AIMS For a better birth...

History and politics of deafness

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Introduction

Deafness, defined as a partial or total inability to perceive or understand sound, currently affects an estimated 1 in 5 people in the UK.[1] Deafness is defined within four categories, mild, moderate, severe and profound.[2] At the last census, 21,971 people aged 3 and over reported using a signed language as their first language.[3]

A study of deaf British Sign Language (BSL) users found that their general health was poorer than that of the general population, with higher rates of misdiagnosis and undertreatment of conditions.[4] Furthermore, in maternity, deaf women are more likely to have caesareans or lengthy hospital stays following birth.[5] Historical issues within the deaf community and a lack of recognition of BSL as a language create complexities in self-advocacy and access to healthcare.

This article will briefly outline deaf history. It will also discuss the competing ideas of deafness as a disability or deafness as a culture to lend context to issues faced by women accessing maternity services.

Deaf History

Sign language is a visual language and so there is limited recorded historical data about deaf people.

Traditionally, deaf history and deaf stories have been passed down either by the written interpretations of hearing people observing the community or by storytelling from one deaf generation to the next until they could be recorded by photography or videography.[6] There is evidence of a deaf community using a manual alphabet in the writings of Socrates and Plato.[7]

There was a perception that deafness was a curse or a punishment from God meaning deaf people were not allowed to attend church, receive an education, make wills or inherit assets from their families[6] Finally, in 1760, a French monk named Abbé de l'Éppé, believing that deaf children should have access to a religious education, developed a "manual method" of educating deaf children.[8] L'Éppé's methods were a success and deaf children were able to leave school and get jobs as, among other things, doctors, teachers and lawyers.[8] At the same time, in the UK, Thomas Braidwood opened a school which also employed a manual language in combination with English. Braidwood saw comparable successes, with the first Teacher of the Deaf in Britain having been educated at Braidwood's Academy[7]

However, the 18th century also saw the beginnings of a more systematic oppression of the deaf community. Samuel Heinicke, a teacher in Germany, believed that speech formed the basis of intellectual ability and that the use of signing impaired language development.[9] He developed an oral method of education, where children were taught to speak using taste, touch and vibration. Sign language was banned in these classrooms. The debate between oral or manual methods of instruction for deaf children persisted for many years.[9]

In 1880, the International Congress on Deaf Education (ICED) held their second meeting in Milan, Italy. The conference had only one deaf person in attendance and the demonstration of the oral method used children who were deafened – meaning they could already speak before they went deaf (Leigh and Marschark, 2016).[10] The students were prepared by the teachers and the audience members were not allowed to interact with the children. No evidence of the attainment of signing children was presented. Despite these notable flaws, attendees voted in favour of oral only education for deaf children (Leigh and Marschark, 2016). This led to an immediate and widespread ban on sign language in education. It also resulted in the immediate loss of jobs for large numbers of deaf people, in particular, deaf educators.[11]

Deaf adults across the years have reported being tied down to prevent them from using their hands, and years of speech and language therapy that forced them to learn to speak.[12] This resulted in large numbers of children leaving school with little to no functional education beyond being able to make sound.[7] This left them in limbo between a hearing world they could not fully access and a deaf world that they could not fully communicate within.[13]

The ban on sign language in education continued until 1980 but it was not until 2010, that the ICED formally rejected the 1880 resolutions and acknowledged the harm that had been done to generations of the deaf community through its actions.

BSL as a recognised language

The legal recognition of sign languages has been slow to achieve.[14] In the 1960s, an American linguist proved that American Sign Language (ASL) was a fully formed and grammatically sound language, distinct from American English.[15] His work inspired similar research in the UK. However, it was not until 2003 that the UK government recognised BSL as a language. Scotland's British Sign Language Act was introduced in 2015 and, after significant campaigning, the British Sign Language Act was given royal assent in April 2022 and came into force in June 2022.[16] The Act recognises BSL as an official language of England, Wales and Scotland. Work is now ongoing to ensure that the Act gives deaf people their legal right to information in their first, and sometimes only, language.[16]

Deafness as a disability

Following the decisions of the 1880 Milan conference, deaf adults were no longer able to educate deaf children and pass on deaf history or culture.[17] Society saw deafness as a disability and something in need of a cure.[11] Rather than being educated and integrated members of society, deaf people had to conform to the hearing world by speaking and "hearing" via aids and lipreading.[11] The medical model of disability was applied to deaf people. Medicalised discourse romanticises people who are seen to overcome their disability and promotes the idea that everyone should aspire to be "normal".[17], [18] The medical model places a focus on curing or removing the impairment. In the case of deafness, by using cochlear implantation or genetic screening.[19], [20] Disability is seen as personal loss or a tragedy that has befallen the individual.[21]

Conversely, the social model asserts that people had (and have) disability imposed on them by structures that "unnecessarily isolated and excluded [them] from full participation in society".[22] These structures include societal perceptions, building designs or governmental policies.[23] For example, a deaf person missing a train due to a platform change being announced over a tannoy system rather than displayed on the platform screens. In this example, the deafness is not necessarily the issue but rather that the train station did not display the information in an accessible way.

Critics of the social model highlight that it oversimplifies the issue of disability, creates a binary model and links all disabled people together as a homogenous group.[24], 18 It cannot be assumed that people experience the same issue in the same way or that there is overall shared experience of disability.[18], [17],[25] Oliver and Barnes (2012)[21] highlight that it is unrealistic to say that all socially created barriers can be removed thereby resolving all issues for disabled people. Much disability research is now moving away from a binary approach and tries to understand disability through both the medical and social issues unique to an individual.

Deafness as a cultural identity

It is important to recognise that many deaf people do not identify as disabled at all. Many profoundly deaf people may feel part of a cultural and linguistic minority, particularly when they use BSL as their first language.[26] Previous studies have used the term Deaf, with a capital "D", a noun, used to denote a

cultural identity. Deaf with a small "d" was used as a descriptor of hearing status rather than identity. This approach is well recognised in the literature. However, in line with the criticisms of disability models, it is coming under criticism for oversimplifying the complex issue of identity within the deaf community.[27], [28] For example, Davis (1995)[17] argues that someone may be deaf and primarily use BSL but not feel that they are a member of the Deaf community. Alternatively, the hearing Child of a Deaf Adult (CODA) may have been raised with BSL as their first language, be a member of the Deaf community but not have the same issues owing to being able to hear.

In the Deaf community, terms such as "hearing impaired" or "hearing loss" may be considered offensive.[29] Deaf people may argue that they are not impaired, nor did they have any hearing to lose. Despite this, medical literature and national guidelines continue to use the term. This forces deaf people to attend "hearing impaired units" at school or tick "hearing impaired" on health questionnaires.[30] In response to the term "hearing loss", the term "Deaf Gain" was coined in the 1990s. Deaf Gain argues that there are advantages to being deaf that include a shared language and identity, a global community and a different perspective of the world.[31]

More recently, the commercialisation and misrepresentation of sign language in the media and by hearing people for their own gain, has become an important topic in the deaf community. In particular, hearing people with limited signing experience (for example, having learnt level 1, a qualification predominantly focussed on vocabulary rather than grammar or culture) using BSL to promote themselves on social media (SeeHear, 2020)[32] or using "fake" sign language. Further to this, mainstream media frequently use Makaton or Sign Supported English (SSE) interchangeably with BSL (BBC Newsbeat, 2019).[33] Makaton and SSE are both invented communication tools designed to support communication in English, whereas BSL is a naturally occurring and legally recognised language.[34]

The advent of baby sign has also brokered debate in the Deaf community. Baby sign is used by hearing families to improve language acquisition in babies by signing important, key words.[35] This comes after years of the families of deaf children being told that signing will harm language acquisition[12] This has caused frustration in the deaf community, who were denied access to their own language or have been told that their own deafness will lead to language delay in their hearing children[12], [35] While baby sign is actively promoted and encouraged for hearing children, deaf children are still being denied access to sign language.[36] They continue to have their language development assessed in English without recognising acquisition of BSL.[37] Furthermore, the argument persists that parents must choose between oralism or sign language and that a child cannot or should not acquire both[36]

Even within the deaf community, finding consensus is complex and there are many different and even opposing views held. While some groups are calling for bilateral cochlear implants (CIs) to be provided to adults on the NHS,[38] other groups discuss how CIs and other "cures" are a form of ethnic cleansing.[39], [40] Deaf BSL users, who identify as members of a deaf community, argue that, when integrated into the deaf community, they are not disabled, and that rather it is the hearing non-signers who are the ones who are impaired.[41] However, this idea is complicated by the way that accessibility support is provided. For

example, many young deaf adults say they do not identify as disabled but to get support to attend university they must apply for Disabled Student Allowance.[42]

Developing a "deaf identity" is a complex issue. Deaf children born to deaf parents will acquire their culture naturally through a shared language and world view.[12] However, 90% of deaf children are born to hearing parents.[43] A desire to have a shared family identity combined with the increased use of CIs and other aids can lead to deaf children identifying as hearing.[44] Sometimes, when a child is not able to cope in mainstream school, the shift to a deaf unit or even a deaf school can be a shock. Children may feel a sense of grief to find out that they are "deaf" and not "hearing".

Many deaf children do not experience deaf culture until much later in life. In a recent programme about students at Gallaudet University, a deaf university in America, it was clear that there are ongoing issues with young deaf people finding their deaf identity.[45] Students talked about not realising there was a culture that they could be part of until arriving at university. Some students then decided to dispose of their aids and fully join the deaf community. Other students reported feeling a deaf hierarchy predicated on how well you represented being "deaf". For example, deaf signing children with deaf parents were considered "more deaf" than deaf children who used oral methods of communication. They also felt pressure to conform to a fully deaf identity when they felt that using a mixture of communication methods helped them to navigate the hearing and the deaf world.

It is important to recognise that literature by deaf academics has shown a focus on issues of audism,[46] hearing privilege and cultural appropriation since the 1980s. These conversations may put deaf issues more on par with minority culture debates.[47] This means that deaf people may be an oppressed linguistic minority rather than a disability group.[12], [11]

The health of deaf people

Deaf people are less likely to have general knowledge about good health and healthcare systems.[48], [49] This is likely due to the fact that they do not pick up incidental information such as overhearing dinner table conversations and have limited access to interpreted or subtitled media[47], [50], [51] The research that informed the 2014 Sign Health "Sick Of It" report[52] found that the health of the deaf signing population in the UK is poorer compared to the general population despite lower rates of smoking or alcohol consumption.[4] This study found higher rates of misdiagnosis and that deaf people were unwilling or unable to attend their GP as often as they wished due to not having access to adequate communication.[4]

When looking at maternity care, there is limited data about pregnancy outcomes for deaf women. Two American studies looking at the outcomes for deaf signing women found they were more likely to have a caesarean section, or an increased length of hospital stay following vaginal birth[5], [53] One of the studies further found that deaf mothers were more likely to have pregnancy complications such as placental abruption or pre-eclampsia.[5] They were also more likely to have pre-existing hypertension or diabetes.[5]

It appears from these studies that deaf women are more at risk of complex, and potentially traumatic, births that result in longer hospital stays. While it is difficult to apply these finding to the UK population, the Sick Of It report found deaf BSL users, a sample which included women of childbearing age, were more likely to have hypertension or diabetes (Emond et al, 2015), a factor which could be contributing to the poorer outcomes noted.

Deaf women report similar rates of mild to moderate postnatal depression (PND) but are less likely to report severe PND.[54] The researchers suggest that this may be due to not wishing to report PND for fear of being seen as a bad mother or not having access to the resources to report. It may also be because deaf mothers are often part of a community and so have access to culturally sensitive peer support from other women.[55] Research and statistics exploring PND specifically in the deaf community is lacking, but it is notable that rates of mental health issues are reported to be two or three times higher in the deaf community than in the general population.[56] There is little current, up-to-date UK based research exploring the experience of deaf BSL using women accessing maternity services specifically. The challenges faced by both deaf women and the midwives who care for them are unique to the circumstances they face and so other healthcare guidance, while applicable in many scenarios, cannot address all the concerns that deaf women have when pregnant, giving birth or being a mother.

Conclusion

This article has offered a summary of research into deaf history and culture in order to highlight that the deaf community is not a homogenous group for whom a single policy approach will work. Midwives and other maternity care providers should have an understanding of the multifaceted complexities arising from the family a deaf woman is born into, their access to language and education and their healthcare literacy. By doing so, they are better able to work with women and their families to produce individualised care plans, including communication and education needs.

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