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Nebraska Deaf-Blind Project

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Deaf-Blind Culture

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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;

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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

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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 �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

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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.

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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 �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

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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 incapabilities 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

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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.

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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.

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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.

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Identifying with Deaf-Blind Culture

Of course, not every deaf-blind individual believes there�s 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

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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.

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