Becoming deafblind: Negotiating a place in a hostile world

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Abstract

This study addresses the situation of adults who become deafblind. To date, their everyday lives have received little attention in the research literature. Of the few studies conducted many involve surveys, the findings of which present the characteristics of people who are deafblind such as their rates of employment, need for support, or use of equipment. There are also a small number of qualitative studies that have explored the effects of having a dual sensory impairment, and particularly in relation to communication and psycho-social wellbeing.

Important as these research efforts have been, there is little empirical information available about the everyday lives of people who become deafblind and their concerns, nor any systematic attempt to theorise their experiences. There are however many personal anecdotes typically presented at conferences or through community publications and newsletters.

This project aimed to redress the gap in the literature by developing a theoretical framework to explain the everyday experiences of adults who become deafblind. In doing so, it built upon the research and anecdotal literature with an overall purpose of presenting, through rigorous research, the experiences of adults who become deafblind and to do so within the broader discourse on disability and disablism. The study was informed by the social relational understanding of disability developed within the Nordic countries. Grounded theory was the method of choice to examine the lives of adults who become deafblind from their own perspective.

Participant observation was employed through direct engagement in shared experiences with adults who have become deafblind both at a social group and via an e-mail list group. Multiple in-depth interviews were undertaken both face-to-face and by e-mail with a smaller group of eight participants.
The core finding from this study is that people who become deafblind are rendered interactionally powerless in a society predicated on seeing and hearing. The powerlessness that they experience comes from having this dual impairment in a world in which being able to see and hear are expected both in the physical and the social environment. The inability of people who become deafblind to ‘know and be’ in the world in the same way as others results in them feeling, and experiencing interactional powerlessness. In response, people who become deafblind actively engage in trying to minimise or remove their powerlessness. They do this by working to negotiate a place in this hostile world. They adopt four interrelated strategies, namely, doing things differently, managing support relationships, surviving others’ perceptions and presenting sides of self.

This study, with its central tenet that interactional powerlessness drives ongoing attempts to negotiate a place makes a theoretical contribution to understanding the experience of becoming deafblind. The findings support the concept of disability as social relational. Disability is not the same as the sensory impairment, rather it is expressed in the organisation of personal relations in society which render some more powerful than others and in this case, some less powerful due to their inability to use the natural means of communication of hearing and sight. Moreover, the study findings propose that professionals working with people with this dual sensory impairment must endeavour to reduce their part in the hostile world by providing information about options and support available; recognising the complexity of these adults support requirements; and considering the link between psycho-emotional issues and disablism. Further research is needed to understand empirically and theoretically the relative contribution of personal relationships vis a vis organisational or structural relationships in disabling people who become deafblind.
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