# *Developing our understanding of an impairment much misunderstood: Researching the experiences of deafblind people*

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## Introduction

Deafblindness, sometimes termed dual sensory loss, is a complex impairment, and deafblind people have been described as some of the most vulnerable in society (Simcock 2017). Yet, the condition is also a much misunderstood impairment, and despite both its known psychosocial impact and the substantial diversity of the deafblind population, work with deafblind people has been largely marginalised by the social work profession. In this chapter, I describe the provenance of my long-standing practice and research interest in deafblindness, before exploring some of the challenges that can result in the exclusion of deafblind people from social work research. I then outline the ways in which funding from the BASW Social Workers' Educational Trust helped me to respond to these challenges during my doctoral studies (2012-2020) involving older deafblind people. Recognising that research on vulnerability has principally concentrated on policy analysis and theoretical debate, my study explored the lived experience of the phenomenon amongst adults ageing with deafblindness, a subgroup of the deafblind population about whom little is known. The chapter presents the core findings of the study, paying particular attention to the ways in which misunderstanding contributes to older deafblind people's felt vulnerability, and then highlights the implications of these findings for social work practice in the field. The chapter concludes with some suggested further reading and helpful resources.

## Deafblindness: A long-standing Practice and Research Interest

In the late 1990s, I took the opportunity to undertake British Sign Language classes at a local Adult Education College. One day, a representative from a local organisation for visually impaired people joined our class with a request for volunteers for the deafblind social group that she co-ordinated. At the time, my only knowledge of deafblindness was vague recollection of a school lesson about Helen Keller; I was therefore intrigued and duly volunteered. The following week, for the first time in my life, I met a deafblind person. She was profoundly Deaf and registered blind (now termed severely sight impaired). As I sat next to her, she felt my presence and extended out her hand to receive tactual communication. With my then rudimentary deafblind manual communication skills, we muddled through a game of bingo and engaged in conversation. This brief interaction determined the course of my career, such was the impact it had upon me. I went on to complete further academic and professional qualifications and became a specialist social worker for deafblind people.

Very few practitioners specialise in this field, and the social work profession has paid little attention to the condition. A 2020 article in the journal *Qualitative Social Work* exploring the impact of Covid19 and associated social distancing requirements on touch practices, and the implications for practice (Green and Moran 2020) illustrates this oversight. The authors consider children in care, people with mental health problems, older people in care homes and bereaved families, but overlook deafblind people, the one group for whom touch is the most important sense. As Luey (1994) argues, this ostensible disinterest is curious, when one considers the psycho-social impact of the impairment, often more significant than the audiological and ophthalmic matters, and known to adversely affect quality of life (Wittich and Simcock 2019). Although deafblindness is a minority impairment, prevalence is expected to rise (Robertson and Emerson 2010), and lack of attention to the condition in social work education appears to be a concern to those in the field:

> We're frustrated that most social work courses don't appear to have a module or aspect to the course that included sensory. We are concerned about where the next crop of sensory social workers will come from (Email to the author from local authority social worker, 2021).

## Marginalisation in Social Work Research

In 2010, I left social work practice to take up an academic position. I soon became aware that just as deafblind people are marginalised in practice, they also receive limited research attention, both nationally and internationally (Rönnberg and Borg 2001, Janssen et al. 2021, Roy et al. 2021). There is a paucity of literature on deafblindness and its consequences, especially UK based research (Kyle and Barnett 2012), studies focused on deafblind people's experiences (Jaiswal et al. 2018, Roy et al. 2021), and exploration of the impact of the impairment on family members (Lehane et al. 2016). Furthermore, previous studies with deafblind people are critiqued for homogenising the population (Dammeyer, 2015), with study authors failing to make explicit the specific subgroup of the deafblind population concerned. It is important to acknowledge that heterogeneity among deafblind people is not limited to varying features of the impairment, such as aetiology, age of onset, and the interval between impairment of each sense; for example, deafblind people, like the general population, are diverse across, *inter alia*, age, gender, race, and sexuality domains.

Nevertheless, in addition to specialist practitioner authored material and biographical accounts recording the lives of famous deafblind people, such as Helen Keller (Keller and Berger 2004), published studies do exist. There is a body of clinical research into deafblindness aetiologies (Gullacksen et al. 2011), a range of prevalence studies, and research investigating the psychosocial impact of the condition (Wittich and Simcock 2019). A particularly positive, recent contribution is the collection of 20 papers, edited by Janssen, Hartshorne and Wittich and published in the open access journal *New Frontiers,* which reports on contemporary research findings in the field (Janssen et al. 2021). With the aim of encouraging further investigation into deafblindness, this collection comprises studies about congenital, acquired and age-related deafblindness, and covers health and wellbeing, communication and learning, and assistive technology.

Deafblind people are described as 'one of the most challenging [groups] to engage in… research' (Roy et al. 2021:71). Challenges are both practical and methodological, and contribute to the limited number and variable quality of studies, and deafblind people's lack of involvement in formal research (Heine and Browning 2015, Tiwana et al. 2016, Simcock and Manthorpe 2020). Wittich and Simcock (2019) suggest that researchers may shy away from deafblindness because of recruitment difficulties, methodological challenges, and struggles to secure funding. Deafblind people have certainly been identified as a 'hard to reach' group (Kyle and Barnett 2012, Evans 2017). Nonetheless, the importance of hearing diverse perspectives and co-producing knowledge with people with lived experience is increasingly recognised in social work research, and as challengingly observed by a participant in the British Institute of Human Rights' recent consultation workshop:

> … there is no such thing as hard to reach groups, there are just easily ignored or forgotten about groups (British Institute of Human Rights 2021).

As my career in social work education progressed, I recalled my first encounter with a deafblind person, described earlier in this chapter. I reflected on my perception of her vulnerability. She seemed to be very vulnerable, but is this how she felt? Whilst a practitioner, the deafblind people I met demonstrated high levels of independence, resilience, coping and strength. My perceptions of deafblind people's vulnerability were challenged, and I was curious as to their own experiences and views on the phenomenon. I decided to embark on a doctoral study to satisfy my curiosity. However, cognisant of the reported exclusion of deafblind people from research and in the absence of good practice guidance for their inclusion (Roy et al. 2018), I needed to explore how the barriers to their participation could be addressed, as part of this endeavour.

## Addressing Barriers to Deafblind People's Inclusion in Research

Before commencing a study involving older deafblind people, I had to consider physical, linguistic and communicative barriers to participation. Harris and Roberts (2003:14) maintain that whilst it 'takes time and energy as well as determination' to engage those who face such barriers, 'it is clearly possible, and adds to the range of experiences highlighted by qualitative research'. Recruitment of deafblind participants can be particularly challenging (Evans 2017, Roy et al. 2021). Although researchers often make use of flyers, posters, and leaflets to raise awareness about a study and seek participants, these are not always accessible to deafblind people (Schneider 2006, Ellis and Hodges 2013). There are also challenges in completing research interviews with deafblind people, owing to the multiplicity of language and communication methods used, and insufficient numbers of qualified interpreters with appropriate experience (Oleson and Jansbøl 2005, Hersh 2013, Roy et al. 2021).

Very little is written about the practicalities of undertaking studies with deafblind people, although the financial implications and time consuming nature of research involving interpreters is acknowledged (Almalik et al. 2010, Regmi et al. 2010). Support from the BASW Social Workers' Educational Trust (SWET) was fundamental to facilitating the involvement of deafblind people in my study. Monies from the SWET grant (2012) and scholarship (2013) were used to fund membership of Deafblind International and attendance at their international conferences. Such engagement enabled the development of relationships with academics and practitioners in the field. As

Liamputtong (2007) highlights, relationships with individuals who are trusted by the population of interest can be a particularly effective way of facilitating recruitment, and some participants were recruited to my study, when it was introduced to them by those I met through my involvement in Deafblind International.

SWET funds were also used to cover the cost of producing flyers and participant information sheets in a range of formats to ensure their accessibility to deafblind people. This included standard, large and extra large print, Grade 1 and Grade 2 Braille, Moon (a system of embossed reading devised by William Moon in 1845), and audio CD. I was also able to commission a local specialist interpreter agency to produce a filmed British Sign Language version of the participant information sheet, with colour contrasting subtitles. Nevertheless, the usefulness of SWET funding went beyond recruitment; it also supported both data collection and data analysis. While face-to-face in person interviews are reported to promote positive rapport and elicit candid responses from study participants (Padgett 2008), they are also a practical necessity for many deafblind people, especially those using tactual methods of communication. Undertaking the interviews involved travel across the country. Furthermore, it required the use of video equipment to record the interactions and the involvement of specialist deafblind interpreters. These interpreters were also involved in the first stage of analysis, as the video recordings were reviewed and data were clarified. Although this helped ensure rigour and credibility of study findings (Squires 2009), such extended involvement had financial implications. The SWET monies assisted with all these matters, enabling the voices of the older deafblind people involved to be heard and authentically represented.

## Findings of the Vulnerability and Deafblindness Study

Full study findings are reported elsewhere (Simcock 2020, Simcock *et al.* 2022), but here I offer a summary, principally paying attention to the ways in which misunderstanding contributes to deafblind older people's felt vulnerability. The participants interpreted their vulnerability as layered: they explained what they felt vulnerable *about*, what they felt vulnerable *to*, and *when* they felt vulnerable. These layers were not discrete, but interwoven, with instances of one impacting on another. Feeling vulnerable about the future, particularly potential further deterioration in hearing and vision were described, and a range of adverse outcomes to which they felt vulnerable were identified: physical harms or injury associated with falling and accidents, social isolation, and being a victim of crime. Although some participants disclosed fears of being exploited, those involved in the study made little to no reference to feeling vulnerable to abuse, particularly in the context of social care and support.

It was the participants' stories of *when* they felt or feel vulnerable that dominated their interpretations of their experiences, rather more than their descriptions of the matters they felt vulnerable about or negative outcomes they felt vulnerable to. Although telling of times when they felt vulnerable, participants also recounted times of safety and security. Times when participants felt vulnerable were situation and setting specific, and both fleeting moments and extended periods were reported. Such findings strengthen arguments against the categorisation of deafblind people as permanently and immutably vulnerable. The situations and settings engendering vulnerability were individual to each participant. Nonetheless, social settings, losing control or being controlled, feeling unable to withstand challenges, lacking full information, and being in situations where required support was unavailable or ineffective, were shared elements of the vulnerability experience. However, it would be inaccurate to suggest that participants lacked agency or were passive actors in such situations. They adopted a range of strategies and demonstrated creativity in developing solutions to the challenges they encounter.

Participants explained how the experience of vulnerability can be dependent on the responses or perceptions of other people, whether or not these were intentionally antagonistic. Misunderstanding is considered significant in the construction of disabled people's vulnerability (Gill 2006), and being, feeling and expecting to be misunderstood were all described by participants in my study. For some, feeling misunderstood began in childhood, but was experienced throughout life, and was somewhat persistent. Deafblindness itself was misunderstood, but also the extent of the impairment, its nature and impact, and participants' behaviour, and linguistic and communicative methods and needs. Family, members of the public and also health and social care professionals were all reported as misunderstanding. One participant critiqued a local authority care and support survey, noting how a perceived misunderstanding of the impact of deafblindness rendered it difficult for his needs to be accurately captured:

> On a recent survey I had to fill in, there's a, do you need help indoors? This was [name of local authority] care and support… Question mark, exclamation mark… I'm fine indoors in my own home thank you. But what about some, another home, place, in the borough. It could be erm, shops, it could be town hall, anything, I need help, all the time.

Participants tried to understand the reasons for such misunderstanding, and identified factors such as ignorance, unconscious incompetence, and comparatively low prevalence rates such that it is outside most practitioners' experience. They also commented on the invisible or hidden nature of deafblindness as a contributing factor. Irrespective of the reasons, being, feeling or expecting to be misunderstood was associated with a range of negative outcomes. It left some feeling reluctant to tell others about their deafblindness, and even led some to decline or refuse to use the aids and assistive technology they were offered:

> That's why I can't use my white stick. Cos I can't use my white stick and then go into work… because people won't understand that.

Participants told stories of how misunderstanding of deafblindness had resulted in them erroneously being perceived as rude or unsociable, and how it negated the effectiveness of their social care support. Social care was adversely affected particularly when participants were misunderstood not only as deafblind people, but also as unique individuals. Such misunderstanding led participants to feel that their needs had been ignored, or contributed to experiences of unrequested help and overprotection.

For me as researcher, an especially moving moment was the realisation that participants had substantially altered my own thinking in relation to the experience of being misunderstood. I have often felt frustrated at the lack of understanding of deafblindness among health and social care professionals. As participants described their own difficulties understanding and explaining deafblindness, and explicitly acknowledged that misunderstanding was 'no-one's fault', my frustration dissipated, and my perspective became more sympathetic. This was just one of the ways in which the study was personally challenging and emotional, yet also transformative.

## Implications for Social Work

Roy et al. (2021) assert that deafblind people want to be involved in research. In view of the limited studies to date that do involve them, a priority therefore appears to be determining the most effective ways of doing so, particularly in relation to older deafblind people and those using tactual communication methods. It is positive to note that this work has already begun (see, for example, Skilton et al. 2018, Jaiswal et al. 2020, Bacchini and Simcock 2020, Roy et al. 2021). The need for future research in the field to be inter-disciplinary is also recognised (Wittich et al. 2016), and I hope that those involved in social work research will be key contributors.

The findings of my doctoral study suggest that social workers should avoid focusing solely on impairment as an indicator of vulnerability, as this risks disempowering deafblind people and provides an impoverished understanding of their experience. Adopting a layered approach to assessment, exploring what deafblind people feel vulnerable about and to, and analysing the situations and settings when they vulnerable, may offer social workers a detailed, yet more nuanced understanding of deafblind people's needs and enable the identification of what is important to them. Findings from my study also support calls for increased awareness and better understanding of deafblindness among social workers. However, it is essential that any awareness raising activities transcend knowledge about the impairment and emphasise the diversity of the deafblind population, especially as domains such as ethnicity and gender can impact on the experience of the impairment. For example, particular disadvantages faced by deafblind people from black and minority ethnic communities have been reported (Joule and Levenson 2008). Such awareness raising activities have the potential to ensure that deafblind people are no longer *mis*understood, but are seen, heard and understood.

## Suggested Further Reading

Simcock, P., Bond, J. & Duncan, L. (2021) 'Deafblindness: the psychosocial impact makes it core social work' *Professional Social Work* [online], available: https://www.basw.co.uk/resources/psw-magazine/psw-online/deafblindness-%E2%80%93-psychosocial-impact-makes-it-core-social-work

Simcock, P. (2017) '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.

Roy, A., McVilly, K.R. & Crisp, B.R. (2021) 'Working with deafblind people to develop a good practice approach' *Journal of Social Work,* 21(1), 69-87

## Helpful Resources

Sense (2006) *Fill in the gaps: a toolkit for professionals working with older deafblind people*, London: Sense. https://www.sense.org.uk/umbraco/surface/download/download?filepath=/media/1728/seeing-me.pdf

Sense (2014) *A practical guide to implementing the Care Act for Deafblind people*, London: Sense. https://ca1-ecl.edcdn.com/Implementing-the-Care-Act.pdf?mtime=20200303160326&focal=none

National Resource Centre for Deafblindness: https://nkcdb.se

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