness (Pollington 2008; Wolf 2006).

Three references are 'practitioner knowledge'. Two of these are by the same author and all three are written by social workers. These accounts draw on practice experience, but also make use of other literature and interviews with deafblind people. They are not considered as 'research knowledge', as information from the interviews is used for illustrative purposes, rather than subject to any clear data analysis. None of these reports focus solely on the experiences of old age and ageing with deafblindness.

Table 5 summarises the 24 references.

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### *Synthesis*

Dammeyer (2015) observes that research in deafblindness is still in its infancy, and calls for greater interest in the field amongst the research community. Lack of a 'research infrastructure' for studies with deafblind people (Brennan and Bally 2007:282) was apparent in this review. Neither a common deafblind population nor a common definition of deafblindness is evident across the 24 references, as similarly identified by Wittich *et al.* (2013) in their systematic review of terms and definitions of deafblindness across clinical and research literature. Various definitions are used and differing populations included, making comparison across the material problematic. The majority of the material adopts a functional definition, focusing on the implications of dual sensory impairment. However, there are subtle differences. Yoken (1979:4) observes that all but one of the participants in her study 'fall into the standard, accepted description of deafblindness', yet there is no clear identification in her work of this 'standard, accepted description', albeit that there is some earlier reference to functional implications of the condition. Stoffel (2012:ix) makes no reference to functional limitations in his definition, referring instead to 'a significant hearing loss and visual impairment' and in his personal account, Cohn (1998:19) suggests a clear distinction between people with hearing and visual impairment and those who are 'truly deaf-blind people'.

Studies do highlight particular differences between the needs and experiences of those acquiring deafblindness in later life, and those who have aged with the impairment. However, there is often a lack of clarity in reporting age of onset of deafblindness and current age, making it impossible to determine to which of these populations research participants belong. Furthermore, in studies that have included deafblind participants across the age groups, authors using direct quotations from participants or commenting on participants' views do not always make clear the relevant age/age of onset details of the particular participant, albeit that such participant characteristics are detailed in the methods sections.

Deafblind people use a range of languages and methods of communication (Barnett 2001) and may use a variety of methods depending on the situation (for example, environment, location and time of day). Deafblind people may also use different methods for expressive and receptive communication (Sauerburger 1993). As such, research with deafblind people, including most, though not all, of that included in this review, often involves interpretation and translation. Use of interpreters and translation poses practical and epistemological challenges in qualitative research (Berman and Tyyskä 2011; Regmi *et al.* 2010; Temple and Young 2004). Temple and Young (2004), writing specifically about research with British Sign Language users, stress the epistemological challenges of interpreter and translation use. They note that users of different languages may construct different views of the social world, which presents a challenge to the researcher in accurately representing participants' experiences in a different language. Many of the deafblind participants in the research studies in this review use sign languages (tactually or utilizing residual vision);

however, their direct quotations are always represented in written English. Furthermore, some studies involve multiple translations, not only from Sign Languages to English, but also from a range of other European languages (for example, Norwegian, Swedish, and Danish) to English (Göransson 2008; Gullacksen et al. 2011; Oleson and Jansbøl 2005; Spring et al. 2012). Temple (2002) highlights that interpreters are not neutral but are themselves constructors of knowledge in the interpreting act. Whilst some of the studies note the use of interpreters in the research (Gullacksen *et al.* 2011; LeJeune 2010; Spring *et al.* 2012; Yoken 1979), Oleson and Jansbøl (2005) are the only authors to recognise their role as constructors of knowledge, noting that their presence in qualitative interviews may affect the participants' responses to questions posed.

Kyle and Barnett (2012) suggest that knowledge of deafblind people's experiences can be gained through their autobiographical work. Gullacksen *et al.* (2011:18-20) argue that:

these personal stories relay important knowledge... [and that the] most important source of knowledge when it comes to understanding ... how people cope with a life with deafblindness, are the people who actually experience it.

However, many of the personal accounts identified in this review are limited in detail and depth, offering only a 'snapshot' of their life experiences. Furthermore, such accounts cannot be considered representative of the experiences of all deafblind people. The deafblind people writing or contributing to these accounts have their own particular backgrounds, which impact on their experiences. The majority of those contributing to the personal accounts also have contact with organisations for and of deafblind people, either as service-users, employees or volunteers. Contact with such

organisations is also the main method of participant recruitment in the majority of the research studies. The potential for bias that this engenders should be acknowledged (Padgett 2008).

### *Older People Ageing with Deafblindness: a Hidden Population*

Wolf (2006:2) argues that older deafblind people are 'often invisible and ignored'. Whilst she is referring here to all older deafblind people, this review suggests that it is those who have aged with deafblindness that are most 'invisible'. As noted, no research literature focusing specifically and solely on the experiences of those ageing with deafblindness was identified. Whilst various researchers and practitioners have highlighted the important distinction between those ageing with deafblindness and those acquiring deafblindness in later life (Göransson 2008; Jansbøl 1999; Sense 2009; Spring *et al.* 2012; Wolf 2006), the majority of the research literature addresses the experiences and needs of the latter group. Indeed, over 80 references were found during the literature search relating to this population. There is evidence of an inherent assumption in the literature that 'older deafblind people' are those who have acquired the impairment in later life. Journal articles with titles such as 'Vision and hearing loss in older adults' (Berry *et al.* 2004), 'Dual sensory impairment in an aging population' (Saunders and Echt 2011), 'Dual sensory impairment in older age' (Schneider *et al.* 2011) and 'An overview of dual sensory impairment in older adults' (Saunders and Echt 2007), *inter alia*, focus exclusively on those who have acquired deafblindness in later life; whilst in some this is made evident in the abstract or introduction, in others it is merely implied.

In those studies including a range of deafblind people, the 'ageing with deafblindness' population appears to be marginalised. Furthermore, the studies' oldest participants are often at an age that would be considered the 'young old' (Moody and Sasser 2012). One research study refers rather unspecifically to the oldest participants as being 'over 46 years of age', despite its stated focus on the difficulties in remaining independent for those with Usher Syndrome who are 'getting older' (Damen *et al.* 2005). This lack of inclusion of older people ageing with deafblindness, may be linked to participant recruitment difficulties, rather than choice; indeed, Kyle and Barnett (2012:15) observe that it 'proved more difficult to find older Deafblind people' than younger Deafblind people for their study.

Marginalisation of older people who have aged with deafblindness is also evident in those references concerned with the 'life course' or 'life cycle'. For example, Miner (1995) includes significantly less material on later life, than that on issues related to infancy and childhood, adolescence, school experiences and early adulthood. Miner (1995:294) herself suggests that 'much more work needs to be done on elderly people's experiences with Usher syndrome'. The section titled 'ageing with deafblindness' in Göransson's (2008) study of the experience of deafblindness across the age groups is also significantly shorter than those concerned with childhood and adolescence; whilst this section starts with the profile of an 81 year old woman who has aged with deafblindness, the majority of the chapter explores the experiences of those acquiring the impairment in later life. The publication of the follow up study by Gullacksen *et al.* (2011) contains chapters on both childhood and adolescence, but no separate chapter

on old age. The studies by Ellis and Hodges (2013) and Oleson and Jansbøl (2005) seek to explore the experiences and lives of people with Usher Syndrome and deafblind people respectively. Whilst neither study adopts a life course perspective or approach, it is interesting to note that in both studies, the researchers clearly state a choice to focus on young deafblind people and those in early adulthood.

Crow (2000:845) observes that the well-known American deafblind woman Helen Keller 'was a woman who lived to old age, yet is fixed in the public imagination as an eternal child'. A number of personal accounts of living with deafblindness offer limited coverage of the experience of ageing. Both Coker (1995) and Murphy (1991) acquired deafblindness in childhood and are now in later life, yet in neither account do they report on nor describe their experience of getting older, choosing to focus on childhood, schooling and early adulthood; these accounts were therefore excluded from the review. Those included in review, with the exception of Pollington (2008) and Wolf (2006), offer limited discussion in relation to getting older; they focus predominantly on experiences earlier in their lives, particularly diagnosis, education, adolescence and transition to adulthood.

### *Ageing with Deafblindness: Ongoing Change and Adjustment*

Whilst sensory impairments have been described as 'stable' conditions (Kelley-Moore 2010; Shakespeare and Watson 2001), such description appears contrary to the experiences of those ageing with deafblindness. The concept of change, in both the impairment and its impact as people age, is common across all the literature reviewed.

Göransson (2008:16) concludes that 'deafblindness can never be regarded as something static' and the experience of change forms the central theme of Pollington's (2008) personal account.

Changes in vision and hearing are one particular experience noted. Wolf (2006:24) observes that even those 'who may have been [deafblind] for many years, see a worsening of their condition'. Older deafblind people report deterioration in both their hearing and vision (Duncan *et al.* 1988; Göransson 2008; Gullacksen *et al.* 2011; LeJeune 2010; Oleson and Jansbøl 2005; Pollington 2008; Spring *et al.* 2012; Stiefel 1991; Stoffel 2012; Yoken 1979), with changes in vision in particular for those with Usher Syndrome, owing to the nature of retinitis pigmentosa (RP) (Butler 2004; Damen *et al.* 2005; Duncan *et al.* 1988; Ellis and Hodges 2013; Miner 1997; Miner 1995; Stiefel 1991; Stoffel 2012). Lastrup (2004) identifies that some of these changes result from the original aetiology of deafblindness and potential late manifestations of these aetiologies; others are attributed to other conditions, including age-related conditions. Barr (1990) describes the experience of both. Lastrup (2004) also highlights that progressive impairment of vision and hearing is not limited to those ageing with conditions related to acquired deafblindness, but also those with congenital deafblindness. This challenges the perception of congenital sensory impairment as 'stable' or 'static', and also Göransson's (2008) suggestion that for those ageing with congenital deafblindness the core challenge is external changes throughout the lifecourse, rather than changes in hearing and vision. The nature and timing of hearing and vision deterioration are variable and periods of stability and fluctuation are reported; two older deafblind participants in the Oleson and Jansbøl (2005:14) study



discuss changes in vision having no 'fixed pattern'. It is important to note that changes in hearing and vision are not restricted to deterioration; some people ageing with deafblindness experience improvements as a result of changes in their condition or medical intervention (Stoffel 2012; Yoken 1979).

As a result of these changes, those ageing with deafblindness often describe a need to make adjustments, and 'individual adjustment' is a concept common across the literature, particularly adjustment to loss. Miner (1995:287) states that 'Usher syndrome.... *requires* multiple adaptations throughout the life cycle' and her later paper on Usher Type II focuses specifically on 'adaptations' (Miner 1997). Adjustment is not a 'one-off' event. Yoken (1979), Stiefel (1991), Göransson (2008), Gullacksen et al (2011) and Wickham (2011) all report repeated and ongoing adjustment. Ann Black, a contributor to Duncan et al's (1998:8) collection of personal accounts refers to 'a constant adjustment' as she ages with Usher Syndrome. The literature observes those ageing with deafblindness making a range of adjustments: psychosocial adaptation and emotional 'acceptance' of deteriorating senses; changes in relationships, including personal relationships and relationships with social care services; and having to learn new ways to complete activities of daily living, use modern assistive technologies and access information (Duncan *et al.* 1988; Ellis and Hodges 2013; Göransson 2008; Gribb *et al.* 1995; Gullacksen *et al.* 2011; Miner 1997; Miner 1995; Oleson and Jansbøl 2005; Stoffel 2012).

A particularly common adjustment experience concerns communication method. Participants in a number of studies, practitioners and those offering personal accounts describe how changes in hearing and vision render existing communication methods

unsatisfactory, making communication difficult (Damen *et al.* 2005; Göransson 2008; Gullacksen *et al.* 2011; Miner 1997; Oleson and Jansbøl 2005; Spring *et al.* 2012; Stoffel 2012). Many older deafblind people describe how they have needed to learn new methods of communication over their life course (Göransson 2008; Gullacksen *et al.* 2011; Spring *et al.* 2012).

### *Ageing with deafblindness: inter-related experience*

Pollington (2008:32) states that she 'cannot divorce ageing from deafblindness because that is what I am'. The relationship between ageing and deafblindness and the impact they have on each other are recurring themes across the literature. Gullacksen *et al.* (2011) note that adjustment to deafblindness is a process that occurs alongside the ageing process: changes related to ageing occur concurrently with changes in the dual sensory impairment. Brennan and Bally (2007) highlight that, for many older people acquiring deafblindness in later life, the effects of age-related conditions exacerbate the dual sensory impairment and *vice versa*. It appears that this reciprocal exacerbation is also an experience of some of those who have aged with deafblindness. Stiefel (1991) and personal accounts in Wolf (2006) and Stoffel (2012) include descriptions of a combination of age-related conditions and deafblindness adversely impacting on mobility, communication and activities of daily living. The impact of this exacerbation is captured in the words of a 71-year-old woman, deafblind from adolescence:

I have spent most of my adult life living alone with increasing disabilities... Now that I'm of retirement age, the difficulties are closing in (Contributor in Stoffel 2012: 201-2).

Age-related conditions, or late manifestations of the original aetiology of deafblindness as people age, result not only in increased physical, neurophysiological and cognitive impairment (Dammeyer 2010; Laustrop 2004), but may also affect strategies previously utilised by deafblind people when younger. For example, one 77-year-old participant in Yoken's (1979) study describes how loss of sensitivity in his fingers as he has aged, has resulted in braille (a method previously used to access information) no longer being accessible. Stiefel (1991) experiences such increased impairment and wider effects as 'accelerated' ageing. Laustrop (2004) also observes incidences of what he identifies as 'early' or 'premature' ageing in data collected on the ageing process of deafblind adults with congenital rubella syndrome.

It is not just physical changes related to ageing that exacerbate the challenges of deafblindness. Göransson (2008) and Wickham (2011) note that living with deafblindness over a long period of time, combined with environmental changes, impacts on older deafblind people's experiences. Events over the life course can be experienced with a sense of uncertainty or difficulty when one has had a life of reduced access to information, communication difficulty and high levels of isolation (Gullacksen et al. 2011; Wickham, 2011). Grandparenthood, a role associated with old age (Green 2010), is reported as challenging by a woman ageing with Usher Syndrome Type I:

I can never be just a regular grandmother. Grandmothers can help their daughters and keep babies in their houses overnight alone. I can never do that (Deafblind woman aged 55 in Miner, 1995:6).

Changes in social networks and loss of friends, particularly those able to use deafblind communication methods, are described as challenging by deafblind people as they age

(Göransson 2008; Gribs *et al.* 1995; Stoffel 2012; Yoken 1979). Such changes and loss can be the result of age-related difficulties facing the friends themselves, bereavement or geographical distance. People with Usher syndrome Type I report particular difficulties in maintaining links with the Deaf community, as they age and their vision deteriorates (Kyle and Barnett 2012; Miner 1995).

The relationship between ageing and deafblindness is not always perceived as negative. Pollington (2008) describes the potential for her to be 'forever young' as she cannot see physical effects of ageing, such as changes in hair colour and wrinkling skin. She also describes becoming increasingly similar to her generational peers, as they acquire age-related sensory impairments: rather than standing out as a person with impairment, she describes 'merg[ing] into the background' (ibid: 33).

#### *Independence: maintained or threatened*

For some older deafblind people, living with the condition for a long time has facilitated easier adjustments, enabled them to maintain their independence and become increasingly self-reliant (Göransson 2008; LeJeune 2010; Stoffel 2012; Yoken 1979). Yoken (1979) observes that for two of her participants, the condition is considered no more than a human characteristic comparable to gender, age or race. This perception is mirrored in the words of a 54-year-old man, deafblind from the age of eight:

The hearing and vision losses have been with me so long that I have practically taken them as they have come... My vision and hearing losses are not a big deal (Deafblind contributor; in Stoffel 2012:88-9).

Similarly, Bejsnap (2004), deafblind since adolescence, describes almost forgetting that he is deafblind, now that he is in later life.

In contrast, for some older people, living with deafblindness for a long time does not make maintaining independence or coping easier. Damen *et al.* (2005) observe that people with Usher syndrome, particularly Type I, had increased difficulties maintaining their independence as they aged. Stiefel (1991) uses the metaphor of 'madness' in her personal account of the challenges of living and ageing with Usher Syndrome Type II and there is evidence in her narrative that living with deafblindness for a long time does not make things easier. Comparably, a 50-year old woman with Usher Syndrome Type II in Butler's (2004) paper suggests that life gets harder each year, not easier. As described by participants in Göransson's (2008) study, just as one adjusts and 'gets used to' deafblindness, then vision and/or hearing deteriorate further and one is faced with the need to adjust again.

As a result of these challenges and age-related changes, a deafblind person's independence can be threatened, as they get older. However, not all deafblind people state a desire to be independent. Barr (1990:336) explicitly expresses a dislike of the concept, stating that she is 'always grateful for a helping hand'; she adds that it is her 'freedom' rather than independence that she values. This 'helping hand' may come from family, friends, other informal carers or formal social care services.

### *Relationship with Social Care Services*

Older people acquiring dual sensory impairment in later life rarely consider themselves deafblind (Göransson 2008; Pavey *et al.* 2009; Sense 2006); as such, they do not always make contact with, nor are referred to, specialist social care services (Horowitz 2003; Roberts *et al.* 2007; Sense 2009). In contrast, in many of the personal accounts, older people who have aged with deafblindness express a desire to continue to engage in further training and rehabilitation services, even in later life (Barr 1990; Duncan *et al.* 1988; Pollington 2008; Stoffel 2012). This includes learning how to use new assistive technologies (Stoffel 2012), using new mainstream technologies (Stoffel 2012), and engaging in rehabilitation services (Gribs *et al.* 1995; Pollington 2008; Stoffel 2012).

Some older deafblind people express concern about the ability of deafblind services to meet their needs as older people (Cohn 1998; Göransson 2008; Gribs *et al.* 1995) and mainstream older people's services to meet their needs as deafblind people (Göransson 2008; Spring *et al.* 2012; Stoffel 2012). Miner (1995) highlights that those ageing with Usher syndrome Type I are not always even aware of the ageing process nor health and social care services for older people, owing to a life of reduced access to information.

Those who have aged with deafblindness now living in mainstream older people's residential settings (for example retirement villages and care homes) describe particular experiences of isolation and unmet need (Göransson 2008; Spring *et al.* 2012; Stoffel 2012). The isolation is not only a consequence of staff lacking relevant communication skills, but also a result of being the only deafblind person in the setting.

Advances in assistive technology for deafblind people are also not always considered positive for those ageing with the condition. For example, older participants in Göransson's (2008) research report having difficulties with assistive technology owing to changes in their fine motor skills, and Cohn (1998) explains having difficulties with changing technologies, including modern, and invariably smaller, hearing aids. Helen Gribs is also described as disliking her newer telecommunications equipment, compared to the equipment used earlier in her life that 'she loved for so many years' (Gribs et al. 1995:197).

## **Discussion**

Whilst research on disability and research on older people are plentiful, Priestley and Rabiee (2001) note that there is a dearth of research on disability in later life. In particular, there is a paucity of research exploring the experiences of older people ageing *with* a variety of impairments. This is mirrored in the activities of charitable organisations for older people, who have campaigned 'for greater rights for older people without making reference to disability rights explicitly' (Phillips *et al.* 2010:77). Reflecting this research gap, no studies focusing solely and specifically on the experiences of older people ageing with deafblindness were identified in this review: those ageing with the impairment are largely an invisible sub-group of the deafblind population.

Some studies of those ageing with a range of impairments are emerging, and these have identified shared experiences amongst this population: ongoing life changes, related to both impairment and ageing, and a consequent need for adaptation; the effects of ageing

being experienced as a 'second disability'; and anxiety related to maintaining independence (Gilson and Netting 1997; Jeppsson Grassman *et al.* 2012; Zarb and Oliver 1993). These experiences are evident in the literature relating to those ageing with deafblindness, as illustrated above, and may be considered features of what Putnam (2012:92) describes as the 'uniqueness to ageing with disability'. Early social theories of ageing did not always recognise the unique differences in people's ageing experiences (Phillips *et al.* 2010), and Putnam (2002) maintains that many theories of ageing do not examine the impact of life-long disability in particular. Oldman (2002) similarly argues that there is limited evidence of links being made between disability issues and ageing theory. Of particular note is the tendency in social gerontology to view disability solely from a medical perspective (Phillips *et al.* 2010). Some gerontologists have questioned the usefulness of exploring links between social models of disability and ageing theory, suggesting that it may reinforce the perception of old age as a time of inevitable decline (Oldman 2002). However, with its focus on disabling physical, social and attitudinal barriers, rather than individuals, Oldman (2002) argues that the social model avoids any construction of old age. Furthermore, debates concerning the social model and its relationship with social care services have brought the concepts of rights and independence 'under the gerontological gaze' (Phillips *et al.* 2010:207); whilst such concepts are valued by older people generally (Secker *et al.* 2003), they appear to be of significant concern to those ageing with impairments.

Some older deafblind people report that living with the impairment for a long time had made future adjustments easier; however, others felt that coping with deafblindness did not get easier, and for some, things became harder with old age. Similar experiences are



reported by people ageing with physical impairments (Jeppsson Grassman *et al.* 2012; Zarb and Oliver 1993). These challenges are perceived as a threat to independence (Butler 2004; Damen *et al.* 2005; Göransson 2008; Jeppsson Grassman *et al.* 2012; Zarb and Oliver 1993). However, not all those ageing with impairments report a desire to be independent (Zarb and Oliver 1993) and as identified in this review, this includes those ageing with deafblindness (Barr 1990). This may reflect differing interpretations of 'independence', as noted by Kyle and Barnett (2012). Rejecting 'independence', Barr (1990) states a clear desire for assistance or a 'helping hand'. Nonetheless, in redefining 'independence' the disability movement argues that it does not relate to the refusal of or lack of need for assistance, but rather concerns being in control of how and when that assistance is provided (Morris 2004). Comparably, research exploring the meanings older people give to independence highlights that many view remaining autonomous and in control, *inter alia*, to be as important as being able to care for one self (Secker *et al.* 2003). Such interpretations of independence have influenced the development of contemporary adult social care in the UK, largely through the provision of direct payments and personal budgets (Prideaux *et al.* 2009). There is evidence that such services can promote positive outcomes (Netten *et al.* 2012; Woolham and Benton 2013) and they should therefore be made available to those ageing with impairments, including deafblind older people.

The 'successful ageing' paradigm (Rowe and Kahn 1998), with its emphasis on the avoidance of disease and disability, maintenance of physical function, and advocacy of individual behaviour modification is also clearly problematic from a disability perspective (Minkler and Fadem 2002). For many people, a life lived with impairment

does not make it easier to avoid or face further impairment or ill health, nor is an existing life-long impairment experienced as static. For example, while congenitally deafblind people may not have fully developed their proprioceptive sense (Brown 2005; Sauerburger 1997), those ageing with deafblindness may experience further decline in proprioceptive function as they age, as a consequence of changes in the peripheral and central nervous system (Goble *et al.* 2009). This may pose a particular challenge for those who have relied on the range of sensory systems encompassing 'touch', impacting on their balance and other sensorimotor tasks (Brown 2005).

The experience of ongoing change and necessary adaptation described by those ageing with deafblindness is an experience also described by adults ageing with physical impairments (Jeppsson Grassman *et al.* 2012; Zarb and Oliver 1993). Zarb and Oliver (1993) adopt the concept of a 'career' to describe the way those ageing with impairments have to make repeated adaptations; this is a concept that could be used to describe the ongoing adaptations made by deafblind people as they age, particularly in relation to changes in communication, which may necessitate the learning of new methods. However, a model of individual adjustment to describe the experience of disability over the life course has been subject to critique by those adopting a 'strong' social model of disability (Oliver *et al.* 2012; Shakespeare and Watson 2001). Oliver *et al.* (2012) argue that such an individual adjustment model neglects the wider social situation. Whilst their research data are interpreted using a model of adjustment, Göransson (2008) and Gullacksen *et al.* (2011) identify this as a 'life adjustment model'. This model acknowledges that adjustment is not just an individual response to impairment, but that deafblind people also need the social environment and service

providers to adjust as they age. In the context of communication, as a deafblind person learns a new communication method as their dual sensory impairment changes, so too must service providers, family members and social networks, in order for communication to be meaningful and indeed, to be established. This need for others to adjust is not always acknowledged in the literature (Hersh 2013).

In understanding the meanings older people themselves attribute to successful ageing, Bowling and Dieppe (2005) observe that, in addition to maintaining health and function, enjoying life and being socially active were considered important. As highlighted in this review, some people ageing with deafblindness describe experiences of learning new skills, undertaking work, active engagement with rehabilitative services, and making new friends in later life (Barr 1990; Bejsnap 2004; Duncan *et al.* 1988; Gribs *et al.* 1995; Pollington 2008; Stoffel 2012). Furthermore, case study examples of older people ageing with deafblindness learning new skills much later in life have also been presented at inter-disciplinary conferences (Jenson and Christiansen 2011; Schoone and Snelting 2011). These experiences represent a direct challenge to the social construction of old age as a period of inevitable decline and withdrawal (Andrew 2012) and support Kelley-Moore's (2010:106) suggestion that:

... persons who are ageing with disabilities... tend to be more proactive in the planning and management of potential long-term care needs.

Those ageing with deafblindness appear to value care and support services, and express concerns about ongoing service availability, accessibility and funding for support, as do people ageing with both physical and intellectual impairments (Jeppsson Grassman *et al.* 2012; Ward 2012). For Bejsnap (2004), an older person deafblind from adolescence,

it is lack of support that is central to the experience of *being* deafblind, rather than the impairment itself:

As soon as I let go of my interpreter, I am deaf and blind and all alone in the world. But when I am in contact again with my interpreter, I can communicate and get information about what's going on around me (ibid.: 72).

In order to ensure appropriate care and support services, it is important to develop knowledge and understanding of the unique experience of those ageing with impairment, and to recognise the differences between this population and those ageing into disability. However, Verbrugge and Yang (2002) suggest that such distinction between the groups can be simplistic. They argue that disability and ageing interweave throughout the life course, and that it is essential to view them as intertwined. More detailed understandings are therefore required, necessitating further research and theorizing in the field of disability in later life.

## **Conclusion**

Older people ageing with deafblindness are an under-studied population, receiving little attention in the literature; this reflects the dearth of research on those ageing *with* a range of impairments. No empirical studies specifically and solely exploring the experiences of older people ageing with deafblindness were identified in this review. The research gaps are thus immediately evident. However, studies exploring the experiences of deafblind people more generally were found to contain relevant data and when read alongside user testimony, and practitioner knowledge, certain themes emerged. Similarities in experience were identified between those ageing with deafblindness and those ageing with other impairments: ongoing change and the

resultant need for enduring adaptation; a particular relationship between ageing and impairment, with one exacerbating the other; a sense that whilst one can learn adaptive strategies having lived with impairment for a long time, it does not necessarily get easier; and a particular relationship with care and support services. These experiences are illustrative of the unique nature of ageing with impairment, and challenge gerontologists to engage in further research and theorising in the field of disability in later life.

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*Table 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)

*Table 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

ageing OR aging OR old\* OR senior\* OR elder\* OR aged OR “old age” OR gerontol\*

*Table 3: Search engines and websites*

Internet Search Engines	Websites
<p>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)</p>	<p>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</p>



*Table 4: Inclusion and exclusion criteria*

Included references which:	Excluded references which:
<ul style="list-style-type: none"><li>• Related to older deafblind people who have been deafblind for most of their lives.</li><li>• Included the views and experiences of older deafblind people.</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><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>	<ul style="list-style-type: none"><li>• Related only to those with single sensory impairment.</li><li>• Related only to deafblind children.</li><li>• Related only to those older people acquiring deafblindness in later life.</li><li>• Lacked clarity in relation to the deafblind population concerned.</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>

Table 5: References included in the review

Author(s) & Title	Type of Knowledge	Description	Deafblind Population	Limitations
<p>Yoken (1979) <i>Living with Deafblindness: Nine Profiles</i></p>	<p>Research Knowledge</p>	<p>Nine deafblind individuals (and their families and acquaintances) were interviewed by a Technical Service Specialist at Gallaudet College, Washington DC, United States of America (USA). The interview data and data from records are presented as nine profiles, with the aim that the deafblind individuals tell their own stories from which readers can draw meaningful conclusions.</p> <p>The profiles are presented in a book, published in the USA by The National Academy of Gallaudet College.</p>	<p>Nine deafblind adults, age range 23 to 71. Four of these are older adults who have been deafblind for the majority of their lives. Their ages are: 55, 64, 64 and 72.</p> <p>Some experiences of the husband of one of the nine individuals are also described. He is aged 77 and has also been deafblind for most of his life.</p> <p>The nine individuals have different family backgrounds and live in various regions of the US and in communities of various sizes.</p>	<p>The nine profiles draw on data from the deafblind participants, their families, records and 'the impressions of the interviewer / writer' (Yoken 1979: 6). It is not always clear in the profiles which data source is being used, and the text offers limited indication of how the 'impressions of the interviewer / writer' were formed.</p> <p>Deafblind people with recordable speech were recorded directly. Otherwise, the author (or the interpreter) spoke into the machine. Potentially, transcripts reflect only the interpreters'</p>

				<p>meaning and visual features of signed language are not recorded.</p> <p>There is limited ethnic and racial diversity – acknowledged by the author.</p>
<p>Lastrup (2004) <i>The ageing process and the late manifestation of conditions related to the cause of congenitally deafblind adults in Denmark</i></p>	<p>Research Knowledge</p>	<p>Summary of research survey in Denmark, which collected information from 58 deafblind adults about the ageing process and late manifestations of congenital conditions.</p> <p>The complete report of the study is only available in Danish. This summary is published in the biannual Deafblind International Magazine.</p>	<p>58 congenitally deafblind adults. 26 with Congenital Rubella Syndrome (CRS) and 32 with other aetiologies (not recorded); 5 of the 32 non-CRS participants stated an unknown aetiology.</p>	<p>The complete report of the study is only available in Danish. This summary is published in the biannual Deafblind International Magazine.</p> <p>It is evident that the deafblindness of the participants is congenital; however, no current age of participants is given, just that they are aged '18 and over'.</p>
<p>Damen et al (2005) <i>The Usher lifestyle survey: maintaining independence: a multi-</i></p>	<p>Research Knowledge</p>	<p>European research study using a cross-sectional survey; data analysed using SPSS version 12.0. This survey was part of the CAUSE Project (an 18 month European Union project aimed at raising awareness of Usher Syndrome) and had a specific research</p>	<p>93 adults with Usher Syndrome (Usher Type I n=60; Usher Type II n=25; Usher</p>	<p>No exact current age of participants is given: the very non-</p>

<p><i>centre study</i></p>		<p>question: Is it more difficult to remain independent while getting older, with regard to the type of Usher?</p> <p>Results and analysis are published in the international peer reviewed journal <i>International Journal of Rehabilitation Research</i>.</p>	<p>Type III n=4; unknown Type n=4) from seven European Countries: France, Germany, Ireland, Italy, Spain, UK, and The Netherlands.</p> <p>36.6per cent (n=34) of the participants were 'aged over 46'.</p> <p>In this paper, results of Usher Type I and II are presented.</p>	<p>specific term 'older than 46' is used. The age categories of participants are described by the authors as arbitrary.</p> <p>It is not possible to determine from the paper the Type of Usher for those over 46.</p> <p>All participants members of organisations of and for deafblind people</p> <p>Data from Usher Type III not presented.</p>
<p>Oleson &amp; Jansbøl (2005) <i>Experiences from people with deafblindness – a Nordic Project</i></p>	<p>Research Knowledge</p>	<p>A five-year Nordic research project aimed at the systematic collection of deafblind people's experiences. In-depth phenomenological interviews took place over a five-year period. Participants were interviewed six times.</p> <p>Analysis of the interview data is presented in six booklets, each with a different theme: theory and methods; receiving a diagnosis; getting support; being active; getting an education and work; narratives of everyday life.</p>	<p>20 adults with Usher Syndrome from across the Nordic Countries (Norway-7; Sweden-6; Iceland-1; and Denmark-6).</p> <p>Age range of Participants: 17-63</p>	<p>The authors explicitly acknowledge the impact of the researcher and research itself on the phenomenon being studied. In particular they note the potential implications</p>

			years old.	<p>of the pre-existing relationships between some of the deafblind participants and their interviewers; this includes the possibility that participants may have been reluctant to discuss certain topics with someone known to them in a professional capacity.</p> <p>Study involves multiple translation and interpretation; the authors do recognise the role of the interpreters as constructors of knowledge, and note that their presence in qualitative interviews may have affected the participants' responses.</p>
Göransson (2008) <i>Deafblindness in a Life Perspective</i>	Research Knowledge	<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</p>	Deafblind people of all age groups and different types of deafblindness.	Participants recruited via specialist organisations of and for deafblind people: potential for bias.

		<p>Organisation's International Classification of Functioning, Disability and Health, and two focus groups.</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>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>Focus groups not organized for older people reducing data available for this group.</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>Dammeyer (2010) <i>Interaction of Dual Sensory Loss, Cognitive Function, and Communication in People Who Are</i></p>	<p>Research Knowledge</p>	<p>A Danish study using a survey /questionnaire, building on the survey summarised by Lastrup (2004). The aim of the study was to investigate the relationship, if any, between communication abilities and cognitive function in congenitally deafblind adults. Data were analysed with SPSS Version 17.0</p>	<p>Data from 117 congenitally deafblind adults in Denmark. 22per cent of the participants were aged 50-59 years old; 7per</p>	<p>Questionnaires were completed by 'deafblind consultants' or care staff rather than deafblind people</p>

<p><i>Congenitally Deaf-Blind</i></p>		<p>The research is presented in the international peer-reviewed journal entitled <i>Journal of Visual Impairment &amp; Blindness</i>.</p>	<p>cent were aged between 60-80 years old.</p>	<p>themselves.  The title of the paper suggests a focus on congenital deafblind people, yet 3per cent of the participants have Usher Syndrome (whilst this is a congenital syndrome, the impairment of deafblindness is acquired).</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).</p> <p>Data were gathered from focus groups, exploring issues related to persons ageing with both hearing and vision impairment.</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. Focus on those with single sensory impairment, acquiring a second sensory impairment in later life.</p> <p>Nine Focus Groups, total of 68 participants. All participants were aged over 55, with the majority being over 62.</p> <p>7 Focus groups concerned those who</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>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>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:  20per cent African American; 80per cent White American  64per cent women;  36per cent men</p>	
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			<p>31per cent blind, 69per cent visually impaired; 26per cent Deaf American Sign Language Users; 74per cent Hearing impaired speech users.</p> <p>3 participants had a cochlear implant.</p> <p>2 participants were in paid employment.</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>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;</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>majority aged between 35-50.</p> <p>11 were congenitally 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</p>	<p>Difficult to cross-reference data on age, age of onset and communication preferences.</p>
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			women, 1 man, all communicating via spoken Danish. Norwegian Focus Group: equal number of men and women, using mix of communication methods.	
Kyle & Barnett (2012) <i>Deafblind Worlds</i>	Research Knowledge	<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. Quantitative data were also gathered on the characteristics of the participants.</p> <p>The research had not been formally published at the time of this review, but the full report was kindly 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>85per cent of participants had hearing loss before the age of 5 years old.</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>41per cent 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. 41per cent aged 21-35 years old. Six of the participants were aged between 51-65 years old.</p> <p>77per cent used visual BSL by preference.</p>	
<p>Spring et al (2012) <i>Deafblindness in Switzerland: Facing up to the facts. A Publication on the study "The living circumstances of deafblind people at different stages of their lives in Switzerland</i></p>	<p>Research Knowledge</p>	<p>Empirical research study in Switzerland, using qualitative and quantitative methods, exploring the living circumstances of deafblind people registered with Swiss National Association of and for the Blind (SNAB) Centres.</p> <p>The study included semi-structured interviews with deafblind people.</p> <p>The research is published in Zurich by the Swiss National Association of and for the Blind.</p>	<p>35 deafblind people, 20 of whom were aged between 75 and 90.</p>	<p>The age of the participants is given, but not always the age of onset of deafblindness.</p> <p>When using direct quotations from participants or commenting on participants' views the authors do not always make clear the relevant age/age of onset details of the</p>

				particular participant, albeit that such details of participants are detailed in the methods sections.
Ellis & Hodges (2013) <i>Usher Project Update – Interim Report.</i>	Research Knowledge	<p>An interim report from an ongoing University of Birmingham, UK based study. At the time of the review, the study was yet to be completed. The aim of the research was to provide an insight into the lives of people with Usher Syndrome.</p> <p>This interim report was published online by the University of Birmingham, UK.</p> <p>N.B. Since completing this literature review, the final report has subsequently been published.</p>	30 people with Usher syndrome from throughout the UK were interviewed. 12 participants were aged between 36-56.	<p>The paper lacks detailed information on data analysis methods and interview protocols, and demographic information on participants is absent; however, this is an interim report on a research project that is ongoing at the time of writing.</p> <p>The oldest participant in the study is 56; the majority are younger adults.</p>
Duncan et al (1988) <i>Usher's Syndrome. What is it, How to Cope, and How to Help.</i>	User Testimony	<p>User testimony collated in the initial chapter of a textbook, published in the USA, on Usher Syndrome. The personal accounts are from individuals with Usher Syndrome, who, according to the title of the chapter, were interviewed. Direct quotations from the individuals are presented under the following themed sub-titles:</p> <ul style="list-style-type: none"> <li>• Living well with Usher Syndrome</li> <li>• Feelings of Isolation and Rejection</li> </ul>	Six individuals with Usher syndrome, two of whom are in their mid-forties: a man, aged 44 and a woman aged 46.	<p>No inclusion of those older than 46.</p> <p>There is a clear focus on adolescence to middle age and the issues relevant to</p>

		<ul style="list-style-type: none"> <li>• Naming the Problem</li> <li>• Coping with Usher Syndrome (in school and 'on the job')</li> <li>• Social and Recreational Activities</li> <li>• Satisfaction and Goals</li> </ul>		<p>those at this life stage: diagnosis, education and schooling, work life.</p> <p>There is no clear information on how the six individuals were selected.</p> <p>Accounts based on personal experience. The two individuals in their 40s both work in sensory impairment services, a particular experience not representative of all deafblind people.</p> <p>The first language of the individuals is ASL, but direct quotations are presented in English.</p>
<p>Barr (1990) <i>Visiting the land of green ginger (with a little help from my friends).</i></p>	User Testimony	<p>A personal account of living and ageing with deafblindness published in a UK based professional publication for those working with people with visual impairment entitled <i>New Beacon</i>.</p>	<p>The author was registered as deafblind in 1966 and the account is published in 1990. She is over 70 years of age and</p>	<p>The exact age of the author is not made explicit.</p> <p>The account is based solely on personal</p>

			describes having over 20 years of increasing blindness and 10 years of total deafness.	experience.
Steifel (1991) <i>The Madness of Usher's. Coping with Vision and Hearing Loss (Usher Syndrome Type II).</i>	User Testimony	A personal account of living with Usher Type II written by an American woman, self-defined as ' now in her fifth decade of deafblindness'.  The account is presented in book published by The Business of Living Publications, Texas, USA.	The author is a 60-year old American woman with Usher Type II.	The account is based on personal experience and the author has a particular background, not representative of all deafblind people, including a private education.  The author has contact with organisations of and for deafblind people.
Gribs et al (1995) <i>A brief look at my life as a deaf-blind woman.</i>	User Testimony	A personal account of living with deafblindness, printed in the international peer-reviewed journal, <i>Journal of Visual Impairment &amp; Blindness</i> . The author presents her account by responding to questions posed by the co-authors, one of whom is a rehabilitation worker and one of whom is a personal friend.	The account concerns an 87-year-old American woman who has been deafblind since her late teens.	The account is based solely on personal experience and limited in detail and depth.
Cohn (1998) <i>Problems experienced by hearing and visually impaired people</i>	User Testimony	A personal account of living with hearing and visual impairment published in peer-reviewed journal <i>British Journal of Visual Impairment</i> .	The author's current age not explicitly defined, though it is possible to determine	Exact age of the author not identified.  The account is based

			from content, that he is now in later life. The author has experienced dual sensory impairment since his early teenage years and lives in England.	on personal experience and the author has a particular background not representative of all deafblind people: he is a qualified physiotherapist.
Bejsnap (2004) <i>An account about being deafblind.</i>	User Testimony	A personal account of living with deafblindness published in booklet accompanying a video aimed at promoting awareness of deafblindness in Denmark.	The author is a Danish man who has been deafblind since his teenage years. His current age is not made explicit, but he identifies as post retirement age.	Exact age of the author not identified.  The account is based solely on personal experience; this experience includes having deafblind parents.
Butler (2004) <i>Usher 2: How is it for you?</i>	User Testimony	A collection of personal accounts / user testimony as shared with and recorded by a UK based charitable organisation for deafblind people.  The accounts are published online by the charitable organisation Sense.	Five people with Usher Type II living in the UK. The ages of those sharing their experiences with the author are: 46, 50, 63 and 65. The age of the fifth person is not stated.	No contribution from the 'old old' with Usher Type II.  Whilst the author interviewed the contributors to this piece, there is no information on the interview schedule and the piece presents as journalistic in style



				<p>(reflecting its purpose). Direct quotations are included however.</p> <p>All the contributors are involved with the charitable organisation publishing the piece: one has worked for it in a paid capacity.</p>
<p>Wolf (2006) <i>A challenging time: older people's experiences of deafblindness</i></p>	<p>User Testimony</p>	<p>Personal accounts from five older people with deafblindness living in the UK as reported to and published by a charitable organisation.</p>	<p>Five older deafblind people; two have acquired the impairment in later life (aged 92 and 78), two were born Deaf and have acquired sight loss in later life (described as 'early retirement age') and one has aged with deafblindness (aged 88; born profoundly Deaf and acquired increasing sight loss over a number of years).</p>	<p>Personal accounts with limited detail.</p> <p>All the contributors are involved with the charitable organisation publishing the piece. There is a clear focus in the publication on the importance and positive outcomes that can be achieved through support, much of which is provided by the charitable organisation publishing the work.</p> <p>Direct quotations are</p>

				<p>included, but for BSL users these are produced in English.</p> <p>Only one of the contributors has aged with deafblindness.</p>
<p>Pollington (2008) <i>Always change – the transitions experience by an older woman with declining sight and hearing.</i></p>	User Testimony	<p>A personal account of living and ageing with deafblindness, published in charitable organisation’s periodical. The author of this publication also contributed to the piece by Butler (2004).</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>Based solely on personal experience.</p>
<p>Stoffel (Ed) (2012) <i>Deafblind Reality. Living the Life.</i></p>	User Testimony	<p>An edited text containing personal contributions from deafblind adults from various countries. The stated aim of the collection is to provide a ‘genuine’ understanding of the unspectacular but ongoing challenges of daily life for deafblind people. The editor himself is deafblind.</p> <p>The editor divides the text into separate topics:</p> <ul style="list-style-type: none"> <li>• Family Reaction and Support</li> <li>• Education (Primary and Secondary School)</li> <li>• Transition to Adulthood</li> <li>• Degeneration</li> <li>• ‘Bad medicine’</li> <li>• Rehabilitation</li> <li>• Adult Education</li> <li>• Careers</li> <li>• Daily Life</li> </ul>	<p>12 deafblind adults from the following countries:</p> <p>USA n=9 England n=1 South Africa n=1 New Zealand n=1</p> <p>Five of the 12 contributors are over 50 years old and have been deafblind for most of their lives:</p> <p>Age 52 (woman, England); Age 54</p>	<p>Vague definition of deafblindness: ‘a significant hearing loss and visual impairment’</p> <p>Greater focus on earlier to mid-life experiences and less attention on old age experiences. Only one contributor over 70.</p> <p>Author notes that some volunteers were recruited from an</p>

		<ul style="list-style-type: none"> <li>• Adult Relationships</li> <li>• Communication</li> <li>• Cochlear Implants</li> <li>• Coping</li> </ul> <p>Contributors answer questions related to each of these topics. They were asked by the editor to share 'real experiences' rather than merely stating opinion.</p>	<p>(man, USA); Age 53 (woman, USA); Age 71 (Woman, New Zealand); Age 57 (Woman, USA).</p>	<p>Internet group of deafblind people. It is indicated that other recruitment methods were used, but these are not made explicit.</p> <p>Some contributors wrote their own 'articles' on the topics, whilst others just answered the questions posed and the editor expanded these into 'articles'. Whilst all material was sent to the contributors for proofreading and checking for accuracy, there is no indication in relation to which contributors wrote their own articles.</p>
<p>Miner (1995) <i>Psychosocial Implications of Usher Syndrome Type 1 throughout the Life Cycle.</i></p>	<p>Practitioner Knowledge</p>	<p>A practitioner report drawing on practice experience, other literature, clinical vignettes and interviews with people with Usher Syndrome, Type 1.</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 report is published in the international peer-reviewed journal, <i>Journal of Visual Impairment &amp; Blindness.</i></p>	<p>39 people with Usher Syndrome Type 1. The age of those interviewed ranged between 16-67 years old.</p>	<p>Two of the 39 participants in 1995 paper were known to the author personally. Such pre-existing relationships, particularly that between social worker and client,</p>

				raises both methodological and ethical issues (Padgett 2008); these are largely unacknowledged and unexplored.
Miner (1997) <i>People with Usher Syndrome Type 2: Issues and Adaptations</i>	Practitioner Knowledge	<p>A practitioner paper drawing on practice experience, other literature and interviews with adults with Usher Syndrome Type II over a four-year period. 32 people were interviewed by the author to illustrate the paper.</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>32 people with Usher Syndrome Type II.</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>The oldest participant was 45.</p>
Wickham (2011) <i>Depression in the Deafblind Community: Working from a Social Work Perspective.</i>	Practitioner Knowledge	<p>A practitioner paper drawing on practice experience and other literature to explore depression in the deafblind community, from a social work perspective.</p> <p>The author is a social worker for the Senses Foundation, Australia.</p>	The author states that the paper is 'mainly related to adults with acquired deafblindness'.	Limited detail on the literature drawn upon. Insufficient information provided in order to locate study referred to

		<p>The paper is published in the biannual publication of Deafblind International.</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>within the paper.</p> <p>Refers to those with 'acquired deafblindness' but offers little further information in relation to age, age of onset and other characteristics.</p>
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