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Editorial

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Welcome to this issue of the *British Journal of Visual Impairment* where again we have another strong international focus. As editor-in-chief, I feel that it is important that the journal not only publishes high-quality international research but also is a vehicle where experts are able to express opinion or add to a national/international debate through the editorial process. As such, I have decided over the next four issues of the journal to allow different voices to be heard in a one-off editorial about issues that concern them deeply.

The first of these editorial pieces is by Dr Damen, Assistant Professor at University of Groningen and Royal Dutch Kentalis, where she researches and teaches about deafblindness. If you would like to contribute to one of these extra special editorials, please email me at john.ravenscroft@ed.ac.uk and we can discuss.

I hope that you enjoy this issue as much as we have putting it together.

John Ravenscroft
Editor-in-Chief
British Journal of Visual Impairment

The challenge of identifying deafblindness

In the digital age, we are used to receiving a considerable amount of social information daily and can communicate non-stop with practically every part of the world. Today, there is a growing emphasis on making social media also accessible to people with disabilities. Several interesting studies have been published in this journal on the use of digital technology by people with visual impairments, such as the 2017 article by Della Líbera and Jurberg on the use of smartphones by teenagers with visual impairments. There are still people with visual impairments, however, who are hardly connected with the digital or even the non-digital world.

A group of people who have difficulties with participating in today's society is the group that has both visual impairments and auditory impairments. The combination of visual and hearing impairments creates a condition that is much more complex than the addition of the two single impairments. To emphasize the complexity of combined visual and hearing impairments, international organizations that strive for support for this target group—Deafblind International (DBI) and the World Federation of the Deafblind (WFDB)—use the term deafblindness for all people with these combined impairments, including people who have some residual vision and hearing.

According to the WFDB (2018), deafblindness is a less-known condition. Lack of knowledge on deafblindness in health and educational providers is problematic because it can lead to wrong diagnoses and a lack of proper services (see Anthony, 2016; WFDB, 2018). To understand what the impact of deafblindness is, one needs to know that people with combined visual and hearing impairments are often not able to use typical forms of communication or to use compensatory strategies and aids that are used for people with a single sensory impairment, such as voice description on the

computer or visual sign language. The commonality between people with deafblindness in various degrees is also that they perceive information mainly or only through the tactile senses. For both people who are born with deafblindness and those who acquire deafblindness early or later in life, DBI (2019) describes three areas that are always affected: communication, information access and orientation and mobility.

Case studies of people who are born with deafblindness or have acquired this before the start of their language development—people with so-called ‘congenital deafblindness’—show that they can become very skilled in using the tactile modality as a source of information (see Janssen, Nota, Eling, & Ruijsenaars, 2007) and can learn a tactile language (Lindström, 2019). There is, however, the problem that tactile information is not continuously present such as is the case with visual information. Tactile information alone or in combination with reduced vision and hearing provides a fragmented image of the world. Touch can only provide information about the proximity and never provides an overview of a situation. Building an understanding of the world through the tactile modality is therefore highly complex, takes a lot of time and effort, and requires the provision of specialized individual support (see, for example, Bruce, 2005).

Studies on the needs of families with a child with deafblindness have shown that intensive support is needed for both the child and his or her family members (see Correa-Torres & Bowen, 2016, for a review). Dammeyer and Ask Larsen (2016) reported in this journal that there appears to be a lack of individual language support for people with congenital deafblindness by their social partners. Research that I carried out with Janssen, Ruijsenaars, and Schuengel in the Netherlands showed that parents, caregivers, and teachers request support to help them adapt their communication strategies to the needs of individuals with congenital deafblindness. The provision of a video-feedback communication intervention for these educators significantly improved their communication with individuals with congenital deafblindness (Damen, Janssen, Ruijsenaars, & Schuengel, 2015).

The abovementioned studies show that social and educational environments are usually not or at least not naturally adapted to people with deafblindness and this is confirmed by the latest global report of the WFDB (2018). There is, however, a debate on how much a lack of proper adaptations contribute to the frequently reported severe developmental delays in people with congenital deafblindness (see, for example, Dalby et al., 2009). Especially for those people with hereditary syndromes, such as CHARGE¹, Goldenhar, or Zellweger, the question is whether the deafblindness perhaps coincides with intellectual disabilities. The fact is that we do not know yet how functional impairments in vision and hearing, personal characteristics and environmental factors together lead to specific developmental, learning and quality of life outcomes. Longitudinal research on the developmental trajectories and factors influencing these trajectories is lacking, and such research cannot be carried out properly if we are not able to identify people with deafblindness in the first place.

Identification of deafblindness involves recognition of deafblindness and acknowledgement of the specific support needs of this target group. Deafblindness is, however, still not formally acknowledged as a distinct disability in most countries today (WFDB, 2018). Furthermore, individuals with deafblindness are often not assessed by a multidisciplinary team of specialists in deafblindness with assessment methods that are suitable for the target group (see Chen, Rowland, Stillman, & Mar, 2009). The prevalence and incidence rates of deafblindness are unknown in many countries (WFDB, 2018) and deafblindness can be overlooked, especially in settings for people with intellectual disabilities (see Fellingner, Holzinger, Dirmhirn, Van Dijk, & Goldberg, 2009) and older adults (see Roets-Merken, Zuidema, Vernooij-Dassen, & Kempen, 2014).

The Nordic countries are an exception to the global lack of identification of deafblindness with their national multidisciplinary identification teams. In this journal, already in 2012, Dammeyer introduced the Danish identification method, which not only focuses on the medical problems but also assesses the way the individual uses vision, hearing, and touch in daily interaction and communication.

The Nordic approach is a good example for other countries of how deafblindness can effectively be identified. Timely identification of disabilities is especially significant in young children because the brain is most plastic at an early age and therefore interventions should start as early as possible (see Rimrodt & Johnston, 2009). An excellent case example that supports the idea that deafblindness does not have to lead to limited functioning and participation is of American writer Helen Keller. Keller was born in 1880, became deafblind at the age of 19 months as a result of a disease, and was the first person with deafblindness to get a university degree. Crucial for her successful development seems to be the fact that she received one-to-one support by an intervener and was taught both tactile fingerspelling and braille.

When thinking of the case example of Helen Keller, we can wonder how many Helen Kellers are out there now or will be born. Longitudinal studies are needed to find out which interventions contribute to the realization of their learning potentials. Developing evidence-based practice within health care and education for people with deafblindness is, however, relatively complex because of the small size and heterogeneity of the target group. Research on deafblindness is often carried out locally, with small numbers of participants, and hardly involves effect studies (see the reviews of Parker, Davidson, & Banda, 2007; Rönnerberg & Borg, 2001). Research even becomes more difficult if people with deafblindness are not identified as such, as I stated earlier. In a literature study that I carried out with Ask Larsen on definitions of deafblindness, we found that researchers themselves often use various terminologies, definitions, and criteria for the target group and are often not clear about the characteristics of the participants in their studies (Ask Larsen & Damen, 2014).

A way to further develop the research area of deafblindness is to establish more collaboration between universities and practitioners, and more international collaboration. A first step could be to formulate an international research agenda for the coming years by researchers, members of the target group and practitioners together. In my opinion, a priority should be given to international collaborative research on effective methods of identifying deafblindness and the gathering of up-to-date data on the prevalence and incidence rates. These are essential steps towards specialized services for all people with deafblindness in the world.

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Note

1. CHARGE is an abbreviation for several features of the disorder: Coloboma, Heart defect, Atresia choanae, growth Retardation, Genital abnormalities and Ear abnormalities.

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