# Chapter 17

# When Gucci Makes Hearing Aids, I'll Be Deaf: Sensory Impairment in Later Life, and a Need to define it According to Identity

**Simon Hayhoe**[1]

**Abstract** This chapter examines my experience of late hearing impaired – becoming hearing impaired, being diagnosed as such and then living with this new impairment. The analysis considers this experience of impairment from the point of view of subjective and objective disability. I argue that I am currently less impaired now that I have been diagnosed as being hearing impaired than I was when I was not considered to be hearing impaired. The chapter concludes that impairment is subjective, and should be considered so. It also concludes that context and age of impairment should be considered when understanding disability.

**Keywords** deaf, blind, impairment, disability, inclusion, culture, epistemology, ontology

---

[1] Assistant Professor Canterbury Christ Church University / London School of Economics and Political Science
Email: simon.hayhoe@canterbury.ac.uk

## Introduction

Are legal definitions of perceptual impairments always effective? Are the words *deaf* and *blind* merely descriptions, individual identities or are they practical problems that need to be overcome? Many people I have interviewed who became sensory impaired later in life, particularly people who lost their perceptions in old age, often find it difficult to adjust to an impaired identity (Hayhoe, 2008, 2013a, 2014). These people mix more with sighted and hearing people. They maintain their old habits. They communicate and understand the world through their previous identity. Many of these people also express confusion about why they are seen in a similar way to other people with different forms of disability. These others' experiences of life have little relevance to their own.

General models of a disability have been forthcoming (see for example, Pfeiffer, 2002). Yet there are few that accurately epistemologically and ontologically define disability as it relates to individuals from all walks of life. There are even fewer that define how we can identify and classify disabled people who acquire their impairments later in life. There is also little attempt to measure aspects of its antonym "ability" as a universal concept (Hayhoe, 2012). Hence, such issues remain entirely subjective in the context of method and study.

Perhaps a reason for holding with an idea of a whole sensory disabled identity is the need for institutional convenience. It is also the inability of science, social science and philosophy to overcome reductionist aspects of the mind-body problem in our understanding of the world (Nagel, 2012). Importantly, beyond social scientific models and definitions, government organizations have had to introduce workable, holistic definitions of disability. This allows them to perform operations such as the distribution of funds and practical support. It also allows them to provide a workable explanation that can be used as the basis of legislation (Tibble, 2004). Similarly, over the past 35 years, the World Health Organisation has attempted to define a holistic intra-cultural notion of disability in relation to the terms such as "normalisation", "impairment" and "handicap" (World Health Organisation, 1980, 2014; Barbotte, Guillemin & Chau, 2001). However, these brief definitions appear less clear than the academic models they were informed by. Criticism of cultural norms and the difficulty of imposing a social identity on another person make such terms especially meaningless at best and dangerous and undemocratic at worst. This was illustrated clearly in my research on blindness and computer programming. During this study, I observed that blind programmers who became impaired later in life had a conception of programming that mirrored their previous sighted life. By contrast, those who had been born blind had a conception of technology according to their experiences in schools for the blind or inclusive mainstream education (Hayhoe, 2011).

So how can we best understand what it is to be sensory impaired in the context of social scientific and philosophical study? Furthermore, how can such concepts ever be defined in a capacity that gives meaning to disparate cultures with different ideals of social and cultural identity? This chapter explores these questions through an analysis of the social identity of disability, impairment and thus an implied definition of ability. It also examines the broader social-philosophical notions of subjective and objective cultural identity. This chapter begins this task with an exemplar problem of my own late deafness and the anomalies that this has caused, in order to illustrate this problem. This essay is conducted using an auto-ethnographic approach, with my own experiences being examined qualitatively (Ellis, Adams & Bochner, 2011). My reason for using this methodology was that I felt it reflected my own experiences of the process of my ambiguous cultural identity. In addition, it lessened any ethical issues of constructing a case study of experiences of impairment.

## *A problem of late deafness*

I can define my problem thus: I am 45 years old. Tinnitus runs in my mother's family. My mother has it; my uncle had it; my grandmother had it for as long as I can remember. When I was in my mid-twenties, I began to notice my hearing deteriorating. Because this problem was in my family, doctors monitored my progress. Early tests revealed that this problem wasn't so great. I resisted further hearing tests until my mid-thirties, when it became too much of a problem to ignore. At this point, I had a further hearing test and discovered I had lost enough high frequencies to be classified hearing impaired. I now have to wear an ugly National Health Service hearing aid, until I earn enough to afford a high tech Danish hearing aid that can sit in my ear (virtually) invisibly.

So, am I disabled by my perceptual impairment? I would argue, not. There could have been a case for me being slightly disabled between my mid-twenties and the time the hearing therapist put a harsh plastic earpiece in my ear and asked me whether it was comfortable or not. After that moment my problem was more manageable. Despite the pain, his was the clearest voice I had heard for ages. Then when he plugged the chord into his computer to adjust its settings and rang a small bell, it felt unlike anything I had felt or heard for a long while – the sound was too loud and sharp. It was completely the opposite problem to the one I had had before. Before this time I had to rely solely on staring at my family, students and friends, hoping to see their voices as accurately as possible.

The initial answer to *my* problem then is that I have never felt disabled although I could have been said to be once. I grew up in a community where I was treated as an able-bodied person. I managed to handle what was felt to be my impairment in my own way, something to be controlled. In fact, I now overcompensate for it. Like some closet gay men who desperately bed women to preserve their manhood, I try to become super able, super normal. I wear Paul Smith jeans, Burberry socks, and dress for work with Austin Reed suits and Hawes & Curtis shirts; I buy Gucci sunglasses; I have taken degree upon degree; I have to think that my health, blood pressure, heart rate and waistline always have to be in good form; I write, draw and photograph as if my life depends on it. I am trying to move away from the life and the disability that I have seen in others. It was something they fought and hated, and it is something I feel I do not want to be a part of now. So who does feel disabled by sensory impairment, and how do we take account of whether a person wants to define himself or herself as disabled or, to use a word that is often defined alongside it, impaired (Cameron Rochdale, Chadwick, Howie-Finn, Roelofs, 1996)?

In order to build a workable definition of what sensory impairment and any subsequent disability[2] "is", it is arguable that disability should be regarded as a description of how a person is excluded from behaving in a comfortable or *normal* fashion by their society. However, this understanding of *the normal* has been found to be dependent on the two dimensions of the historical era and the social and cultural environment in which a disabled person resides (Hayhoe, 2000, in press, 2008, 2012). In addition, disability can be visible or invisible, and it can also depend on individuals' circumstances, such as their social class or occupation (Hayhoe, 2010, in press). Medically, disability is not an illness. It most often is, however, the outcome of an illness. Practically, it can be regarded as an injury to the functioning of culturally defined tasks (Crow, 1996). In this chapter, it is this last aspect of this definition that is of particular importance, and in the discussion that now follows this concept shall be broken into two further sub-concepts: subjective and objective aspects of disability.

## Subjective and objective aspects of disability

In order to simplify the "definition problem" of disability, it is necessary to see these conceptualisations in the context of social and cultural phenomenology. Firstly, the individual can define disability given particular circumstances: what an individual can do in those circumstances. In this chapter I refer to this as Subjective Disability. It is so called, because it examines each person's trait according to its context and subject: the environment, the task, the man, the woman,

---

[2] For brevity in this essay I refer to disability alone in many circumstances where disability and impairment are seen as being a similar social concept.

the girl or the boy, *not* the disabled identity of the person. For instance, I have no hearing impairment whilst I am reading a book, but I have a walking impairment when I am carrying heavy shopping bags. Thus, my identification as a hearing impaired person by others is based on many different concepts to those of a perception of my lived reality in many situations; i.e. although my hearing problem only takes up a little of my life and its degree of annoyance or disability is dependent on individual circumstances, this is felt to control enough of my *normal* existence to constitute disadvantage, suffering or discomfort. In a social context, however, this conception of disability is related to the social and cultural consequences of its medical causes, such as whether a person can still make money or participate in the broader economy (Oliver, 2013), whether they can present themselves in a way that is felt to be acceptable by their society or whether they can perform other social tasks as expected by their society (Goffman, 1990). For instance, subjectively a person is never blind or an amputee never crippled when they are on the telephone, they are only felt to be disabled when they are presented with visual information or asked to walk or lift objects.

Secondly, disability can be seen as what a society tells a person they can or cannot do in particular circumstances. In this chapter I call this concept Objective Disability. It is so called because it classifies a group of people with similar traits as an object, a group or a sub-culture (Oliver, 2013; Hayhoe, 2012). It is then thought of as an identity, and symbols such as hearing aids, white canes and walking sticks – implements which are designed to help its common subjective traits, such as the amplification of sound, the information gained from the vibrations of a cane or the control of balance when walking - tell the greater society that the person possessing the symbol has a disability – hence the white of the white cane or the brown plastic of many modern functionalist hearing aids from the British NHS, which is for the purpose of the viewer and not the deaf or blind user. Similarly, social scientific modes of examining the constrictions and classifications of these deviant traits which are thought to be inherent in disability are discussed and framed by authors such as Michel Foucault (1989) and Erving Goffman (1990, 1991) in terms of deviance, disadvantage or social labelling; although their mode of describing these concepts and their conclusions differ radically according to their separate political conceptualisation. Foucault in particular takes a radical neo-Marxist approach to explaining this problem (Steinmetz, 1994), whereas Goffman proffers a more liberal and contextual symbolic interactionist interpretation (Goffman & Best, 2005) in which the individual is seen in the almost theatrical setting of his or her greater society.

In terms of the cognitive sciences, the paradoxes and problems of crossing from one identity to another is particularly apparent in the sudden change from a disabled identity to a non-disabled identity (Berkeley, 1899; Gregory, 1974; Sacks, 1993) or able bodied to disabled (Hull, 1990). The most extreme phenomenon associated with this latter change of identity is illustrated by Merleau-Ponty (2002) in his description of the phantom limb. In this instance, patients who have had a limb amputated still consciously believe it is still present, and in this way the new objectively disabled human has a subconscious denial of his or her new condition.

Thus there are many conditions that need to be fulfilled for a man to be considered Objectively Disabled (Hayhoe 2004, in press). For instance, if a person has injured legs he or she will be considered objectively disabled. He or she will not be able to walk to his or her local shops without severe discomfort. He or she can use a wheelchair. However, this would also make him or her less agile or fast on most pavements / sidewalks than people walking normally. Whilst walking or in his or her wheelchair he or she will look very different and travel more slowly. His or her wheelchair is also associated with others with crippled legs. The man or woman cannot do anything to change his or her crippled legs, even with strengthening exercises. His or her legs will not heal themselves. His or her condition is also rare and extreme enough to be different from a great number of people in society.

In terms of a more esoteric example, considered to be on the edge of social reasoning since the Enlightenment (Hopkins, 2005), we can define blindness as referring to a range of symptoms that affect the optical information required to fulfil many socially visual culturally tasks - it must again be made clear at this point that blindness itself is not a disease, it is the outcome of a disease, a trait it leaves behind. It can also have a range of forms and blindness can cause Subjective Disability, although in its social context it can also be considered an Objective Disability. For instance, for individuals to draw a realistic picture it is assumed that they require some degree of visual acuity. They must picture their subject as a whole. They must know that they are drawing correctly shaped and shaded areas on paper. An individual must have feedback from the lines that he or she has drawn. This allows a person to know where to put further lines. However, these difficulties can be overcome to a large extent, allowing an artist with no sight to touch. Persons can also be educated about what they are touching, and they can be taught to use tactile media such as German film, which rises as soon as it is scribed with a pen (Hayhoe, 2008). Blindness in this case is not such a grave Subjective Disability.

Thus, to be considered blind in terms of a visual arts culture, an Objective Disability, a man or woman must not be able to perform what society deems to be most normal tasks without great assistance. For instance, even though blind people can read Braille or large print with residual vision, their relative speed of reading is severely restricted and thus more time should be given to allow for this in controlled situations (Warren, 1994). The extra technology needed also requires more storage space. This is less efficiently produced (Hayhoe, 2013b). Blind people often have eyes that look different to people who are considered to be sighted. They wear glasses and carry white canes. If they are congenitally or early blind, they also often move their heads when talking. Blind or deaf people often have little chance of reversing their impairments in the short term. If their condition is operable, it usually takes a while for healing to take place. Their sight, hearing and bodies must also adjust or readjust. Some permanent conditions that cause impairments, such as cataracts, glaucoma, or tinnitus can be reversed or at least controlled as a result of diet, exercise, relaxation techniques or therapy. This takes a long time, however.

Furthermore, small sensory impairments that require regular prescription glasses for correction are frequent. This is because these are relatively common implements that do not symbolise rare physical or psychological conditions or impairments and can be used by many members of the public temporarily or impermanently – this is particularly true of walking sticks and clear glasses as the strength of the impairment is not denoted by the objects themselves; for example, the difference between glasses for permanent, serious sight problems and weak reading glasses is not apparent until they are examined closely and the difference between the lenses becomes apparent. Yet conditions that do not necessarily lead to normal dysfunctioning of the body apart from the limited ability to move, see or hear at a particular speed and in certain lighting or environmental conditions, such as amputation, paraplegia, multiple sclerosis, photophobia, achromatism and tinnitus, are rarer and thus regarded as disabilities. There are also cultural anomalies in this scientific process, and these are now discussed below.

## ***Cultural anomalies and disability***

Most cultures have formalised their rules of defining disabilities such as blindness or deafness as objective disabilities. Legislation in many western countries in particular has taken this a stage further. Such countries legally classify the level at which this weakness of optical functioning disables most social tasks. In the British Isles, for instance, legal blindness is measured at 5% sight or $^{1}/_{20}$ visual acuity or less, and has been for many years (Coakes & Holmes Sellors, 1992). This reductionist definition is too simplistic, however. For example, in the case of traits such as achromatism, visual acuity can increase through lack of *normal* light perception (Sacks, 2001; Hayhoe, 2008). The testing of this visual acuity must therefore take place in what are considered to be normal lighting conditions. As a consequence, the whole of the person is not judged according to a rigid scientific test at a particular point in time, under culturally defined conditions.

Aside from people who have no light or sound recognition whatsoever, each person's visual impairment is perceptually unique. Scientifically, however, the range of symptoms can be classified as:

blurred vision, tunnel vision (where peripheral vision is missing), peripheral vision only, tinnitus, spots in vision, achromatism (lack of certain or all colours), loss of low frequencies, loss or high frequencies, or a combination of all these symptoms. It is also very rare for someone to be totally blind or deaf. It is much more common for them to have a small amount of light or sound perception. However, in many circumstances policies are often targeted at the rarest rather than the most common strengths of impairment (Hayhoe, 2013c). Therefore, psychologically and sociologically, blindness and deafness can be classified in three further ways - I acknowledge help from Lowenfeld's (1981) psychological definition of blindness for this classification:

1. *Congenital blindness*: When a man or woman is born blind. The consequence of congenital blindness is that a person will have no visual memory or his or her visual memory will be based solely on his or her highly restricted light perception.
2. *Early blindness*: When a man or woman has gone blind in childhood. Men who are early blind often have visual memories and can often understand visual reference.
3. *Late blindness*: When a man or woman goes blind in adulthood. For example, at the turn of the millennium around 70% of all blind people in England and Wales were over 75 (Department of Health, 2001). This number is still increasing as the older population increases. Much of this population's perceptual reference is still related to vision.

Thus we find that all of these attempts to classify even a subset of disability can hold no single, measurable or firm answer, or workable definition in the context of academic scientific study.

## Conclusion

When attempting to understand the concept of disability in relation to sensory impairment the background of these issues and, moreover, the background of the people thus classified are often not taken into account in many academic or institutional discourses on disability. In truth, some people who are objectively classified as impaired or disabled later in life will still want to be associated with an able bodied culture; and if they are disabled later in life, they will want to relate their identities with their previous experiences and cultural and social groups. Indeed, these people, as Merleau-Ponty found, even subconsciously will want to feel they are that same person they used to be. Therefore the experience that they are now legally entitled to is largely an adapted version of their able bodied experiences. Hence, the language used to describe such people is more often than not the same as an able bodied person. The social and cultural references are those you would give to any other person because, in their mind, there is no difference.

The person who has a sensory impairment from a very young age, though, can often be said to have a different culture. They often want to feel that they are of the class, gender, ethnicity, or religion they were born into, but the cultural medium they have to refer to this culture will be different, as a result of their institutional experiences. This means that certain technologies and objects, such as walking sticks, canes, dark glasses or hearing aids, which are associated with disability, may have a greater symbolic meaning to the person with the impairment than the person without it. To use the metaphor of art, for instance, I like the works of Klimt, Bacon, Freud, Gilbert & George, Mozart, Puccini, and Debussy. However, do their pieces mean the same to a person who has never seen or heard their works of art as I have? Or do these art works mean nothing to anyone who has never heard of these artists?

It does not matter whether we see or hear, touch or smell as everyone else does, we can still engage culturally and emotionally in any subject matter uniquely according to our personal histories. These emotions come from different life experiences. Therefore, the different experiences of educational, medical, governmental, or cultural institutionalisation, and the exclusion that is derived from this institutionalisation, in relation to the congenitally and early disabled person must be considered when communicating or developing policies and support for them, just as the need to feel as a person did when they were more able bodied should be to the person who develops a later sensory impairment. Moreover, in this process perhaps the phrase *unique context* should be emphasised. When Gucci makes a National Health Service hearing aid or white cane, just as they make fashionable glasses, many more people will be happy to call themselves deaf. But until institutions and the greater society they say that they represent accept that such people want to be considered equal in the culture they were raised in, yet preserve a unique sense of identity and self-expression, they will often continue to keep their deafness or blindness as close to the closet as their physically and socially painful hearing aids and white canes will allow them to.

**Acknowledgments** To John Kennedy, and in memory of John Hull and Oliver Sacks whose help with my writing was invaluable..

## References

Barbotte, E., Guillemin, F. & Chau, N. (2001). Prevalence of impairments, disabilities, handicaps and quality of life in the general population: a review of recent literature. *Bulletin of the World Health Organization, 79*, 11, 1047-1055.

Berkeley, G. (A.C. Fraser Ed.) (1899). *Selections from Berkley*: 5th Edition amended. Oxford: Clarendon Press.

Cameron Rochdale, L., Chadwick, A., Howie-Finn, I. & Roelofs, S. (1996). The Disability Discrimination Act: A Policy and Practice Guide for Local Government by Disabled People. Leeds: University of Leeds.

Coakes, R.L. & Holmes Sellors, P.J. (1992). *An outline of Ophthalmology*. London: Butterworth-Heinemann.

Crow, L. (1996). Including All of Our Lives: Renewing the social model of disability, In C. Barnes and G. Mercer Eds. *Exploring the Divide: illness and Disability.* Leeds: Disability Press.

Department of Health. (2001). Registered blind and partially sighted people year ending 31 March 2000, England. London: HMSO.

Ellis, C., Adams, T.E. & Bochner, A.P. (2011). Autoethnography: An overview. *Historical Social Research, 36*(4), 273-290.

Foucault, M. (R. Howard Trans.) (1989). *Madness and civilisation*. London: Routledge Classics.

Goffman, E. & Best, J. (2005). *Interaction ritual: essays in face-to-face behaviour.* Piscataway, New Jersey: Aldine Transaction.

Goffman, E. (1990). *Stigma: Notes on the management of spoiled identity.* London: Penguin.

Goffman, E. (1991). *Asylums.* London: Penguin.

Gregory, R.L. (1974). *Concepts and Mechanisms of Perception.* London: Duckworth.

Hayhoe, S. (1995). *The art education of blind adults.* Thesis presented in support of the degree of MEd by research, Leicester University, British Isles.

Hayhoe, S. (2000). The effects of late arts education on adults with early visual disabilities. *Educational Research & Evaluation, 6*(3), 229-249.

Hayhoe, S. (2004). *The development of an epistemological model of disability: The Enlightenment, scientific theories on blindness & arts/crafts education in the US.* Guest lecture presented at Toronto University in March, 2004.

Hayhoe, S. (2005). *Social and cultural influences on art education in English schools for the blind.* Thesis presented in support of the degree of PhD, Birmingham University, British Isles.

Hayhoe, S. (2008). *Arts, culture and blindness: Studies of blind students in the visual arts.* Youngstown, New York: Teneo Press.

Hayhoe, S. (2011). Non-visual programming, perceptual culture and mulsemedia: Case studies of five blind computer programmers, In G. Ghinea, F. Andres, & S. R. Gulliver (Eds.) *Multiple Sensorial Media Advances and Applications: New Developments in MulSeMedia.* Hershey, PA: IGI.

Hayhoe, S. (2012). *Grounded theory and disability studies: Researching legacies of blindness.* Amherst, New York: Cambria Press.

Hayhoe, S. (2013a). Expanding our vision of museum education & perception: An analysis of three case studies of independent, blind, arts learners. *Harvard Educational Review, 83*(1), 67-86.

Hayhoe, S. (2013b). *A review of the literature on the use of mobile tablet computing as inclusive devises for students with disabilities.* Proceedings of the Current Trends in Information Technology 2013 Conference, Dubai, 11-12 December 2013. New Jersey: IEEE Xplore Digital Library.

Hayhoe, S. (2013c). The philosophical, political and religious roots of touch exhibitions in 20th century British museums. *Disability Studies Quarterly, 33*, 3, http://dsq-sds.org/article/view/3760/3273.

Hayhoe, S. (2014). An enquiry into passive and active exclusion from sensory aesthetics in museums and on the Web: Two case studies of final year students at California School for the Blind studying art works through galleries and on the web. *British Journal of Visual Impairment, 32*(1), 44-58.

Hayhoe, S. (In Press). *Philosophy as disability & exclusion: The development of theories on blindness, touch and the arts in England, 1688-2010.* Charlotte, North Carolina: IAP.

Hopkins, R. (2005). Thomas Reid on Molyneux's Question. *Pacific Philosophical Quarterly, 86*(3), 340–364.

Hull, J. (1990). *Touching the Rock: An experience of blindness.* London: SPCK.

Lowenfeld, B. (1981). Effects of blindness on the cognitive functioning of children. In Berthold Lowenfeld, *On blindness and blind people: Selected papers.* New York: American Federation for the Blind.

Merleau-Ponty, M. (C. Smith Trans.) (2002). *Phenomenology of perception.* London: Routledge Classics.

Nagel, T. (2012). *Mind & cosmos: Why the materialist neo-Darwinian conception of nature is almost certainly false.* New York: Oxford University Press.

Oliver, M. (2013). The social model: A victim of criticism. *Disability Now*. Retrieved from http://www.disabilitynow.org.uk/article/social-model-victim-criticism.

Pfeiffer, D. (2002) The philosophical foundations of disability studies. *Disability Studies Quarterly, 22*(2), 2-23.

Priestly, M. (2003). *Disability: A life course approach.* London: Wiley-Blackwell.

Sacks, O. (1993). *A neurologist's notebook: to see and not to see.* New York: The New Yorker Magazine.

Sacks, O. (2001). *The island of the colour blind.* London: Picador.

Steinmetz, G. (1994). Regulation theory, post-Marxism, and the new social movements. *Comparative Studies in Society and History, 36*, 176-212.

Tibble, M. (2004). *User's guide to disability estimates and definitions.* London: Department of Work and Pensions.

Warren, D.H. (1994). *Blindness and children: An individual differences approach.* Cambridge: Cambridge University Press.

World Health Organisation. (2014). *Disabilities.* Retrieved from http://www.who.int/topics/disabilities/en/ on the 1st April 2014.

World Health Organization. (1980). International Classification of Impairments, Disabilities, and Handicaps: *A manual of classification relating to the consequences of disease.* Geneva: World Health Organisation.