**Are older deafblind people being left behind? A narrative review of literature on deafblindness through the lens of the *United Nations Principles for Older People*.**

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**Abstract**

Underpinned by the United Nations Convention on the Rights of Persons with Disabilities (CRDP), Agenda 2030 and the Sustainable Development Goals (SDGs) is the international goal to ‘leave no one behind’. However, the World Federation of the Deafblind have argued that deafblind people have been excluded from international welfare and disability development programmes. Despite making up the majority of the deafblind population, it appears that older deafblind people are particularly invisible. This paper builds on the work of [Overbury *et al.* (2005](#_ENREF_85)), who translated the *UN Principles for Older Persons* into the language of older visually impaired adults, by using them here as the lens for a narrative review of the literature on older deafblind people. It argues that existing research demonstrates that older deafblind people are not only being ‘left behind’ in benefiting from implementation of the UN Principles, but also that the focus of the UN Principles themselves risks maintaining or enhancing their exclusion. Further research and policy development with older deafblind people is required to ensure that international and national social welfare policies and provision are not nugatory to the older deafblind population.

**Keywords**

deafblind; dual sensory loss; older people; UN Principles for Older Persons; exclusion

**Introduction**

Deafblindness is a particularly complex condition ([Bodsworth *et al.* 2011](#_ENREF_10)). It is considered a minority impairment, although attempts to determine its prevalence accurately are problematised by, *inter alia*, inconsistent definitions, contrasting approaches to measurement, and limitations in self-reporting assessments ([World Federation of the Deafblind 2018](#_ENREF_138), [Wittich and Simcock *forthcoming*](#_ENREF_132)). According to the [World Federation of the Deafblind (2018](#_ENREF_138)), an analysis of census data, including more than 97.6 million people across 22 countries, suggests that 0.2% of the global population have ‘severe’ deafblindness, while 2% experience a ‘milder’ dual sensory loss. There is a dearth of literature on the impairment and its consequences ([Rönnberg and Borg 2001](#_ENREF_96), [Brennan and Bally 2007](#_ENREF_11), [Roy *et al.* 2018](#_ENREF_98)), and the field is still considered to be in its infancy ([Dammeyer 2015](#_ENREF_23)). Existing research is of mixed quality ([Saunders and Echt 2007](#_ENREF_99), [Heine and Browning 2015](#_ENREF_50), [Tiwana *et al.* 2016](#_ENREF_124)) and tends to focus on deafblind people in particular circumstances ([World Federation of the Deafblind 2018](#_ENREF_138)). In their scoping review of global deafblind literature, [Jaiswal *et al.* (2018](#_ENREF_53)) note the lack of qualitative inquiry into deafblind people’s experiences and the particular paucity of literature about deafblind people in low and middle-income countries. This latter knowledge gap was also noted by the World Federation of the Deafblind in their 2018 global report, which drew on data from the largest ever population-based study of deafblind people, a review of current literature, case studies, and Sense International surveys ([World Federation of the Deafblind 2018](#_ENREF_138)).

Noting that disabled people are not a homogeneous group, the World Federation of the Deafblind (2018) maintain that certain people remain marginalised and therefore ‘invisible’. Lack of research knowledge is a consequence and possible contributing factor to deafblind people’s exclusion from decision-making processes, development programmes, and participation in political and public life ([Jaiswal *et al.* 2018](#_ENREF_53), [World Federation of the Deafblind 2018](#_ENREF_138)). [Roy *et al.* (2018: 72](#_ENREF_98)) note the absence of good practice guidance for engaging deafblind people in policy development and argue that ‘consultation processes rely on methodologies that assume participants have full use of all their senses and that they are part of a hearing and sighted world’. Despite an international principle ‘to leave no one behind’, underpinned by the United Nations Convention on the Rights of Persons with Disabilities (CRDP), Agenda 2030 and the Sustainable Development Goals (SDGS), it is perhaps unsurprising, therefore, that the World Federation of the Deafblind argue that deafblind people have been excluded from international development programmes. Although the CRDP acknowledges deafblind people’s unique needs ([Jaiswal *et al.* 2018](#_ENREF_53)), having monitored implementation of the CRDP for a decade, the World Federation of the Deafblind observe that, from the data available, only 37% of countries (n=50) officially recognise deafblindness as a distinct disability. They suggest that such lack of recognition ‘leads to invisibility in statistics, policies, programmes and services… perpetuating [deafblind people’s] exclusion’ ([World Federation of the Deafblind 2018: 8](#_ENREF_138)). Furthermore, they note only six specific references to deafblind people in the CRDP concluding observation review up to December 2016, 20 times less than for single sensory impairment. The earlier World Report on Disability ([World Health Organization 2011](#_ENREF_139)) makes only seven references to deafblind people, ten times less than references to those with single sensory loss.

A particular group that appears to be ‘invisible’ is older deafblind people, despite overall consensus amongst the studies that have considered differing sub-groups of the deafblind population (see, for example, [Evenhuis *et al.* 2001](#_ENREF_35), [Chia *et al.* 2006](#_ENREF_19), [Guthrie *et al.* 2018](#_ENREF_45)) that prevalence of the impairment increases with age ([World Federation of the Deafblind 2018](#_ENREF_138), [Wittich and Simcock *forthcoming*](#_ENREF_132)). Research concerning the older deafblind population did not particularly emerge until the 1980s, with earlier studies focusing on deafblind children and their educational and rehabilitation needs ([Wittich *et al.* 2016](#_ENREF_131)). This focus is also evident in the CRDP: the specific mention of deafblindness in Article 24 relates only to deafblind children; General Comment Number 2 on Article 9: Accessibility of the Committee on Rights of Persons with Disabilities (CRPD/C/GC/2) makes two references to deafblind people, but the second specifically concerns deafblind students, in the context of the school curriculum.

More generally, the omission of age in the 1948 *UN Universal Declaration on Human Rights* as a grounds upon which discrimination is prohibited, and the lack of a specific international convention to protect older people’s human rights, led [Hill (2015](#_ENREF_52)) to argue that there has been ‘very little attention given to the human rights of older people by human rights mechanisms’. However, older people’s rights have not been completely disregarded at an international level; as a result of demographic change, most notably population ageing ([Lloyd-Sherlock 2002](#_ENREF_67)), and debates about the inter-generational distribution of resources ([Walker 2017](#_ENREF_127)), Walker (2017:1) observes that ‘[a]geing is frequently… at the top of the policy agenda, locally, nationally and internationally’. In December 1991, the UN General Assembly adopted *The United Nations’ Principles for Older Persons* ([United Nations 1991](#_ENREF_125)), which were proclaimed again during the International Year of Older Persons in 1999. Given their structure and accessible format, the *Principles* were designed to be more readily implemented and incorporated into the development of national policies, as was the recommendation and intent by the UN ([United Nations 1991](#_ENREF_125)). As a result, even stakeholders outside the structure of policy and government have shown interest in this document, such as [Overbury *et al.* (2005](#_ENREF_85)), who translated the UN Principles into the language of older visually impaired adults in order to inspire vision rehabilitation service development priorities, that were presented at the International Society for Low Vision Research and Rehabilitation (https://www.islrr.org/home). Inspired by this work, the present paper uses a similar approach to [Overbury *et al.* (2005](#_ENREF_85)) and extends this perspective to include older adults with combined vision and hearing loss, by using them here as the lens for a narrative review of the literature on older deafblind people. It argues that existing research demonstrates that older deafblind people are not only being ‘left behind’ in benefiting from implementation of the UN Principles, but also that the focus of the UN Principles themselves risks maintaining or enhancing their exclusion. Before considering each ‘principle’ in turn, the paper outlines a definition of deafblindness.

**Defining deafblindness**

Deafblindness is generally used as a term to describe the continuum of combined vision and hearing loss, independent of severity, as well as age or order of onset ([Wittich *et al.* 2013](#_ENREF_133), [Ask Larsen and Damen 2014](#_ENREF_8)). What deafblind people have in common is impairment in the distance senses (sight and sound) ([McInnes 1999](#_ENREF_74)) and the consequent experience of difficulties with communication, access to information, mobility and social interaction ([Department of Health 1997](#_ENREF_28), [Jaiswal *et al.* 2018](#_ENREF_53)). Although the evidence base relating to the presence of and nature of any additional or multiplicative impact of dual over single sensory loss is inconclusive ([Schneider *et al.* 2011](#_ENREF_101)), a defining feature of deafblindness is considered to be the notion of synergy: the sum (deafblindness) is greater than the parts (hearing and vision impairment) ([Saunders and Echt 2007](#_ENREF_99)). Therefore, deafblindness is considered a *unique* impairment, as recognised in 2004 by the EU Parliament ([European Parliament 2004](#_ENREF_34)). Furthermore, [Lagati (1995](#_ENREF_61)) demonstrates international consensus over the use of the unhyphenated term ‘deafblind’, rather than ‘deaf-blind’, in recognition of this status. Notwithstanding the unique nature of the impairment, deafblind people form a heterogeneous population ([Simcock 2017a](#_ENREF_110), [Roy *et al.* 2018](#_ENREF_98)) and, like other disabled people ([Peters 2000](#_ENREF_87), [Purdam *et al.* 2008](#_ENREF_91)), may have a sense of multiple identity, which, along with environmental factors ([Jaiswal *et al.* 2018](#_ENREF_53)) impacts on life experiences.

The majority of *older* deafblind people are those who have acquired dual sensory loss in later life ([Munroe 2001](#_ENREF_80), [Robertson and Emerson 2010](#_ENREF_94), [Wittich *et al.* 2012](#_ENREF_134)). Nevertheless, not all older deafblind people have acquired the impairment in their old age ([Simcock 2017a](#_ENREF_110)). The United Kingdom (UK) Department of Health (1997) identified four further groups of older deafblind people: 1) Those living with sight impairment who subsequently acquire hearing loss; 2) deafened or hearing impaired older adults using speech to communicate, who subsequently acquire visual impairment; 3) Older culturally Deaf people using Sign Language who subsequently acquire visual impairment; and 4) those who have been deafblind for all or the majority of their life. The present paper considers research across all these groups; however, it is evident that most research literature focuses on the experiences of those with late-life acquired deafblindness, and, like the experiences of those ageing with a range of impairments ([Newell 2008](#_ENREF_82), [Jeppsson Grassman *et al.* 2012](#_ENREF_54)), little is known about those ageing with the condition ([Simcock 2017a](#_ENREF_110)).

**The UN Principles**

The *UN Principles for Older Persons* are divided into five major groupings: independence, participation, care, self-fulfilment and dignity.

***Independence***

In outlining how the principle of independence should be realised, the UN adopt a wide perspective: older people should have access to adequate food, water, shelter, clothes, health care and community support (§1); opportunities to work and participate in decisions regarding withdrawal from the labour force (§2 and §3); and access to educational and training programs (§4). Many deafblind people achieve a significant level of independence ([Alley and Keeler 2009](#_ENREF_5)); nonetheless, deafblindness can challenge a person’s independence, particularly as they get older, or if the impairment is acquired in later life ([Brennan *et al.* 2005](#_ENREF_12), [Oleson and Jansbøl 2005](#_ENREF_84), [Pavey *et al.* 2009](#_ENREF_86)). Research findings suggest that deafblindness adversely impacts upon older people’s ability to maintain independence in relation to both activities of daily living (ADL) and instrumental activities of daily living (IADL) ([Lupsakko *et al.* 2002](#_ENREF_69), [Brennan *et al.* 2005](#_ENREF_12), [Tiwana *et al.* 2016](#_ENREF_124), [Roets-Merken *et al.* 2018](#_ENREF_95)); this impact can be exacerbated by the presence of additional age-related impairments and health problems (Pavey et al. 2009). For some older adults ageing with deafblindness, living with the condition over time facilitates easier adjustments, enabling them to maintain independence (LeJeune 2010, Stoffel 2012). However, this is not a universal experience: [Damen *et al.* (2005](#_ENREF_22)) observe that people with Usher syndrome, a genetic condition causing hearing impairment and progressive sight loss, had increased difficulties maintaining their independence as they aged.

Arguably, all services for older deafblind people are intended to facilitate independence, and there is evidence to suggest that deafblind people value such support ([LeJeune 2010](#_ENREF_64), [Bodsworth *et al.* 2011](#_ENREF_10)). Older deafblind adults’ ability to complete IADL is supported by ‘intervenors’ ([McInnes 1999](#_ENREF_74)), who exist globally under different names (for example, guide-communicators, guide-helps, interpreter-guides, communicator-guides, and partners) ([Hersh 2013](#_ENREF_51)); such support has been described as ‘truly responsive to the compounded support requirements of persons with deafblindness’ ([World Federation of the Deafblind 2018: 5](#_ENREF_138)). According to McInnes (1999), an intervenor can be anyone who assists deafblind individuals with any functional activity. Nevertheless, there are specifically trained and designated individuals that carry the job title *intervenor*, for example, in the healthcare system of Ontario, Canada. In the UK, adults with acquired deafblindness are supported by communicator-guides who act as their ‘eyes and ears’ enabling them to undertake IADL ([Sense 2015](#_ENREF_106)). Since 2001, statutory guidance has required local authorities in England to make such one-to-one support available to those with an assessed eligible need ([Department of Health 2001](#_ENREF_29), [Department of Health 2016](#_ENREF_30)). However, data from surveys undertaken by the charitable organization *Sense* highlight inconsistent provision ([Sense 2010](#_ENREF_104), [Sense 2012](#_ENREF_105)); some survey participants report receiving insufficient hours of support or receiving no support at all. Similarly, [Hersh (2013](#_ENREF_51)) observes that there are insufficient communicator-guides throughout the UK and the Czech Republic. More recently, the [World Federation of the Deafblind (2018](#_ENREF_138)) identified, from the data available, that such support is only available in 58% of high-income countries; this reduces to just 10% in low and middle-income countries.

It is well documented that engagement in work provides multiple benefits ([McDonnall 2011](#_ENREF_72)), and having the opportunity to work is explicitly listed as an element of the independence principle. While for increasing numbers of older people the primary reason to continue working is financial need, [McDonnall and LeJeune (2008](#_ENREF_73)) observe that for many, work provides enjoyment and job satisfaction. A 2017 UK based study identified that within five years of retiring, up to one in four older people return to paid employment, a process termed ‘unretiring’ ([Platts *et al.* 2017](#_ENREF_89)). The study authors argue that recently retired people should not therefore be overlooked in policies aimed at maintaining people in work. Reference to employment in the UN Principles is therefore welcome, especially as older people can experience discrimination in the workplace and multiple barriers to engaging in paid employment ([Dordoni and Argentero 2015](#_ENREF_32)). Nevertheless, there is a paucity of research on the employment of older people with sensory impairments, including deafblindness ([McDonnall and LeJeune 2008](#_ENREF_73)). Whilst some studies have been conducted on the employment and employability of deafblind people ([Scheffelin 1981](#_ENREF_100), [Goetz *et al.* 1991](#_ENREF_41)), these reports do not extend beyond the age of 65, but rather focus on students ([Busse 1985](#_ENREF_16), [Everson and Goodall 1991](#_ENREF_36)) or young adults ([Gaylord-Ross *et al.* 1995](#_ENREF_39)). Compounding the lack of knowledge about the employment experiences of older deafblind people is the exclusion of those aged 65 and over in the employment section of the WFDB Global report ([World Federation of the Deafblind 2018](#_ENREF_138)). Nonetheless, as part of the United States of America (USA) based ‘Persons Ageing with Vision and Hearing Loss (PAVHL)’ study, [McDonnall and LeJeune (2008](#_ENREF_73)) did explore employment amongst older deafblind people (those aged between 55 and 70 years old with existing single sensory impairment and subsequently acquiring a second sensory impairment), by drawing on primary survey data and national secondary data. The authors found that many older deafblind people either work or have a desire to work.

Such findings directly challenge the negative paradigm of ageing often espoused in social policies ([Lloyd-Sherlock 2002](#_ENREF_67), [Walker 2017](#_ENREF_127)). However, deafblind people are more likely to be unemployed than those with other impairments ([World Federation of the Deafblind 2018](#_ENREF_138)) and as members of two stigmatised and marginalised groups ([Phillips *et al.* 2010](#_ENREF_88)), older deafblind people may experience high levels of exclusion from the labour market. Analysis of the secondary data in McDonnall and LeJeune’s 2008 study revealed that of those older people not in employment, hearing-sighted people had chosen this status, whilst deafblind older people had not. Furthermore, despite a number of countries raising their retirement age ([Dordoni and Argentero 2015](#_ENREF_32)) and many older non-sensory impaired employees reporting that they envisage a continued life beyond this age ([Brown 2003](#_ENREF_14)), early retirement following the onset of deafblindness is common ([World Federation of the Deafblind 2018](#_ENREF_138)). Some focus group participants in the PAVHL study felt that acquiring a second sensory impairment had resulted in the termination of their employment, and those acquiring a second sensory impairment once aged over 55 describe feeling that their employer expected them to retire early ([LeJeune 2010](#_ENREF_64)).

***Participation***

Defined as ‘the practice of consulting and involving members of the public in the agenda-setting, decision making, and policy-forming activities of organizations or institutions responsible for policy development’ ([Rowe and Frewer 2004 512](#_ENREF_97)), public participation is an important goal for national and local government ([Morrow-Howell 2010](#_ENREF_79)); it is also of increasing interest to practitioners, policy-makers and academics ([Rowe and Frewer 2004](#_ENREF_97)). More broadly, [Hammel *et al.* (2008](#_ENREF_47)) observe that the World Health Organization’s 2001 replacement of ‘absence of handicap’ with ‘participation’ in the *International Classification of Functioning, Disability and Health,* led to an interest in the concept in the areas of medicine and rehabilitation. It is therefore unsurprising that increased participation was identified as a common research and rehabilitation priority by practitioners working in the deafblind field ([Wittich *et al.* 2016](#_ENREF_131)).The *UN Principles for Older Persons* cover both political and social participation, and describe participation as: integration in society, via active involvement in the formulation and implementation of policies that affect well-being (§7); having opportunities to serve the community and volunteer (§8); and being able to form movements or associations (§9). Although [Hersh (2013](#_ENREF_51)) maintains that deafblind people can and do become active participants in their communities, [Jaiswal *et al.* (2018](#_ENREF_53)) contend that deafblind people, regardless of age or impairment aetiology, face multiple barriers to social participation.

Over the last decade, the dominant idea across public services in the UK, and a number of European states, has been ‘personalisation’ ([Ferguson 2007](#_ENREF_37)), an agenda focused on increased service-user choice and control. Whilst co-production is seen as an essential contributor to the full realisation of personalisation in health and social care ([Social Care Institute for Excellence 2015](#_ENREF_115)), [Roy *et al.* (2018](#_ENREF_98)) observe a paucity of guidance on good practice for involving deafblind people in such activity, unlike that for older people generally ([see, for example, Sharif *et al.* 2012](#_ENREF_109)). Furthermore, there is little evidence of older deafblind people participating in the co-production of policies and services that promote their well-being. Nevertheless, the involvement of deafblind people in co-production is not completely absent in practice. For example, in Wales, deafblind people were involved in the co-production of a practical guide on new legislation for health and social care professionals ([Sense Cymru 2016](#_ENREF_108)), although how many of those involved were older people is not recorded.

Informed by activity theory ([Havighurst 1961](#_ENREF_49)), volunteering has been viewed as a key way to promote older people’s participation following retirement ([Morrow-Howell 2010](#_ENREF_79)) and there is now an extensive body of research on the volunteer activities of older adults (see, for example, [Kovacs and Black 1999](#_ENREF_59), [Mutchler *et al.* 2003](#_ENREF_81), [Burr *et al.* 2005](#_ENREF_15), [Foster-Bey *et al.* 2007](#_ENREF_38), [Li 2007](#_ENREF_65), [Butrica *et al.* 2009](#_ENREF_17), [Tang *et al.* 2009](#_ENREF_121), [Hank and Erlinghagen 2010](#_ENREF_48), [Morrow-Howell 2010](#_ENREF_79), [Tang *et al.* 2010](#_ENREF_120)). While [McDonnall (2011](#_ENREF_72)) observes that older deafblind adults are less likely to volunteer than their non-sensory impaired peers, both authors of this paper are aware of older deafblind people engaging in voluntary work; in most cases, this is within organizations for deafblind people. However, in contrast to the large body of research on older volunteers, research on older deafblind volunteers is very limited. As part of a larger study, [McDonnall (2011](#_ENREF_72)) does examine the experiences of older deafblind volunteers, specifically testing the hypothesis that voluntary activity will moderate the impact of dual sensory loss on depressive symptoms. Just as [Morrow-Howell (2010](#_ENREF_79)) observed a reduction in depressive symptoms amongst non-sensory impaired older people engaging in volunteering, [McDonnall (2011](#_ENREF_72)) found that older deafblind people who volunteered had lower levels of depression compared to both non-sensory impaired older adults who did volunteer, and older deafblind people not engaged in such activity. She suggests that this may be linked to reduced social isolation and loneliness, increased control over one’s life, and a sense of being needed. McDonnall (2011:244) goes on to argue that ‘an intervention involving volunteering may be a viable option to help address depression’ amongst older deafblind people.

Movements or associations of older people may offer opportunities for social connectedness. As deafblind organisations have become concerned with the needs of older people, a range of such groups have emerged; these include UK based peer support groups supported by the charitable organisation Deafblind UK, groups organised by Habilitation Services in Stockholm, Sweden, and groups supported by the Helen Keller National Center for Deaf-blind Youths and Adults in New York, USA.

***Care***

Care for older people is provided in a range of settings, by various agencies and professionals, and also by family, friends, and communities. Such provision may include assistance withADL, housing, nutritional intake, financial matters, and health concerns. The complexities in providing care for older people are noted by the UK Health Service Ombudsman ([Abraham 2011](#_ENREF_2)), who also highlights the distress caused by poor standards of care. [Dewar and Nolan (2013](#_ENREF_31)) observe that international literature on the topic reveals increased concern about the standards of care of older people, particularly in hospitals. The *UN Principles for Older Persons* adopt a wide view of care: older persons should benefit from and have access to family and community care (§10), physical, mental and emotional health care (§11), legal services (§12), and appropriate institutional care, that respects their dignity, beliefs, needs, fundamental freedoms and human rights (§13 and §14).

[Walker (2017](#_ENREF_127)) observes an overall improvement in the health of the UK older population, but acknowledges variation in health status according to characteristics such as social class, race and gender. The existence of impairment can also impact on health. Sensory impairments are known to be associated with adverse health outcomes for older people ([Crews and Campbell 2004](#_ENREF_21), [Wahlqvist *et al.* 2016](#_ENREF_126)), and deafblindness in particular can affect confidence in the self-management of health conditions ([Davies 2012](#_ENREF_24)). [Lloyd-Sherlock (2002](#_ENREF_67)) argues that in low-income countries, older people’s access to primary healthcare services remains problematic. Although little is known about the health status of older deafblind people living in low and middle-income countries ([World Federation of the Deafblind 2018](#_ENREF_138)), in high-income countries, older deafblind people’s access to healthcare services varies widely. For example, [Bodsworth *et al.* (2011](#_ENREF_10)) and [Sense (2016](#_ENREF_107)) identify factors that have a negative impact on the healthcare experiences of older deafblind people: inaccessible information, lack of deafblind awareness among staff, and limited communication support. In Sweden, [Göransson (2008](#_ENREF_42)) observes that some deafblind people feel anxious when accessing healthcare services, owing to fears that communication difficulties will result in their needs being misunderstood.

[Lehane *et al.* (2016b: 34](#_ENREF_63)) note that one person’s acquired sensory loss ‘can have a significant impact on the well-being of the entire family’. This may be as a result of increased dependency within relationships ([Lehane *et al.* 2016a](#_ENREF_62)). However, while [Wolf (2005](#_ENREF_135)) highlights that providing care for an older deafblind person can be particularly stressful for family, there is a paucity of research examining the impact of acquired dual sensory loss on couples or other family members ([Brennan and Bally 2007](#_ENREF_11), [Lehane *et al.* 2016a](#_ENREF_62)). In their integrative review of research on couples’ psychosocial and marital experiences of acquired sensory impairment, [Lehane *et al.* (2016a](#_ENREF_62)) identified only one study exploring the impact of dual sensory loss in this context ([See Westaway *et al.* 2011](#_ENREF_128)). The *International Study of Support and Sensory Loss* (ISSSP) project, launched in July 2016, seeks to develop an understanding of acquired deafblindness as a shared experience, by identifying the most effective support and coping mechanisms for couples living with the impairment over time ([Lehane *et al.* 2016b](#_ENREF_63)). In the context of care, an enhanced understanding of this shared experience is essential, particularly as older deafblind people are not only recipients of care, but also providers of care for other family members ([Hersh 2013](#_ENREF_51)).

***Self-fulfilment***

According to [Gewirth (2009: 3](#_ENREF_40)), self-fulfilment means ‘carrying to fruition one’s deepest desires or one’s worthiest capacities’, a central concern throughout human history. In his theorising on human motivation, [Maslow (1943: 382](#_ENREF_71)) defines self-actualisation as the need for self-fulfilment, which he defines as ‘the desire to become more and more what one is, to become everything that one is capable of becoming’. Though the terms self-actualisation and self-fulfilment are not synonymous ([Gewirth 2009](#_ENREF_40)), both have been connected with happiness, increased self-esteem and positive self-concept ([Adams 1992](#_ENREF_3), [Tam Sing-Fai 1998](#_ENREF_119)). The *UN Principles for Older Persons* note that older people need opportunities for the full development of their potential (§15) and access to a range of educational, cultural, spiritual and recreational facilities (§16), if their self-fulfilment is to be realised.

Writing almost four decades ago, [Smithdas (1980](#_ENREF_114)), the then Director of Community Education for the Helen Keller National Center of Deafblind Youths and Adults, and himself a deafblind adult, argued for additional statutory services for deafblind people. Smithdas argued that such services were required to enhance independence and self-fulfilment. By the 1990s, [MacDonald (1994: 499](#_ENREF_70)) observed that

a strong movement exists for deaf-blind people… that is leading rapidly to a desire among deaf-blind individuals for self-determination, self-respect, and *self-fulfilment* (emphasis added).

Many organizations of and for deafblind people throughout the world now state the achievement of deafblind people’s self-fulfilment as a central element of their overall mission ([see, for example, Able Australia 2015](#_ENREF_1)), as a desired outcome of their activities ([Tal 2012](#_ENREF_118)) or an indicator of the success of their programs ([Tennessee Organization of the Deaf-Blind 2016](#_ENREF_122)). [Adams (1992](#_ENREF_3)) notes a ‘clear connection’ between self-determination and self-fulfilment, and observes that deafblind people face multiple barriers to the development of the former. She conceptualises these barriers as threefold: attitudinal, limited choice and lack of experience. However, Adams largely focuses on the experiences of deafblind children and it appears that much less is known about self-fulfilment among older deafblind people. Nonetheless, there is anecdotal evidence of older deafblind people engaging in opportunities for the development of their potential (see, for example, Barr 1990 and Gribs et al. 1995).

In personal accounts of living with deafblindness, older people express a desire and willingness to engage in further training, even in much later life ([Barr 1990](#_ENREF_9), [Pollington 2008](#_ENREF_90), [Stoffel 2012](#_ENREF_117)), directly challenging the negative construction of old age as a period of inevitable decline and withdrawal ([Andrew 2012](#_ENREF_6)). This includes learning how to use new assistive and mainstream technologies (Stoffel 2012), and engaging in rehabilitation services ([Gribs *et al.* 1995](#_ENREF_43), [Pollington 2008](#_ENREF_90), [Stoffel 2012](#_ENREF_117)).

***Dignity***

The UN *Universal Declaration of Human Rights* clearly affirms the inherent dignity of all human beings. [Woolhead *et al.* (2004](#_ENREF_137)) observe an increasing emphasis on dignity in policies concerning the health and social care of older people in the UK and other European nations. Dignity also appears as an essential value in nursing and social work professional codes of practice, perhaps reflecting research findings suggesting that the maintenance of dignity is most at risk in health and social care settings ([Rahemi and Wiliams 2015](#_ENREF_92)). Studies also suggest that upholding dignity in such settings is a particular concern of older people themselves ([Woolhead *et al.* 2004](#_ENREF_137)). In the *UN Principles for Older Persons*, dignity is associated with security and freedom from exploitation and abuse (§17) and fair treatment regardless of age, gender, racial or ethnic background, disability or other status (§18). This reflects the perspectives of professionals and older people, which affirm equal treatment as an element of dignity, and increased vulnerability as indicative of loss of dignity ([Woolhead *et al.* 2004](#_ENREF_137), [Ariño-Blasco *et al.* 2005](#_ENREF_7)).

Deafblind people are considered to be one of the most vulnerable groups in society ([Simcock 2017b](#_ENREF_111)); this includes vulnerability to exploitation, abuse and harm ([Kiekopf 2007](#_ENREF_58), [Simcock 2017b](#_ENREF_111)). Kiekopf (2007:23) suggests that deafblind people are ‘potentially [at] greater risk’ of all forms of abuse. He argues that this vulnerability is heightened by the main difficulties associated with the impairment: communication, mobility and access to information. However, he notes that deafblind people’s vulnerability to abuse arises from a complex interplay between the impairment, situational and structural factors. Studies with older deafblind people have highlighted their experiences of feeling vulnerable. [Roberts *et al.* (2007](#_ENREF_93)) refer to this vulnerability in their briefing for health and social care practitioners. Older deafblind people describe feeling vulnerable to specific physical harms or dangers, including fear of being a victim of crime ([Pavey *et al.* 2009](#_ENREF_86), [Kyle and Barnett 2012](#_ENREF_60)) and of accidents in the home (Sense 2012). Pavey et al. (2009) also argue that older deafblind people are at greater risk of financial abuse, owing to passivity and lack of accessible information in relation to decision-making. Notwithstanding increased policy attention on vulnerability among older people generally ([Brocklehurst and Laurenson 2008](#_ENREF_13)), Simcock’s (2016b) systematic review on deafblindness and vulnerability identified few studies exploring the experience of vulnerability among *older* deafblind people in any detail. Literature tends to focus on the vulnerability of deafblind children, those with additional developmental delay, or congenitally deafblind young adults (Simcock 2016b). A need for further research examining vulnerability among older deafblind people therefore appears evident.

There is also a paucity of literature on the experiences of diverse groups of older deafblind people, albeit that research highlighting that dual sensory impairment affects diverse populations in different ways does exist. Some of this work has focused on risk and prevalence rates. For example, in the USA, [Davila *et al.* (2009](#_ENREF_25)) identify higher prevalence rates amongst older people employed in the agriculture, forestry-fishing, and construction sectors. In the UK, [Dawes *et al.* (2014](#_ENREF_26)) observe that low socioeconomic status is associated with increased risk of dual sensory impairment. Drawing on a very large dataset (the UK Biobank Resource), they also report that adults from particular ethnic minorities (Black Other, Bangladeshi, Black African, and Pakistani) are at increased risk of dual sensory loss. Similarly, in the USA, [Ng *et al.* (2014](#_ENREF_83)) identify that those from ethnic minority groups often have higher prevalence rates of vision and hearing loss than the majority white population. Such findings are of concern, as there is some evidence to suggest that deafblind people from minority ethnic communities face particular disadvantage ([Deafblind UK 2006](#_ENREF_27), [Joule and Levenson 2008](#_ENREF_56)). Gender also appears to be associated with diverse experiences. As highlighted earlier, sensory impairments are known to be associated with adverse health outcomes for older people. However, in their population cohort study of Japanese adults aged 65 and over, [Michikawa *et al.* (2009](#_ENREF_75)) found that this association varied by gender; the study authors call for further research to explore this variation.

**Discussion**

Reviewing literature about the older deafblind population through the lens of the *UN Principles for Older People* highlights a range of knowledge gaps. There is a paucity of research on older deafblind people’s experiences of paid employment and volunteering, self-fulfilment and vulnerability, and engagement in co-production. There is also very limited literature on the impact of the impairment on family members, and an overall dearth of material from low and middle-income countries. Such a lack of knowledge contributes to the invisibility of older deafblind people in social welfare policy and disability development programmes ([Jaiswal *et al.* 2018](#_ENREF_53), [Roy *et al.* 2018](#_ENREF_98), [World Federation of the Deafblind 2018](#_ENREF_138)). It is therefore unsurprising that there have been calls for better data and further research ([Roy *et al.* 2018](#_ENREF_98), [World Federation of the Deafblind 2018](#_ENREF_138)), particularly in the context of an ageing population and consequent increase in the prevalence of the impairment ([Wittich *et al.* 2016](#_ENREF_131)). Where literature does exist, this review highlights that it suggests that the *UN Principles for Older People* are not being fully realised for the older deafblind population. For example, there is evidence of, *inter alia,* the non-availability or inconsistent provision of interpreter-guide support, multiple barriers to paid employment and political and social participation, and poor access to health care.

Nevertheless, it appears that the approach of the *UN Principles* themselves homogenises the ageing experience, contrary to the findings of gerontological research, a criticism of much national and international policy on ageing ([Lloyd-Sherlock 2002](#_ENREF_67), [Walker 2017](#_ENREF_127)). As such, their generality renders implementation problematic and risks excluding the older deafblind population. The *UN Principles* place limited emphasis on the concepts of choice and control as central to independence, dignity and participation, despite research suggesting that older disabled people perceive autonomy and control as vital to their realisation ([Secker *et al.* 2003](#_ENREF_102), [Hammel *et al.* 2008](#_ENREF_47), [Lloyd *et al.* 2014](#_ENREF_66)). The concept of ‘care’ has also been subject to critique by the disability movement ([Wood 1991](#_ENREF_136)). [Kelly (2011](#_ENREF_57)) maintains that terms such as ‘care’ and ‘caring for’ have oppressive legacies, which stem from their association with lives that were controlled and institutionalised. Roy et al.’s (2018: 79) study refers to deafblind people’s long-standing experience of ‘control and man handling’; this suggests that any social welfare programme informed by the *UN Principles*, but failing to promote autonomy, choice and control, will not meet older deafblind people’s needs. Furthermore, older deafblind people do not necessarily require assistance with personal care ([Simcock and Manthorpe 2014](#_ENREF_112)), but rather need support to mobilise, to access information, and to communicate, which includes the teaching of a new communication method ([Damen *et al.* 2005](#_ENREF_22), [Kiekopf 2007](#_ENREF_58), [Jaiswal *et al.* 2018](#_ENREF_53)). This requires a broad view of social care and support. However, with reference to general health care, community care and support, and institutional care, the *UN Principles* fail to acknowledge this particular type of support explicitly. There is a risk that publicly funded social welfare support will focus only on the most immediate of personal care needs, particularly at a time of austerity ([Clements 2011](#_ENREF_20)), exacerbating the exclusion of older deafblind people: the limited availability of interpreter-guide support was noted earlier in the paper.

This latter point exposes a further limitation in the *UN Principles* as they apply to the older deafblind population. Whilst access to health care, community and family support, educational and training programmes, recreational activities and volunteering are highlighted, no explicit reference is made to the active and specialist support that may be required by older deafblind people to enable such access, nor to facilitate required opportunities to serve the community and form movements. For example, [Hersh (2013](#_ENREF_51)) observes that many older deafblind people need rehabilitation support to actively participate in society and realise their potential. Nonetheless, in a USA-based exploratory study of the rehabilitation experiences of older deafblind adults, [Luey (1994: 214](#_ENREF_68)) found that ‘very few subjects had received optimal rehabilitation services’, largely as a result of poor coordination between vision and hearing services. Specific support such as transport and accessible training may also be required to enable older deafblind people to engage in volunteering opportunities ([McDonnall 2011](#_ENREF_72)), whilst orientation and mobility training and assistive technology may support older deafblind people to access and maintain paid employment ([McDonnall and LeJeune 2008](#_ENREF_73)). However, the USA based [Thirty-eighth Institute on Rehabilitation Issues (2015: 1](#_ENREF_123)) highlight the ‘persistence of inequitable access to and utilization of [such services] for… people with low-incidence disabilities, such as deaf-blindness (sic)’. This is reflected in PAVHL study findings: more than a third of participants reported not receiving rehabilitative services, whilst over 40% reported having never received such support, despite expressing a desire to work (McDonnall and LeJeune 2008).

Accessible information is also an essential part of this active support. [Miner (1995](#_ENREF_76)) reports that adults ageing with Usher Syndrome in the USA are not always aware of healthcare services for older people, owing to a life of reduced access to information. Similarly, in a Canadian study of the impact of deafblindness on the use of dental care, [Jin and Daly (2010](#_ENREF_55)) observe that few participants had received dental health education and therefore engaged in poor oral hygiene practices. The information and communication barriers associated with deafblindness can also impact on the pharmaceutical care needs of older dual sensory impaired people ([Alhusein *et al.* 2018](#_ENREF_4)).

The specialist nature of the support required to realise the aims of the *UN Principles* is also vital. Older deafblind people have expressed concern about the ability of deafblind services to meet their needs as older people, and for mainstream older people’s services to meet their needs as deafblind people ([Simcock 2017a](#_ENREF_110)). [Whitson and Lin (2014: 1740](#_ENREF_129)) note that sensory impairment has previously been considered an ‘inconvenient but benign consequence of age’ by policy makers. For those acquiring deafblindness in later life, the impairment may be dismissed by non-specialist healthcare professionals as an inevitable part of ageing ([Roberts *et al.* 2007](#_ENREF_93)), resulting in inadequate assessment of need and failure to refer to specialist services ([Sense 2009](#_ENREF_103)). [Bodsworth *et al.* (2011](#_ENREF_10)) and [Wickham (2011](#_ENREF_130)) highlight the lack of specialist mental health care services for deafblind people. This is particularly concerning considering research findings suggesting that older deafblind people are at particular risk of mental health difficulties and psychological distress ([Cacchione *et al.* 2003](#_ENREF_18), [Bodsworth *et al.* 2011](#_ENREF_10), [Schneider *et al.* 2011](#_ENREF_101), [Guthrie *et al.* 2016](#_ENREF_46)). The lack of specialist services also heightens the risk of misdiagnosis, a situation exacerbated by health care professionals’ misinterpretation of the effects of dual sensory loss and their communication difficulties with deafblind patients ([Miner 1997](#_ENREF_77), [Wickham 2011](#_ENREF_130)).

While many deafblind people need such specialist one-to-one support ([Hersh 2013](#_ENREF_51)), the nature of that support can vary, reflecting the significant heterogeneity among the older deafblind population ([Smith 1993](#_ENREF_113)). Those with congenital deafblindness may need ongoing one-to-one educational intervention as they age in order to *develop* their independence, while those acquiring the impairment in later life may need practical help in order to *maintain* their independence. Dual sensory impairment is rarely static ([Göransson 2008](#_ENREF_42)): older deafblind people may experience progressive impairment in vision and hearing, or improvements, as a result of changes in their condition or medical intervention ([Stoffel 2012](#_ENREF_117), [Ellis and Hodges 2013](#_ENREF_33)). Owing to such changes, new skills must be learnt, particularly in relation to communication ([Göransson 2008](#_ENREF_42), [Spring *et al.* 2012](#_ENREF_116)) and ADL ([Oleson and Jansbøl 2005](#_ENREF_84), [Gullacksen *et al.* 2011](#_ENREF_44)). [Hersh (2013](#_ENREF_51)) therefore contends that those acquiring deafblindness in later life ordinarily need specialist support from professionals such as rehabilitation workers, in order to learn these new skills. Those older people who have aged with deafblindness, including those congenitally deafblind, can also benefit from such specialist intervention ([Stoffel 2012](#_ENREF_117)).

**Conclusion**

A paucity of research, failure to acknowledge deafblindness as a distinct impairment, and absence of reference to specific support needs contribute to the exclusion of deafblind people from the CRDP. It appears from this narrative review that older deafblind people are also at further risk of being ‘left behind’ in benefitting from the *UN Principles for Older Persons,* an international provision specifically aimed at older people. This is a result not only of knowledge gaps but also the principles themselves. Reviewing literature through the lens of other international provision would be a positive next step. For example, the Madrid International Plan of Action on Ageing is a more recent agenda aimed at responding to ageing in the 21st century and it does explore disability and ageing (Issue 6: para.87-89). Nevertheless, integral to the Madrid Plan is the concept and policy of ‘active ageing’; central to this policy is the prevention of late-life disability and it is therefore a problematic concept when considering those ageing with impairments ([Minkler and Fadern 2002](#_ENREF_78)). [Walker (2017](#_ENREF_127)) observes that the ‘ageing with impairment’ population have been neglected; therefore, alternative provision needs consideration in order to ensure the inclusion of those older people ageing with deafblindness, in addition to those with late-life acquired dual sensory loss. To remedy such challenges, further research and policy development ‘with’ and not ‘on’ deafblind people, as recommended by the World Federation of the Deafblind appears essential. However, if this does not include the *older* deafblind population, international and national social welfare policy and provision will be nugatory to their situation and inevitably leave them behind.

**References**

Able Australia, 2015. *Vision, mission, values* [online]. Able Australia. Available from: <http://www.ableaustralia.org.au/who-we-are/vision-mission-values> [Accessed 03/09/2016].

Abraham, A., 2011. *Care and compassion? Report of the health service ombusdman on ten investigations into nhs care of older people* London: The Stationery Office.

Adams, J., 1992. Self-determination. *In* Reiman, J.W. & Johnson, P.A. eds. *Proceedings from the national symposium on children and youth who are deaf-blind.* Monmouth, OR: Teaching Research Publications, 223-228.

Alhusein, N.*, et al.*, 2018. ‘Has she seen me?’: A multiple methods study of the pharmaceutical care needs of older people with sensory impairment in scotland. *BMJ Open,* 8 (e023198), 1-8.

Alley, R. & Keeler, G., 2009. *Kent deafblind development project.* Maidstone: Kent Adult Social Services.

Andrew, P., 2012. *The social construction of age* Bristol: Multilingual Matters.

Ariño-Blasco, S., Tadd, W. & Boix-Ferrer, J., 2005. Dignity and older people: The voice of professionals. *Quality in Ageing and Older Adults,* 6 (1), 30-36.

Ask Larsen, F. & Damen, S., 2014. Definitions of deafblindness and congenital deafblindness. *Research in Developmental Disabilities,* 35 (10), 2568-2576.

Barr, D., 1990. Visiting the land of green ginger (with a little help from my friends) *New Beacon,* 74 (880), 336-7.

Bodsworth, S.M.*, et al.*, 2011. Deafblindness and mental health: Psychological distress and unmet need among adults with dual sensory impairment. *British Journal of Visual Impairment,* 29 (1), 6-26.

Brennan, M. & Bally, S., 2007. Psychosocial adaptations to dual sensory loss in middle and late adulthood. *Trends in Amplification,* 11 (4), 281-300.

Brennan, M., Horowitz, A. & Su, Y.-P., 2005. Dual sensory loss and its impact on everyday competence. *The Gerontologist,* 45 (3), 337-346.

Brocklehurst, H. & Laurenson, M., 2008. A concept analysis examining the vulnerability of older people. *British Journal of Nursing,* 17 (21), 1354-1357.

Brown, S.K., 2003. *Staying ahead of the curve 2003: The AARP working in retirement study.* Washington, D.C.: AARP.

Burr, J.A.*, et al.*, 2005. Caregiving and volunteering: Are private and public helping behaviours linked? *Journal of Gerontology: Social Sciences,* 60 (B), S247-S256.

Busse, D.G., 1985. Employment of deaf-blind rubella students in a subsidized work program. *Journal of Visual Impairment and Blindness,* 79 (2), 59-64.

Butrica, B.A., Johnson, R.W. & Zedlewski, S.R., 2009. Volunteer dynamics of older americans. *Journal of Gerontology: Social Sciences,* 64 (B), 644-655.

Cacchione, P.Z.*, et al.*, 2003. Risk for acute confusion in sensory-impaired, rural, long-term-care elders. *Clinical Nursing Research,* 12 (4), 340-355.

Chia, E.M.*, et al.*, 2006. Association between vision and hearing impairments and their combined effects on quality of life. *Archives of ophthalmology,* 124 (10), 1465-70

Clements, L., 2011. Social care law developments: A sideways look at personalization and tightening eligibility criteria’. *Elder Law Journal,* 1, 47-52.

Crews, J.E. & Campbell, V.A., 2004. Vision impairment and hearing loss among community-dwelling older americans: Implications for health and functioning. *American Journal of Public Health,* 94 (5), 823-829.

Damen, G.W.*, et al.*, 2005. The usher lifestyle survey: Maintaining independence: A multi-centre study. *International Journal of Rehabilitation Research,* 28 (4), 309-320.

Dammeyer, J., 2015. Deafblindness and dual sensory loss research: Current status and future directions. *World Journal of Otorhinolaryngology,* 5 (2), 37-40.

Davies, S., 2012. *Annual report of the chief medical officer. Surveillance volume, 2012. On the state of the public's health* London: Department of Health.

Davila, E.P.*, et al.*, 2009. Sensory impairment among older us workers. *American Journal of Public Health,* 99 (8), 1378-1385.

Dawes, P.*, et al.*, 2014. Vision impairment and dual sensory problems in middle age. *Ophthalmic and Physiological Optics,* 34 (4), 479-488.

Deafblind UK, 2006. *Good practice guide. Supporting deafblind people from bme communities.* Peterborough: Deafblind UK.

Department of Health, 1997. Think dual sensory: Good practice guidelines for older people with dual sensory loss. *In* Department of Health ed. London: Department of Health.

Department of Health, 2001. *Social care for deafblind children and adults LAC (2001) 8* London: Department of Health.

Department of Health, 2016. *Care and support statutory guidance. Issued under the Care Act 2014* London: Department of Health.

Dewar, B. & Nolan, M., 2013. Caring about caring: Developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies,* 50 (9), 1247-1258.

Dordoni, P. & Argentero, P., 2015. When age stereotypes are employment barriers: A conceptual analysis and a literature review on older workers stereotypes. *Ageing International*, 40 (4), 393-412.

Ellis, L. & Hodges, L., 2013. *Usher project update - interim report.* Birmingham: University of Birmingham.

European Parliament, 2004. *Declaration of the European Parliament on the rights of deafblind people p5\_ta(2004) 0277* [online]. Available from: <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P5-TA-2004-0277+0+DOC+XML+V0//EN> [Accessed 03/08/2015].

Evenhuis, H.M.*, et al.*, 2001. Prevalence of visual and hearing impairment in a dutch institutionalized population with intellectual disability. *Journal of Intellectual Disability Research,* 45 (part 5), 457-464.

Everson, J. & Goodall, D., 1991. School-to-work transition for youth who are both deaf and blind. *ASHA,* 33 (11), 45-47.

Ferguson, I., 2007. Increasing user choice or privatizing risk? The antinomies of personalization. *British Journal of Social Work,* 37 (3), 387-403.

Foster-Bey, J., Grimm, R.J. & Dietz, N., 2007. *Keeping baby boomers volunteering: A research brief on volunteer retention and turnover* Washington, DC: Corporation for National and Community Service, Office of Research and Policy Development.

Gaylord-Ross, R.*, et al.*, 1995. Individual social skills training and co-worker training for supported employees with dual sensory impairment two case examples. *Behavior modification,* 19 (1), 78-94.

Gewirth, A., 2009. *Self-fulfillment* Princeton, NJ: Princeton University Press.

Goetz, L.*, et al.*, 1991. Employment of persons with dual sensory impairments: Strategies for inclusion. *Research and Practice for Persons with Severe Disabilities,* 16 (3), 131-139.

Göransson, L., 2008. *Dövblindhet i ett livsperspektiv. Strategier och metoder för stöd* Finspång: Mo Gårds Förlag.

Gribs, H., Dougherty, K. & Du Pre, W., 1995. A brief look at my life as a deaf-blind woman. *Journal of Visual Impairment & Blindness,* 89 (3), 197-210.

Gullacksen, A.*, et al.*, 2011. *Life adjustment and combined visual and hearing disability/deafblindness – an internal process over time.* Donningen, Denmark: Nordic Centre for Welfare and Social Issues.

Guthrie, D.M.*, et al.*, 2018. Combined impairments in vision, hearing and cognition are associated with greater levels of functional and communication difficulties than cognitive impairment alone: Analysis of interrai data for home care and long-term care recipients in ontario. *PloS One,* 13 (2), e0192971.

Guthrie, D.M.*, et al.*, 2016. The health and well-being of older adults with dual sensory impairment (dsi) in four countries. *PloS one,* 11 (5), 1-17.

Hammel, J.*, et al.*, 2008. What does participation mean? An insider perspective from people with disabilities. *Disability and rehabilitation,* 30 (19), 1445-1460.

Hank, K. & Erlinghagen, M., 2010. Dynamics of volunteering in older europeans. *The Gerontologist,* 50, 170-178.

Havighurst, R.J., 1961. Successful aging. *The Gerontologist,* 1 (1), 8-13.

Heine, C. & Browning, C.J., 2015. Dual sensory loss in older adults: A systematic review. *The Gerontologist,* 55 (5), 13-28.

Hersh, M., 2013. Deafblind people, communication, independence, and isolation. *Journal of Deaf Studies and Deaf Education,* 18 (4), 446-63.

Hill, K., 2015. *A UN Convention on the rights of older people: From deliberation to action* [online]. Available from: https://ageukblog.org.uk/2015/08/07/a-un-convention-on-the-rights-of-older-people-from-deliberation-to-action/ [Accessed 10/01/2016].

Jaiswal, A.*, et al.*, 2018. Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature. *PloS One,* 13 (9), 1-26.

Jeppsson Grassman, E.*, et al.*, 2012. Long life with a particular signature: Life course and aging for people with disabilities. *Journal of Gerontological Social Work,* 55 (2), 95-111.

Jin, E.Y. & Daly, B., 2010. The self-reported oral health status and behaviours of adults who are deaf and blind. *Special Care in Dentistry,* 30 (1), 8-13.

Joule, N. & Levenson, R., 2008. *People from black and minority ethnic communities and vision services: A good practice guide* London: Thomas Pocklington Trust.

Kelly, C., 2011. Making ‘care’ accessible: Personal assistance for disabled people and the politics of language. *Critical Social Policy,* 31 (4), 562-582.

Kiekopf, S., 2007. Protect and thrive: Some deafblind people can be vulnerable to abuse - how can they be protected? *Talking Sense,* 53 (1), 18-23.

Kovacs, P.J. & Black, B., 1999. Volunteerism and older adults: Implications for social work practice. *Journal of Gerontological Social Work,* 32 (1), 25-40.

Kyle, J. & Barnett, S., 2012. *Deafblind worlds.* Bristol: Deaf Studies Trust and Sense.

Lagati, S., 1995. 'Deaf-blind' or 'deafblind'? International perspectives on terminology. *Journal of Visual Impairment & Blindness,* 89 (3), 306-308.

Lehane, C., Dammeyer, J. & Elsass, P., 2016a. Sensory loss and its consequences for couples’ psychosocial and relational wellbeing: An integrative review. *Aging & Mental Health.* 1-11.

Lehane, C., Wittich, W. & Dammeyer, J., 2016b. Couples' experiences of sensory loss: A research and rehabilitation imperative. *The Hearing Journal,* 69 (8), 34-36.

Lejeune, B.J., 2010. Aging with a dual sensory loss: Thoughts from focus groups. *AER (Association for Education and Rehabilitation of the Blind and Visually Impaired) Journal.* AER (Association for Education and Rehabilitation of the Blind and Visually Impaired).

Li, Y., 2007. Recovering from spousal bereavement in later life: Does volunteer participation play a role? *Journal of Gerontology: Social Sciences,* 62 (B), S257-S266.

Lloyd, L.*, et al.*, 2014. Identity in the fourth age: Perseverance, adaptation and maintaining dignity. *Ageing and Society,* 34 (1), 1-19.

Lloyd-Sherlock, P., 2002. Social policy and population ageing: Challenges for north and south. *International Journal of Epidemiology,* 31, 754-757.

Luey, H.S., 1994. Sensory loss: A neglected issue in social work. *Journal of Gerontological Social Work,* 21 (3/4), 213-224.

Lupsakko, T.*, et al.*, 2002. Combined hearing and visual impairment and depression in a population aged 75 years and older. *International Journal of Geriatric Psychiatry,* 17 (9), 808-813.

Macdonald, R.J., 1994. Deaf-blindness: An emerging culture? *In* Erting, C., Johnson, R.C., Smith, D.L. & Snider, B. eds. *The deaf way. Perspsectives from the international conference on deaf culture.* Washington D.C.: Gallaudet University Press, 496-503.

Maslow, A.H., 1943. A theory of human motivation. *Psychological review,* 50 (4), 370-396.

Mcdonnall, M.C., 2011. The effect of productive activities on depressive symptoms among older adults with dual sensory loss. *Research on aging,* 33 (3), 234-255.

Mcdonnall, M.C. & Lejeune, B.J., 2008. Employment among older adults with combined hearing and vision loss. *Journal of Applied Rehabilitation Counseling,* 39 (3), 3-9.

McInnes, J.M., 1999. *A guide to planning and support for individuals who are deafblind* Toronto: University of Toronto Press.

Michikawa, T.*, et al.*, 2009. Gender-specific associations of vision and hearing impairments with adverse health outcomes in older japanese: A population-based cohort study. *BMC Geriatr,* 9, 50.

Miner, I., 1995. Psychosocial implications of usher syndrome, type 1, throughout the life cycle. *Journal of Vision Impairment and Blindness,* 89 (3), 287-296.

Miner, I., 1997. People with usher syndrome, type 2: Issues and adaptations. *Journal of Visual Impairment and Blindness,* 91 (6), 579-589.

Minkler, M. & Fadern, P., 2002. "Successful aging": A disability perspective. *Journal of Disability Policy Studies,* 12 (4), 229-235.

Morrow-Howell, N., 2010. Volunteering in later life: Research frontiers. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences,* 65 (4), 461-469.

Munroe, S., 2001. *Developing a national volunteer registry of persons with deafblindness in canada: Results from the study 1999-2001.* Fredericton, New Brunswick: Canadian Deafblind and Rubella Association.

Mutchler, J.E., Burr, J.A. & Caro, F.G., 2003. From paid worker to volunteer: Leaving the paid workforce and volunteering in later life. *Social Forces,* 81, 1267-1293.

Newell, C., 2008. Better dead than disabled? When ethics and disability meet: A narrative of ageing, loss and exclusion. *In* Mackinlay, E. ed. *Ageing, disability and spirituality. Addressing the challenge of disability in later life.* London: Jessica Kingsley Publishers, 72-80.

Ng, J.H.*, et al.*, 2014. Beyond black and white: Race/ethnicity and health status among older adults. *American Journal of Managed Care,* 20 (3), 239-248.

Oleson, B.R. & Jansbøl, K., 2005. *Experiences from people with deafblindness - a nordic project.* Herlev, Denmark: Information Center for Acquired Deafblindness.

Overbury, O., Wittich, W. & Spadafora, P., 2005. United nations’ principles for older persons viewed though the eyes of visually impaired seniors. *International Congress Series,* 1282, 428-432.

Pavey, S., Douglas, G. & Hodges, L., 2009. *The needs of older people with acquired hearing and sight loss* London: Thomas Pocklington Trust.

Peters, S., 2000. Is there a disability culture? A syncretisation of three possible world views. *Disability & Society,* 15 (4), 583-601.

Phillips, J., Ajrouch, K. & Hillcoat-Nalletamby, S., 2010. *Key concepts in social gerontology* London: Sage.

Platts, L.G.*, et al.*, 2017. Returns to work after retirement: A prospective study of unretirement in the united kingdom. *Ageing & Society*, 1-26.

Pollington, C., 2008. Always change- the transitions experienced by an older woman with declining sight and hearing. *Talking Sense,* 52 (2), 30-33.

Purdam, K.*, et al.*, 2008. Disability in the uk: Measuring equality. *Disability & Society,* 23 (1), 53-65.

Rahemi, Z. & Wiliams, C.L., 2015. Development of a dignity-enhancing model of caring for older adults. *International Journal for Human Caring,* 19 (3), 36-41.

Roberts, D., Scharf, T. & Bernard, M., 2007. *Identification of deafblind dual sensory impairment in older people* London: Social Care Institute for Excellence.

Robertson, J. & Emerson, E., 2010. *Estimating the number of people with co-occurring vision and hearing impairments in the UK.* Lancaster: Centre for Disability Research.

Roets-Merken, L.M.*, et al.*, 2018. Effectiveness of a nurse-supported self-management programme for dual sensory impaired older adults in long-term care: A cluster randomised controlled trial. *BMJ open,* 8 (1), e016674.

Rönnberg, J. & Borg, E., 2001. A review and evaluation of research on the deaf-blind from perceptual, communicative, social and rehabilitative perspectives. *Scandinavian Audiology,* 30 (2), 67-77.

Rowe, G. & Frewer, L.J., 2004. Evaluating public-participation exercises: A research agenda. *Science, technology & human values,* 29 (4), 512-556.

Roy, A., Mcvilly, K. & Crisp, B., 2018. Preparing for inclusive consultation, research and policy development: Insights from the field of deafblindness. *Journal of Social Inclusion,* 9 (1), 71-88.

Saunders, G.H. & Echt, K.V., 2007. An overview of dual sensory impairment in older adults: Perspectives for rehabilitation. *Trends in amplification,* 11 (4), 243-58.

Scheffelin, M.A., 1981. Employability of persons who are both deaf and blind. *International Journal of Rehabilitation Research,* 4 (1), 92.

Schneider, J.M.*, et al.*, 2011. Dual sensory impairment in older age. *Journal of Aging and Health,* 23 (8), 1309-1324.

Secker, J.*, et al.*, 2003. Promoting independence: But promoting what and how? . *Ageing & Society,* 23, 375-391.

Sense, 2009. *Policy briefing: Older people and dual sensory loss.* London: Sense.

Sense, 2010. *Deafblind guidance: Eight years on. Sense local authority survey report adult services 2009-2010* London: Sense.

Sense, 2012. *Fair care for the future. Why social care matters for deafblind people.* London.

Sense, 2015. *Communicator-guides* [online]. Available from: https://<http://www.sense.org.uk/content/communicator-guides> [Accessed 25/04/2016].

Sense, 2016. *Equal access to healthcare: The importance of accessible healthcare services for people who are deafblind* London: Sense.

Sense Cymru, 2016. *Practical guide to implementing the social services and well-being (wales) act 2014 for deafblind people* Caerphilly: Sense Cymru.

Sharif, N.*, et al.*, 2012. *Co-production and participation: Older people with high support needs* London: Social Care Institute for Excellence.

Simcock, P., 2017a. Ageing with a unique impairment: A systematically conducted review of older deafblind people's experiences. *Ageing & Society,* 37 (8), 1703-1742.

Simcock, P., 2017b. One of society's most vulnerable groups? A systematically conducted literature review exploring the vulnerability of deafblind people. *Health and Social Care in the Community,* 25 (3), 813-839.

Simcock, P. & Manthorpe, J., 2014. Deafblind and neglected or deafblindness neglected? Revisiting the case of beverley lewis. *British Journal of Social Work,* 44 (8), 2325-2341.

Smith, T., 1993. Psychosocial services: Reaction. *In* Reiman, J.W. & Johnson, P.A. eds. *National Symposium on Children and youth who are Deaf-blind.* Monmouth, OR Teaching Research Publications, 21-40.

Smithdas, R., 1980. Reflections of a deaf-blind adult. *American Annals of the Deaf,* 125 (8), 1015-1017.

Social Care Institute for Excellence, 2015. *Co-production in social care: What it is and how to do it* London: Social Care Institute for Excellence.

Spring, S., Adler, J. & Wohlgensinger, C., 2012. *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".* Zurich: Swiss National Association of and for the Blind (SNAB).

Stoffel, S., 2012. *Deaf-blind reality: Living the life* Washington D.C.: Gallaudet University Press.

Tal, A., 2012. The Nalaga'at center in Jaffa Tel Aviv. *DbI Review,* 48, 41-43.

Tam Sing-Fai, 1998. Comparing the self-concepts of persons with and without physical disabilities. *The Journal of Psychology,* 132 (1), 78-86.

Tang, F., Morrow-Howell, N. & Choi, E., 2010. Why do older adult volunteers stop volunteering? *Ageing & Society,* 30 (05), 859-878.

Tang, F., Morrow-Howell, N. & Hong, S., 2009. Institutional facilitation in sustained volunteering among older volunteers. *Social Work Research,* 33 (3), 172-182.

Tennessee Organization of the Deaf-Blind, 2016. *Programs* [online]. Tennessee Organization of the Deaf-Blind. Available from: https://<http://www.google.ca/url?sa=t&rct=j&q=&esrc=s&source=web&cd=70&ved=0ahUKEwjckpbOguTNAhUFyT4KHfLHCqE4PBAWCFcwCQ&url=https%3A%2F%2Fgivingmatters.guidestar.org%2FFullPDF.aspx%3ForgId%3D2216%26preview%3DFalse&usg=AFQjCNFxXNIK68qawzPHeeIyh6h_mEQPUA&sig2=pF4SJNg-sPkhmzl3PBTTgg> [Accessed 03/09/2016].

Thirty-Eighth Institute on Rehabilitation Issues, 2015. *Assume nothing! A monograph from the 38th institute on rehabilitation issues to address underserved populations including individuals who are deaf-blind.* Hot Springs, AR: Arkansas, U.O.

Tiwana, R., Benbow, S.M. & Kingston, P., 2016. Late life acquired dual-sensory impairment: A systematic review of its impact on everyday competence. *British Journal of Visual Impairment,* 34 (3), 203-213.

United Nations, 1991. *United nations principles for older persons* [online]. United Nations. Available from: <http://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx> [Accessed 11/11/2017].

Wahlqvist, M.*, et al.*, 2016. Implications of deafblindness: The physical and mental health and social trust of persons with usher syndrome type 3. *Journal of Visual Impairment & Blindness (Online),* 110 (4), 245.

Walker, A., 2017. Why the uk needs a social policy on ageing. *Journal of Social Policy,* doi: 10.1017/S0047279417000320, 1-21.

Westaway, L., Wittich, W. & Overbury, O., 2011. Depression and burden in spouses of individuals with sensory impairment. *Insight: Research & Practice in Visual Impairment & Blindness,* 4, 29-36.

Whitson, H. & Lin, F.R., 2014. Hearing and vision care for older adults. Sensing a need to update medicare policy. *Journal of the American Medical Association,* 312 (17), 1739-1740.

Wickham, K., 2011. Depression in the deafblind community: Working from a social work perspective. *DbI Review,* 46, 56-58.

Wittich, W.*, et al.*, 2016. Rehabilitation and research priorities in deafblindness for the next decade. *Journal of Visual Impairment & Blindness,* July-August, 219-231.

Wittich, W. & Simcock, P., *forthcoming*. Aging and combined vision and hearing loss. *In* Ravenscroft, J. ed. *The Routledge Handbook of visual impairment.* London: Routledge.

Wittich, W.*, et al.*, 2013. What's in a name: Dual sensory impairment or deafblindness? *British Journal of Visual Impairment,* 31 (3), 198-208.

Wittich, W., Watanabe, D.H. & Gagne, J.-P., 2012. Sensory and demographic characteristics of deafblindness rehabilitation clients in montreal, canada. *Ophthalmic and Physiological Optics,* 32 (3), 242-251.

Wolf, F., 2005. *Come together, right now* [online]. Sense. Available from: https://<http://www.sense.org.uk/content/talking-sense-come-together-right-now> [Accessed 30/08/2016].

Wood, R., 1991. Care of disabled people. *In* Dalley, G. ed. *Disability and social policy.* London: Policy Studies Institute

Woolhead, G.*, et al.*, 2004. Dignity in older age: What do older people in the united kingdom think? *Age and Ageing,* 33 (2), 165-170.

World Federation of the Deafblind, 2018. *At risk of exclusion from crpd and sdgs implementation: Inequality and persons with deafblindness. Initial global report 2018*. Oslo: World Federation of the Deafblind,.

World Health Organization, 2011. *World report on disability* Geneva: World Health Organization.

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