

Deaf, Hard of hearing and Deafblind users: from adopting Social Model of Disability to Accessibility, Equality and Inclusion

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Abstract:

Adoption of the Social Model of Disability implies adopting identity first language rather than Medical language e.g. 'disabled person' rather than 'person with a disability'. However individuals remain free to make their own choices regarding how they wish to refer to themselves. Using proper terminology and understanding the diversity of deaf, hard of hearing or deafblind community is a step one to providing access to information, knowledge and reading that enables and supports disabled people to live independently and participate fully and equally in the society. This way the role of libraries as key actors in promoting inclusion and human rights is strengthened.

Keywords: deaf, hard of hearing or deafblind users, identity first language, social model of disability

Introduction

Terminology for appropriately addressing different groups is changing mainly because after some time negative connotations begin to be attached to a certain term and at the same time because language is constantly evolving. It is evident that our attitude towards a certain group of people is already reflected in the name we use to address them. According to this understanding, unequal treatment or discrimination begins already in the name with which, perhaps inadvertently, we initially labeled a person disabled, less valuable, handicapped, who lacks something, and thereby reduced him to his lack instead of experiencing him as a person who has some difficulties, but at the same time has abilities, desires and needs like all of us. The library has a responsibility to remove all barriers that can prevent any person from using the library starting with the usage of proper terminology. It is critical to listen to the language people use about themselves – they know best how they want to be addressed, referred to and described. Respect begins and ends with listening and should be step one in our efforts to truly serve the entire community. Therefore, priority is always given to emphasizing that it is a person in the full meaning of the word, and then only adding the specificity „person” with (disability, impairment, experience of homelessness, etc.). It is extremely difficult for librarians because different expressions are present in everyday speech, media, associations, local and state institutions.

Four models of disability

There are four models to look at disability: the medical model, the social model, the charitable model and the human rights model. The medical model of disability says that disabled people are broken. They are disabled by something that is wrong with their body or mind. Under the medical model, disabled people are in need of a cure to make them like everybody else. The medical model can be useful when treating the symptoms of a disabled person's impairments. However, it focuses on the impairments and diagnoses of an individual, and often misses what the person needs more broadly as a member of society. It can lead to people losing independence.

The social model is an updated way of considering disability. It says that disabled people aren't disabled by their impairments, but by the world around them. It focuses on barriers that prevent disabled people from participating in society in a way that people are disabled by these barriers. Rather than saying that the problem lies with the individual, the social model argues that the problem is that society is not accessible or inclusive. Under the social model, society needs to be more accessible and inclusive to ensure that disabled people can participate just like everyone else.

The charitable or charity model sees disabled people as in need of help and unable to do things themselves, and that charitable people should step in provide that support on disabled people's behalf. This model centers non-disabled people as „doing a good thing“ in helping disabled people, and can undermine autonomy and disability pride. Disability pride can mean being proud of who you are and embracing your disabled identity. It can also mean feeling confident and not hiding your disability.

The human rights model, in affirming that disabled people are inherently deserving of rights, also emphasizes the pride, community and identity that comes from being a disabled person. By understanding that disability is natural and valid, pride in that experience can be fostered. In some way it combines the realities of having a disability and being disabled by an inaccessible society. It then uses a human rights framework to bring about positive change for and by disabled people and with those that support them.

These models are all imperfect, and each only goes so far in explaining complex ideas. All of them will impact disabled people's life at some point. The charitable and medical model of disability are rooted in outdated ideas. They focus on the diagnosis and the idea that disabled people needed to be 'cured' or 'helped'. The social and human rights models of disability are more progressive ways of looking at disability. They are also useful tools to advocate for positive change and equality for disabled people. [1]

Deafness

Deafness or „hearing impairment“ is called „invisible disability“ because it is difficult to determine whether a person is deaf or hard of hearing by observation alone, so most libraries find it difficult to provide services to deaf and hard of hearing people. Deafness, depending on in which period of life it occurred and the degree of impairment, determines and prefers the means of communication. It can occur: prenatal (before birth), perinatal (during childbirth and two weeks after birth) and postnatal (in all periods of life). We distinguish hard of hearing people - people whose remaining hearing is sufficient to acquire a certain level of spoken

language and thus can communicate with spoken language more or less efficiently, and deaf people - people who cannot use hearing for social contacts but rely entirely on visual forms of communication.

Hearing impairment also has a negative impact on vocabulary development, reading and writing. A poor vocabulary results in knowing only one meaning of a word that has multiple meanings. When language skills are weak and vocabulary is limited, reading skills are also poor. Due to the complexity of the reading and writing process, it is not unusual for deaf and hard of hearing students to struggle in this area, so difficulties in reading lead to lower educational achievements. In many countries, the long-term existence of schools for the deaf that were oriented towards vocational training of students contributed to the fact that many deaf people finished their regular education with a weak and extremely basic knowledge of their native (spoken) language, which created a resistance to reading. With the gradual disappearance of vocational schools for the deaf and the introduction of the practice of integration and inclusion of deaf children in regular education from preschool to higher education, there was a need to sensitize society to the communication needs of deaf, hard of hearing and deafblind people and to familiarize these groups with library programs and services. People who have been Deaf since birth or at an earlier age often have difficulties with reading, so they have no need or habit of coming to the library, and therefore often do not even use its services.

Ableism in Deaf culture

As stated The social model emerged in opposition to the medical model which focuses on the idea that disabled people are broken and need fixing because there is something 'wrong' with them and views disability as the limits that restrict participation in society on an equal level due to institutional, environmental and attitudinal barriers. An impairment is the physical, sensory or cognitive difference with which the disabled person lives. It describes a long-term condition that has an impact on daily life. Ableism is a system of discrimination that oppresses disabled people. It assumes a non-disabled 'norm' rather than recognizing and supporting everyone in all our diversity. It manifests in a range of barriers that prevent disabled people from full participation in their communities and workplaces, from living independent lives and from accessing opportunities that non-disabled people take for granted. Ableist language is, unfortunately, widely prevalent in society. It is sometimes that is used intentionally to insult, and other times takes the form of the casual use of negative stereotypes, phrases and assumptions about disabled people. The use of inclusive language is important to all disabled people and the use of discriminatory language not only causes offence, it holds back disability, equality and inclusion and threatens long struggle for equality and rights. [2]

Deaf communities in the world distinguish between the terms Deaf and deaf. Deaf (with a capital „D”) is a political category and many Deaf people view themselves as a linguistic minority. Furthermore, the Deaf community often rejects the term „impairment” as Deafness is part of their culture and not regarded as an impairment, deficit or absence of hearing. As an example, many Deaf people were born deaf so they did not lose hearing and because of that, they dismiss the usage of the phrase „hearing loss”. It is generally accepted in the Deaf community that, when talking about deaf people, the deaf, hard of hearing and deaf mute are also included in that group. In the book *For Hearing People Only: Answers to some of the most commonly asked questions about the deaf community, its culture, and the “deaf reality”* (Moore and Levitan, 2003) Deaf person is defined as a person who is a member of a cultural-linguistic minority, mostly uses sign language, is proud of their deafness, does not consider it a health problem, considers the use of another language to be the only difference between

themselves and the rest of the world. On the other hand, deaf people are defined as people who have a certain percentage of hearing loss, and most often consider deafness as a medical problem. In countries where there is greater awareness of deaf people, a social model prevails, which addresses deaf people positively, highlights their abilities and notes their value in the society.

From a medical point of view deaf people are those who have a “hearing loss” greater than 90 dB, in contrast to hard of hearing people, whose average “hearing loss” is from 20 to 90 dB. Some deaf people use sign language, and some rely on residual hearing or a combination of both. It is derogatory to call a deaf person a deaf-mute person, because deaf people have a preserved speech apparatus and are certainly not mute. In a conversation with deaf people, you will find out that some had the opportunity to attend speech exercises, but some could not. This certainly does not mean that they are mute, but because they cannot hear themselves, they cannot control their voice in the same way as hearing people, so the voices they produce are less understandable or articulated. The Deaf community is extremely heterogeneous, which implies that it includes deaf people who manage their voice extremely well, but also hard of hearing people who have difficulties with articulation too. Some will rely on lip reading, with which it is possible to recognize about 30% of the sounds so lip reading is actually an exhausting guessing game.

Deaf-mute is a term that was used in the past for deaf people who use sign language. In addition to the incorrect name, connecting an element of one language with the medical condition of a certain percentage of the population leads to ambiguities and misinterpretations. Until the linguistic research of American Sign Language (ASL) conducted by Stokoe in the 1960s, sign languages were considered an iconic and simplified representation of spoken language. Stokoe proved that ASL and thus all other sign languages, are a real and natural languages with all language components: phonology, morphology, syntax, semantics, and pragmatics. Today we know that languages appear in two modalities - spoken and signed, which are used equally. It is a reason why it is not necessary to emphasize the articulation of voices when people want to express themselves. Certain part of deaf people does not use voice expression because they use another form of language in which it is not necessary to articulate sounds. Using sign language does not mean that a person is deaf and mute. Vast majority of Deaf people consider the term mute extremely offensive, and the attitude that a person is mute only because they are less understandable. This is considered audism - discrimination on the basis of hearing. It is a form of ableism that often manifests as a belief that hearing people are inherently more intelligent or successful than people who are Deaf or hard of hearing. Another common manifestation of audism is the assumption that those with hearing loss are unhappy or in need of saving.” Audism is the result of audio centricity — the belief that having the ability to hear and communicate verbally is the „norm”. [4]

Visual forms of communication

In everyday situations, deaf and hard of hearing people use various useful skills that partially or entirely rely on sight in order to communicate. Most often they use lip reading lips and facial expressions, writing thoughts/requests on paper or some electronic/mobile devices, apps that convert speech to text or text to speech, manual forms of communication that include manual alphabets (one-handed and two-handed) and sign language.

Lip reading is a skill that deaf and hard of hearing people use in everyday life as an aid to understand, receive information easier and more accurate. Communication through lip reading

is a skill that must be learned and used regularly. It is necessary to know how to speak to a lip reader. Many factors influence successful communication by lip reading: clear and slower speech, not overemphasizing the movements of the lips, inserting pauses after thematic parts, the lighting on the speaker's face, the vocabulary that the deaf person knows, etc. It is much more important who speaks to the deaf person and in what way than the skill of the lip reader.

Writing thoughts/requests on paper or any electronic mobile device is one of the most widespread ways of communication for deaf and hard of hearing. It is an extremely slow way of communication, especially when speed is of a great importance.

Manual alphabets are a way of communication that instead of vocal expression uses the hands to form certain movements, thus forming letters to construct words. The manual alphabet is actually words spelling and therefore represents a slow way of communication. It is often used as an auxiliary tool in communication when it is necessary and important to capture the structure of words precisely (eg neologisms, professional expressions, names, etc.). The number and shape of hand alphabet characters differs in each languages because it depends on the number of letters in the alphabet of a particular language. There are one-handed and two-handed alphabets and two-handed alphabets are less widespread than one-handed manual alphabets.

Sign language is a communication system that represents the primary language of national Deaf and Deafblind communities. It is language completely separate and distinct from spoken language. It contains all the fundamental features of language, with its own rules for pronunciation, word formation, and word order. It combines simultaneous use of hand movements, posture of the body and head, and facial expression. Facial expressions set the tone for the conversation. By learning sign language, one gets to know the Deaf culture, which is completely different from the hearing culture. There is no universal sign language. Different sign languages are used in different countries or regions. For example, British Sign Language (BSL) is a different language from ASL, and Americans who know ASL may not understand BSL.

Deafblindness

From the medical point of view, deafblindness is a specific and unique double sensory impairment in different combinations of intensity: practical deafblindness, deafness and low vision, blindness and hard of hearing, hard of hearing and low vision. On the sociological side, deafblindness is a combined visual and hearing impairment that limits a person's activities and their full inclusion in society to the extent that society's task is to provide special services, environmental adaptations and/or technology. Deafblind people have difficulties in communication, access to information, movement and socialization. As with deaf people, depending on the time of onset of hearing and vision impairment, congenital deafblindness differs, so these people have difficulties in speech and language development, and acquired when that part of the population already has a formed language system. Communication methods also depend on the time of damage and the intensity and combination of damage, therefore deafblind people use sign language adaptations: tactile sign language, located sign language, guided sign language, tactile alphabets (one-handed, two-handed), finger alphabet (writing on the palm). Today's society still knows very little about deafblindness, so prejudices often arise due to wrong assumptions. Deafblind people, in addition to support in

communication provided by an interpreter, also need support in movement and describing the environment, and this support is provided by an intervenor.

Conclusion

Adopting Social model of disability starting with the usage of terminology accepted by disabled people libraries can build a path to Accessibility, Equality and Inclusion. IFLA Guidelines for Accessible Libraries and Services for Everyone are meant to provide basic ideas and strategies on how to make libraries accessible from terminology to human rights-related laws and Universal design. Educating library staff on the wide range of possible users and their needs is the most challenging. From the Deaf users perspective it would be most welcome but not necessary that library staff learns sign language. Rather more important is that they are familiar with terminology, differences in the Deaf/Deafblind community – hard of hearing, deaf, deafblind, ways of communication, myths vs. facts and advices on how to approach and talk. For a deaf, hard of hearing or deafblind person there is no conversation without looking, that's why they will only speak while you are looking at them.

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