

## When Physical Distancing means Losing Touch: COVID-19 and Deafblind People

On 20th March 2020, the World Health Organisation declared its preference for the term 'physical distancing' over 'social distancing', a move supported by many health experts, academics, social workers and governments. This term is indeed clearer and more accurate, and it emphasises the importance of maintaining social connection, particularly now. Isolation can have a negative effect on our mental well-being: we must stay physically distant but not socially disconnected. But what about those for whom the physical and the social are not so easily separated? Those who rely on physical contact for communication, for access to information, and for safe travel. Those for whom physical contact is a way in which friendship is expressed and through which they understand the world around them. This is the reality of many deafblind people. Deafblindness affects people in different ways, even though they all have impaired or no vision and hearing (McInnes 1999). Touch is their most important sense: it plays a key role in any interaction, essential when both making contact and communicating. For deafblind children it is 'one of the primary teaching and learning tools' (Moss and Blaha 2001:11). Being unable to make physical contact with one's immediate environment can make deafblind people feel more vulnerable (Kyle and Barnett 2012). Connection is particularly important for the mental health of deafblind people, a group who, at the best of times, experience high levels of social isolation and who are at increased risk of emotional distress (Wittich and Simcock 2019). But does the suggestion that the social and physical can be separated suggest that the needs of deafblind people have been overlooked? As John Finn, himself deafblind, has argued, physical distancing may protect the majority, but has made the isolation felt by many deafblind people much worse (Finn 2020).

The World Federation of the Deafblind (2018) reports that only 50 countries (37%) even recognise deafblindness as a distinct disability. The European Parliament formally adopted a written declaration on 1st April 2004 (Declaration on the Rights of Deafblind People 03A\_DN(2004) 04-01 PAR002) acknowledging deafblindness as a third, discrete sensory impairment. It is a complex condition and can challenge a person's independence and social participation, and also has multiple adverse psychosocial effects, impacting on quality of life (Wittich and Simcock 2019).

In an insightful article in *The New Yorker*, Robin Wright explores how deafblind people (such as lawyer and disability-rights activist Haben Girma) are being affected by the COVID-19 pandemic. Access to even basic information about the virus is described as particularly problematic, and the lack of sign language interpreters at White House daily briefings is noted. The absence of accessible information is similarly reported by the Royal National Institute of the Blind (RNIB) and Jacqui Bond highlights the lack of sign language interpreters at the Government's daily briefings in England in the first edition of this online collection. This impacts not only on the Deaf community, but also those deafblind people who use residual vision to access sign language. Needless to say, access to tactile sign language is not even considered in this debate. The adverse impact of a lack of accessible information on the health of deafblind people cannot be overstated. It affects all aspects of their healthcare experiences, and impacts upon mental health, dental care and pharmaceutical based needs, to name just a few (Simcock and Wittich, 2019).

A lack of accessible information also impacts upon deafblind people's awareness of public health distancing regulations. Some deafblind people explain to Wright the difficulties they experience in

maintaining distancing: this includes being unable to see whether they are sufficiently far from others or being unaware of whether people are already in a lift before they enter. Michael Crossland describes such difficulties in observing physical distancing for those living with sight loss. Given that deafblindness as an impairment is often misunderstood, deafblind people in England have found themselves challenged by the police, as they maintain physical contact with another person, who is both communicating with and guiding them (Personal Communication with Specialist Organisation 2020). A welcome amendment was made to governmental guidance in England relating to movement outdoors during the lockdown, for the benefit of those with learning disabilities or autism; however, for deafblind people using sighted-guide support and tactile communication no such clarity is included. That those with sensory impairments may have specific needs is acknowledged in the UK Government's COVID-19: action plan for adult social care, but it offers no further detail (Department of Health and Social Care 2020: para. 3.19).

The communication difficulties associated with deafblindness are further complicated by the presence of protective equipment, such as masks and gloves; for those using tactile communication (for example deafblind manual and tactile sign language), physical distancing is impossible. Functionally, physical distancing becomes a communication disability. In their blog for the BMJ, Grote and Izagarten, two deaf doctors, lament the push for universal mask wearing, arguing that it leaves persons who rely on lip-reading feeling ignored. For deafblind people, fears regarding communication difficulties have previously been reported as impacting on their experiences of healthcare (Göransson, 2008). A hospital is certainly a setting in which deafblind people can feel vulnerable. In the midst of the pandemic, like other disabled people, deafblind people tell Wright of their fear that clinicians will see their lives as not worth saving. In England, the current NHS England visitor guidance, which does not allow a personal assistant to accompany a person with communication support needs, does little to reduce such fears. Legal challenge of this guidance is welcome (Pring, 2020).

Touch facilitates communication and an awareness of one's environment for many deafblind people. Nonetheless, close physical contact is both necessary in interaction, and a potential source of vulnerability. Deafblind children experience more touch than their peers, some of which is of a more intimate nature than would be considered usual among sighted and hearing persons. Deafblind people may also receive mixed messages about appropriate touch and lack information on the social and cultural 'rules' of touch and personal space (Göransson, 2008). Deafblind people are often concerned that others will misinterpret their physical contact as sexual in nature (Simcock, forthcoming). The COVID-19 pandemic has added another layer of vulnerability associated with touch. Deafblind people tell Wright of their concerns of spreading or contracting the virus, because they touch their faces when using sign language, as well as when they handle their red and white canes used for orientation and mobility.

Wright reports that, according to Roberta Cordano (President of Gallaudet University), planning for the pandemic has completely overlooked and forgotten the deafblind population. I have argued before that deafblind people have been, de facto, excluded from welfare policies and development programmes (Simcock and Wittich, 2019). As a lack of research knowledge is a consequence and possible contributing factor to such exclusion, the recent announcement of funding by the Québec

Research Network on Aging for a study by Walter Wittich (Associate Professor, School of Optometry, Université de Montréal) and colleagues, of pandemic preparedness and access to health information for older deafblind people during and post COVID-19 is most welcome. The British Association of Social Workers (BASW) call on the profession to uphold the human rights of those faced with inequalities intensified by the pandemic, in their statement of concerns and demands. The social work profession certainly has much to contribute to the wellbeing of deafblind people. However, as Luey (1994:213) observes, it has been 'curiously inactive in the field' and fails to give deafblindness the 'attention that it deserves'. It appears that principally, it remains left to rehabilitation workers, educationalists, psychologists and specialist health care colleagues to support this population through both direct work and research. As the number of persons living with combined vision and hearing loss is predicted to grow with the ageing of the population, and as deafblind awareness week approaches (24th June 2020), I encourage more social workers to develop their knowledge of deafblindness and to build their capacity in this specialised field. Although some may have forgotten deafblind people during this pandemic, don't let them be forgotten by the social work profession.

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