

Nebraska Deaf-Blind Project
Fact Sheet #3, March 2005

Deaf-Blind Culture

By

Jamie Pope (McNamara), Director of American Association of Deaf-Blind

Introduction

Deaf-blind culture is a fairly new concept. There has been some documentation on this topic, although not a whole lot. Even within the deaf-blind community there are different perspectives on the existence of deaf-blind culture. I am only one deaf-blind person and do not claim to be an expert in deaf-blind culture for all deaf-blind people. This paper is written from my observations, readings, and experiences. This is not a research paper nor is it all inclusive on deaf-blind culture. The basic purpose is to enlighten the reader in some way on what deafblind culture is so the reader can understand the deaf-blind person whom he/she works with or knows in the holistic cultural sense.

What is Culture?

Everyone is part of a culture. Culture is present in everyday life. We grow up in one culture or adopt all or part of another culture. What exactly is culture? There are two dictionary definitions: 1) the customary beliefs, social forms, and material traits of a racial, religious, or social group (Webster's Ninth New Collegiate Dictionary) and 2) the totality of socially transmitted behavior patterns, arts, beliefs, institutions, and all other products of human work and thought typical of a population or community at a given time (The American Heritage Dictionary of the English Language, Fourth Edition).

We can be born into a culture or adopt the social patterns of a particular culture like Michael Brennan notes in his article, A Tale of Two Cultures: People may be born into a culture. They are brought up according to the values of the culture;

personality and behavior are shaped by those cultural values. Or a person may grow up in one culture and later learn the language, values and practices of a different culture, thus becoming **encultured** into that culture. (1994, p.5)

We are all part of a culture whether by roots, the social and religious groups we belong to, the kind of work we do, the languages we speak and so forth. Some examples of culture include: Spanish culture, Jewish culture, deaf culture, corporate culture to name a few. Culture is where we get our identity and sense of belonging from. Our environment has a major influence in our culture upbringing and inner psychology. (MacDonald, 1989, p. 18).

The Dominant American Culture

We hear about America being a melting pot with many cultures living harmoniously together. Even though there are different cultures in the USA, there is a dominant set of behaviors and beliefs that make up American culture.

Theresa B. Smith (1997) gives examples of the dominant American life as speed, individualism, top down thinking, majority rule, and difference as a liability (p. 21).

It would be good to elaborate on each of these examples because that will be where many of our American culture upbringings come from.

Speed in America means getting things done fast, getting to places fast, processing information and speaking fast, living on the fast track, doing multitasks at the same time, beating the clock to save time, etc.

Individualism

focuses on the individual's goals, plans, and achievements done independently with little or no support from other people. We are encouraged to do our own thing by ourselves without much involvement from other people in our lives. Top down thinking looks at what is cost-effective and efficient for the whole group or organization, often making rules and policies that don't work for everyone.

Majority rule is where the most number of people decide what is best. It overcomes other differing perspectives in the minority. Difference as a liability

does not recognize individual differences to an extent where the majority are concerned. If one dresses or behaves differently or is not like most people, this

is viewed as a liability, a problem, a handicap, etc.

Since these are a dominant set of behaviors, not everyone does all these behaviors all the time. It is important to understand how one's attitudes and behavior is influenced by the dominant American culture. This awareness helps us to appreciate the differences in other cultures, especially deaf-blind culture.

Deaf Culture and Blind Culture

Deaf culture and blind culture should be mentioned briefly here because they each are part of the smaller deaf-blind culture, especially when deaf-blind people originally identified themselves as deaf or blind before losing their hearing or vision.

Deaf culture is the culture of deaf people with American Sign Language (ASL) as their native language. They have their own rules of social interactions including how introductions are made (school, family affiliation before names), attentiongetting (waving, flashing lights), leave-taking (hugging, loss of eye contact, waving bye), and communicating on the TTY, a teletypewriter telephone, and through the internet instant messages/email (abbreviated words, not picky about spelling and punctuation, keeping conversations short). They value getting together with other deaf people who use ASL and often have socials at deaf clubs, deaf sporting events, and events at schools for the deaf.

Blind culture is less well known with their emphasis on touch (Braille), hearing (speech communication and orientation to their environment), and mobility (white canes and guide dogs). The blind community tends not to separate themselves from the larger culture. They speak the same language and participate in social events of the majority culture they live in. They do have their own organizations and sporting/social events at schools for the blind, but don't emphasize their

4

culture heritage as much as the deaf do.

The Diversity of the Deaf-Blind Community

Deaf-blindness is unique. This uniqueness gives deaf-blind people their identity, pride, and characteristics which are the foundation of culture. Deaf-blindness involves the loss of vision and hearing senses which have ramifications on

communication, access to information, educational and employment experiences.

The deaf-blind community is much more diversified than just race, ethnicity, age, etc. Let's take a closer look at this unique diversity.

The diversity in the deaf-blind community can cover multitude of variables. The degree of hearing and vision loss is one. Some are hard of hearing and blind, others are deaf and visually impaired, still others are totally deaf-blind. Then there's age of onset. Some become deaf-blind before or after birth, others were born deaf and lose vision later, and still others lose vision as a child then hearing as an adult. The causes of deaf-blindness can be just as diverse. Specific syndromes cause deaf-blindness like Usher and CHARGE syndrome, while others get it from prematurely, injuries, and diseases like high fever, meningitis, etc.

How much a person can see and hear, as well as when the deaf-blindness occurs, is a major influence on communication and language skills which makes the deafblind community even more diversified. For example, a person with Usher Syndrome 1 is born deaf and loses peripheral vision later in life. That person will probably use American Sign Language as their first language and have written English as second language. Later, when vision loss progresses, the signing moves from visual to tactile. A person with Usher Syndrome II is born hard of hearing and loses both vision and more hearing later in life. That person would most likely use residual hearing with hearing aids or assistive listening devices. It is not until more hearing is lost that they consider learning sign language visually until more vision is lost transfer to tactile sign language.

5

It is amazing with the diversity in degrees, types, causes, age of onset of vision/hearing loss as well as language and communication within the deaf-blind community that deaf-blind people stick together and have a community. Imagine those born deaf and those whose language is non-signing English trying to communicate! The similar experiences and frustrations with not being able to hear and see well that limits independence bonds people in the deaf-blind community much more. It is empowering to know one is not alone in his/her struggles with deaf-blindness. Knowing other people with the same hearing/vision loss gives a great sense of support and comradie even if they don't communicate the same way. Language is an aspect of culture, but for the

deaf-blind community, the very nature of its diversity in communication modes constitutes a culture even though there is not one particular language or communication mode used by deaf-blind people.

Why Deaf-Blind Culture?

Just as the deaf community takes pride in their deaf culture, it is the same for the deaf-blind community to be proud of deaf-blind culture. Deaf-blind culture enables deaf-blind people to be proud of who they are, their skills and accomplishments despite living with limited vision and hearing. It is empowering to embrace their deaf-blindness and go on with life, jobs, family, etc. as everybody else. This is opposite of the medical model which looks at deafblindness as a problem that may or may not be fixed rather than looking at the whole person and his/her life. Medical models often come across as pitying and focus on inabilities of deaf-blind people. The key here is the attitude. With deaf-blind culture, the attitude is "I'm deaf-blind, so what. I can still enjoy my life and not let my disability limit me."

We get self esteem by feeling accepted by others. The deaf-blind community provides a place for acceptance and nurturance of self-esteem because the

6

community embraces the social characteristics that make up deaf-blind culture. As a result, identity as a deaf-blind person is developed and nurtured. We don't feel like we're the only person in the world with both hearing and vision loss and don't feel like we're disabled because we are with people who accept us and do not focus on our incapacabilities too much. This is so empowering for deaf-blind people who live far from or do not know of other deaf-blind folks.

Within the deaf-blind community, there are role models who show acceptance of deaf-blind culture. This is especially important to deaf-blind teens and young adults, and those who were just diagnosed with deaf-blindness. These people may have fears and questions living a successful life with deaf-blindness. They also may be getting negative or pitying vibes from people in their world about their inability to lead productive lives. Deaf-blind adults who embrace deaf-blind culture show deaf-blindness can be overcome and accepted as part of life. They model successful strategies to handle various situations, advocate for themselves, and get services or new technology to increase their access to

information and the community.

Aspects of Deaf-Blind Culture

Going back to the definition on culture, the best one that fits the deaf-blind community is pertaining to a ♦social group♦. The deaf-blind community does not embrace one religion or one ethnicity; however, their unique characteristics and behaviors from deaf-blindness warrant it a social group in the culture sense.

There are major aspects of the deaf-blind community that the behaviors and characteristics can be categorized by: touch, communication, time, and social.

We♦ll look at these in-depth.

Touch Touch is the lifeblood for deaf-blind people. It connects them to their world when both ♦information-gathering♦ senses through hearing and vision are

7

not functioning optimally. Deaf-blind people rely on touch to get their information for a variety of reasons. This can be for communication like reading Braille and using tactile sign language; for sensory input like vibrating alert system for doorbell and telephone, feeling the size/shape of objects, and applauding by pounding the table or stamping the floor to send vibrations; and for orientation like bumping into people and things for help with direction. Dancing, slow dance and chain dancing, are favorite activities of deaf-blind people. They can feel their partner♦s movements in slow dancing and copying the dancing steps in chain dancing. At American Association of the Deaf-Blind biennial conferences, there is almost always a dance every night!

Communication Deaf-blindness can be isolating and it♦s no wonder communication is a high value of deaf-blind people. Usually communication is done one-on-one or small groups for deaf-blind people to get direct communication. Interpreters and Support Service Providers (SSPs) are used frequently by deaf-blind people. Also, with the explosion of technology advances in communication, the internet is a boon for deaf-blind people. All the information, news, shopping, and friends are at their fingertips. Plus, they can communicate with many different people through email and instant messages. This is wonderful for deaf-blind people because it takes away barriers in needing someone to help with communication and getting to places. Imagine talking with

four different people in four different conversations on instant messages when you can't do that in person, much less a deaf-blind person! Also, deaf-blind people are known to help interpret for one another if there's no interpreter available. A person with Ushers may help interpret for a person with close vision or one person who uses tactile sign language receives information in left hand and simultaneously pass it on to another deaf-blind person using tactile too thru his/her right hand. It is mind boggling, but shows the beauty of the deaf-blind community pulling together for another for they know how it feels to be alone.

8

Time Have you heard the expression, "deaf-blind time"? It is an idiom to mean it takes a little more time for deaf-blind people but interestingly enough it happens to hearing and deaf people as well when they are late. Earlier speed was mentioned as part of the dominant American culture. Obviously, speed is not part of deaf-blind culture. It takes more time to communicate especially tactilely, more time to read Braille, more time for the deaf-blind person to move around, etc. Also, deaf-blind people need frequent breaks when using interpreters in a long meeting or workshop. They work hard to process information through limited hearing and vision or through a communication method that is still tedious for them to absorb large amounts of information without breaks. Everyone benefits from breaks; however, with deaf-blind people it is a necessity.

Social Socializing comes in very close to communication. Humans are social creatures, including deaf-blind people. Since the normal channels to get information is limited or entirely cut off, it is gratifying for deaf-blind folks to be in contact with others to get social needs met. Hugging to say hello and/or goodbye is common in the deaf-blind community, especially when they don't meet friends very often. It was said that on the last day at an annual camp for deaf-blind people across the USA, goodbyes take three hours because the deafblind campers want to say goodbye to each person individually at the camp! This underscores the value deaf-blind people put on communicating one-on-one and that it takes a little extra time than people with normal vision and hearing.

Also, during introductions, it is common for deaf-blind people to ask personal questions right away like, "where is the person from," "where they went to

school, where they work, what kind of hearing and vision loss. This is especially true if this is a new deaf-blind person they just met. This is similar to how deaf people have introductions; they want to find association with the new person immediately.

9

Since deaf-blind people communicate one-on-one for the most part, interruptions are bound to happen and may cause culture conflicts. For example, a deaf-blind person conversing in depth with a person who is not deaf-blind may not get the background information if suddenly the hearing/sighted person has to leave in the middle of the deep conversation. The hearing sighted person heard someone calling his/her name, informs the deaf-blind person he/she will be back in a few minutes to continue the conversation. Because this happened without warning and they were deep in conversation, the deaf-blind person would feel lost for awhile. Usually people wait to interrupt deaf-blind people when their conversation dies down, and not in the middle of a hot discussion. With people who are not deaf-blind, interruptions happen all the time and it is easy to pick up. Some deaf-blind folks, especially those communicating through tactile, find it difficult to resume the thread of the conversation when interruptions happen frequently.

Cultural Institutions

As with any culture, deaf-blind culture needs places where it is nurtured in community where deaf-blind people congregate. With deaf people, it is well known that deaf clubs and school for the deaf maintain deaf culture. For deafblind people, there are informal social or support groups, and formal local/state organizations of, for, and by deaf-blind people in almost every state. On the national level, American Association of the Deaf-Blind has biennial national conferences where hundreds of deaf-blind people across the United States come together for networking, support, education, and fun. Helen Keller National Center and Seattle Lighthouse for the Blind are two other places where a large number of deaf-blind people learn skills to enable them to live independent lives. Where a large number of deaf-blind people meet regularly to support one another and socialize, deaf-blind culture thrives.

Identifying with Deaf-Blind Culture

Of course, not every deaf-blind individual believes there is a deaf-blind culture. Some look at culture more strictly, especially the language requirement. Others, like me, look at the big picture of the deaf-blind community being a unique social group. Whatever the deaf-blind person believes in and identifies with is their choice and should be respected.

There are ways to tell if a person is a believer in deaf-blind culture. Those individuals that identify themselves as deaf-blind, are proud to put the deafblind before the person as in deaf-blind person rather than a person who is deafblind. Identifying oneself with deaf-blind culture means acceptance and pride with the use of the term deaf-blind.

Also, how a person describes themselves with the deaf-blind term will give a clue about their acceptance of deaf-blind culture. All the words used to describe deafblindness such as deaf/blind, deafblind, blind-deaf, blind/deaf, and deaf-blind are all acceptable. However, for culture identity, deaf-blind is the term most deafblind people prefer. This was determined through a survey of the deaf-blind membership of the American Association of the Deaf-Blind.

Since culture and its positive implications (self-esteem, pride, role models) does not occur outside of a community, it is important for deaf-blind people to meet each other regularly for support and socializing. Deaf-blind people from all walks of life would benefit so much from meeting one another. Sometimes this is difficult when they live far from each other and do not have accessible transportation. The benefits from meeting regularly to celebrate their uniqueness is so important that it will motivate people to find ways to overcome barriers to meet each other.

Young teens who have vision and hearing loss would also benefit from joining

the deaf-blind community. Sometimes it can be overwhelming for a new deafblind person to meet so many deaf-blind people at the same time. One idea to

help with the assimilation into the deaf-blind community and culture is to find one deaf-blind adult who can be a mentor to the young deaf-blind teen and ease the way into feeling more comfortable in the deaf-blind community.

For Additional Information Contact: Teresa Coonts, Project Coordinator
Nebraska Deaf-Blind Project

NDE @ ESU#3

6949 South 110th St.

Omaha, NE 68128

PH: 402-595-1810; Fax: 402-597-4811

Email: tcoonts@esu3.org ; Web: www.nedbp.org