

# DEAFBLIND PEOPLE AND SELF-IDENTITY

– an interview survey



By Ilene Miner

and

Information Center for Acquired Deafblindness

2008





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### Content

Foreword .....	5
<b>1: BACKGROUND.....</b>	<b>6</b>
Purpose and questions .....	6
The process .....	8
Services available to deafblind people in Denmark and in the US – an overview.....	9
Securing services in different communities .....	13
<b>2: RESULTS.....</b>	<b>15</b>
Reactions to diagnosis and process starting .....	15
A new identity added or an old one reconstructed.....	18
Rights and services make the difference – and the identity .....	20
<b>References .....</b>	<b>21</b>



## Foreword

This paper has to start with thanks and gratitude to the deafblind people in Denmark and the US who were so kind as to share their lives with me. Also thanks to Ole E. Mortensen, the Director of the Information Center for Acquired Deafblindness in Denmark (1). In discussion with him, ideas and questions have been considered for this project. Lis Just, also from the Information Center for Acquired Deafblindness, offered valuable help by interpreting between my spoken English and spoken Danish, by setting up interviews, and by giving input to this paper. Riinette Askgaard very competently interpreted from spoken Danish and English to Danish Sign Language and tactile Danish Sign Language.

*Ilene Miner*

Ilene Miner is the Director of a mental health out patient program serving deaf, deafblind, and hard of hearing people in New York City.



# 1: BACKGROUND

## Purpose and questions

### Starting point

In the fall of 2007 I read two articles that caught my interest concerning deafblind identity and how deafblind people think of themselves. Both articles were from Britain: One asked the question: “Is there a deafblind culture in the UK?” by Susannah Barnett (2).

Deafblind people were interviewed by email and had a variety of diagnoses. The conclusion was that there was no deafblind culture in the UK because there was no community. The ten people interviewed had no regular contact with other deafblind people. Only one had any regular contact with others who are deafblind and only three had ever met anyone else who is deafblind. We do not know if the author met the subjects in person or attended any gathering of deafblind people. This meant that she identified interpreters and guides as outsiders and didn't see these roles as part of the culture. Although she allowed that they could be part of the culture, she did not see them as participating in it.

The other article was about a multi-country (France, Ireland, Italy, Spain, UK, Germany) lifestyle interview of 67 people with Usher syndrome, called *Maintaining Independence, A report on the CAUSE Usher Lifestyle Survey* (3).

The survey asked a question on identity by submitting a list of ways people could identify themselves. This list did not include the word “deafblind” because it was stated in the appendix that this term was thought to be negative. Therefore “deafblind” was not offered as a choice, removing the opportunity for any person to even choose this as an option.

### On culture and identity

I wanted to take this further and pursue the following questions: How do people who are deafblind or who have both hearing and vision loss

describe or think of themselves? What does it mean to call oneself deafblind?

I have heard deafblind people identify themselves in many ways over many years: deaf-visually impaired, hard of hearing-visually impaired, Deaf-Usher, hard of hearing-retinitis pigmentosa, Deaf-glaucoma, hard of hearing-glaucoma, blind-hard of hearing, visually impaired-hard of hearing, deafblind, blind-Deaf, etc. The list is as long as there are diagnoses.

Whether or not people call themselves “deafblind” when asked, is this dependent on degree of vision and hearing loss or language use? Who calls themselves deafblind as an identity?

Who uses this term to self-identify and describe themselves – and not just as a description of diagnosis or as a label that society has given them?

The United Nations Educational, Scientific and Cultural Organization (Unesco), from the work of Raymond Williams (2002), described culture as follows:

“... culture should be regarded as the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and ... it encompasses, in addition to art and literature, lifestyles, ways of living together, value systems, traditions and beliefs.” (4)

Theresa Smith, PhD, a cultural anthropologist and master interpreter, who is writing a book about identity, states:

“Identity is ... always about relationships. One's identity is defined or determined by the situations and by the relationship of the people within those



situations". (From a not yet published manuscript.)

Is deafblind part of what we call identity, a secure persistent sense of self? And which possible factors influence the choices of self-identity? Does it relate to belonging to a larger group, a group that might be considered to have its own culture and values? For instance, can one have an identity as a deafblind person in the absence of a deafblind community?

One wonders whether or not people who are deafblind and living in a place where there is a community of deafblind people are more likely to call themselves deafblind as a primary identity or additional identity when compared to people living where access to a deafblind community is not available.

#### **The US and Denmark – different services and views on disability**

People who have acquired deafblindness did not begin their lives as deafblind. They have been

sighted and hearing, or hard of hearing and sighted, or vision impaired and hearing, or any of the other possible combinations. How and when did they start to self-identify as deafblind? And how does that process happen?

The signature issues of deafblindness are isolation and difficulty of access to other people and society. Is the process of self-identification as deafblind similar or different in two countries that have differing views of disability issues and differing kinds of services and access? Because of these different views, different solutions or non-solutions have been developed to provide access to other people and to the fruits of society. Denmark and the US have widely differing approaches to the provision of routine services to people with disabilities and therefore to the opportunity for self-determination and dignity.

A decision was made to interview deafblind people in both Denmark and the US to get some answers.



## The process

Deafblind people in Denmark and the US were interviewed and asked about their lives and experiences and about their self-identification.

The sample was *not* random. The Danish people interviewed were selected by the Information Center for Acquired Deafblindness based on a request to Fddb, the Danish Association for the Deafblind. They were asked to help find members who would be willing to participate, covering as wide a spectrum as possible with regards to age, communication, diagnosis, involvement in the association, etc.

The Americans were a selection of people known to this writer from a variety of settings, mostly, but not exclusively, in New York City.

### The cohorts

27 people were interviewed, 14 in Denmark and 13 in the US. Of the total in both countries, 16 were women and 11 were men. 19 people have Usher syndrome: 9 have Usher 1, 8 have Usher 2, and 2 have documented Usher 3. The remaining people have other conditions, such as Refsum's Syndrome, retinopathy of prematurity with later onset of hearing loss, or later hearing loss and vision loss due to illness and accident.

The Danish Group consisted of 7 sign language users, 3 of whom use tactile sign language. The American Group consisted of 7 sign language users, 5 of whom use tactile sign language.

There were, of course, varieties of language use including tactile Pidgin Sign English, two women use both American Sign Language and spoken language depending on whom they are with, and there were those who depend entirely on spoken language and hearing.

Age range in the Danish group was 23 – 67 years of age. Age range in the American group was 29 – 80 years of age.

### Interviews

Interviews in Denmark were conducted by Ilene Miner with a Danish-English spoken language interpreter or a Danish Sign Language interpreter who is also experienced in tactile Danish Sign Language and in spoken English. All interviews were in person.

Most interviews in the US were conducted by Ilene Miner in person in spoken English or in American Sign Language. Three of the American interviews were conducted by email with people whose first language is English, and one interview was conducted with a deafblind person with Usher who communicates in tactile American Sign Language but who is also fluent in English.

The interviews were 1-1,5 hours in length.

### Content of the interviews

The method was to collect a range of information on:

- age and gender
- communication method
- past and current work situations
- living circumstances
- family constellation
- concerns about their lives
- psychosocial information
- information about the use of services in each country
- contact with other deafblind people and involvement in deafblind associations, and
- issues of identity

Questions were also asked about services in Denmark that have no widely established equivalent in the US such as contact persons, deafblind consultants, and ERFA groups.

First, a presentation of the set up of services available to deafblind people in Denmark and in the US.



## Services available to deafblind people in Denmark and in the US – an overview

The issue for people with disabilities is *access*. Equalizing access will yield productive people. That is the philosophy in the Nordic countries.

“Disability is not seen as a characteristic of the person, but rather of the situation. It is the relationship between persons and their surroundings in a given context that is characterized by the word ‘disability’. ... Thus the word ‘disability’ must be understood both relationally and in context of the circumstances. This means that rather than focusing on a person’s functional impairment, the focus may be on how the situation can be compensated in a manner that, ideally, can equalize the disabled person with others.” (5)

The attitude in the Nordic countries is that access must be provided to all. This philosophy, in practice, results in the law mandating the provision of contact persons. The services are supported by the government, and they are a right, not a gift. The services allow deafblind people to direct their own lives, to be independent and self sufficient.

While the Nordic attitude on disability, access and equality is a common one amongst people with disabilities and those who work with them, it is not the attitude of the government in the US.

### **Services in Denmark**

Among the services available for deafblind people in Denmark, the following four categories are virtually unknown in the US:

- Deafblind consultants
- Contact persons
- ERFA groups
- Social interpreting

### **Deafblind consultants**

Everyone in Denmark who experiences problems due to a combined vision and hearing loss is assigned to a deafblind consultant. This person is an advocate, a counselor, who coordinates services and troubleshoots when things go wrong. Deafblind consultants provide counseling directly to the deafblind person on factors relating to the vision and hearing loss, counseling on the support provided for in social legislation, counseling on technical aids and referral to the regional hearing and vision rehabilitation programs, information about the contact person service and, if relevant, assistance with and applying for a contact person to the local social service authority, referral to relevant education such as mobility and daily living skills, information about existing possibilities for the group of deafblind persons such as participating in the deafblind organization's peer groups. Deafblind consultants also have the responsibility for providing continuous supervision and training for contact persons. (6)

### **Contact persons**

The service of contact persons is stipulated by the Danish Social Legislation. The contact person visits and communicates with the deafblind person, acts as a link to the environment, provides information about the daily news (through newspapers, television, etc.), assists with translating letters, bills, sorting and archiving papers and mail, etc., guides and describes the environment when going shopping, visiting friends and family, going to the bank, post office, etc., guides the deafblind person to and during leisure activities, courses, meetings, vacation travel, etc. (6)

Most deafblind people have between 10 and 25 hours a week of contact person hours. One of the people interviewed had 50 hours of service a week and several had 35 hours of service a week. One man worked with the same contact person for 16 years. There are, of course, problems when contact persons accept other jobs or the deafblind person moves. But the service remains, allowing people to leave their homes for



work or for fun, for meetings, for educational activities, shopping, or just reading the mail.

### **ERFA groups**

“ERFA” is an abbreviation of the Danish word for “experience” (“erfaring”). ERFA groups meet monthly and are organized by the Danish Deafblind Association. They are both political and experiential so that members can discuss their frustrations and successes and teach each other. Here also political positions or actions are planned around issues affecting the entire deafblind community. Many people attend with their contact person, who waits and does not participate. Sign language interpreters are present for groups of sign language users. There are ERFA groups for sign language users and groups for spoken language users. Every deafblind person is offered an opportunity to join an ERFA group, although not every person participates in one.

### **Social interpreting**

An issue for deaf people growing up in hearing families is communication, and particularly communication in groups. In a Danish pilot program, people attending family functions or social events can have an interpreter. This is to avoid the familiar experience of isolation which people report when they attend an event and they have no idea of what is going on. This, too, is a covered service. There is no cost to the deafblind person.

(Note: The social interpreting service was temporarily discontinued in April 2008 because all funds had been used. The service received an additional grant in May 2008 and is now, at the time of writing, running again, though at a lower level. Work is in progress to secure a solution for the continuation of the social interpreting service.)

### **FDDB – The Danish Association for the Deaf-Blind**

FDDB meets regularly and is run equally by those who are culturally Deaf and those who are hard of hearing. FDDB plans events, parties, retreats, and camps, but also competes for money to develop programs. 12 deafblind people have trained to become FDDB consultants. FDDB consultants are mentors who go into the community to meet newly diagnosed deafblind people. They are available to deafblind people in addition to their regular deafblind consultants. FDDB is funded by lottery grants among other

sources.

### **Mental Health services**

In Denmark there are a few psychologists who provide services to deaf and deafblind people and there is an inpatient psychiatric unit that has 4-7 beds available with staff members who know sign language. Some psychologists can see deaf and deafblind people with an interpreter. A few psychologists know sign language themselves and can see deafblind clients without an interpreter. One receives services by asking for a referral from one's primary care physician. Services are provided when there is a crisis, illness or death, or other upsets in life, and they are generally available for 10-12 sessions. If more sessions are needed, application must be made to the municipality.

### **Hearing and Vision Rehabilitation**

Deafblind persons have access to the services from the regional system of vision and hearing rehabilitation and counseling. Instruction is provided in vision related topics such as daily living skills, mobility, etc., as well as in topics related to hearing such as communication and instruction in use of hearing aid. This system also has specialist competence on technical aids for vision and hearing.

The instruction is adapted to the individual needs and wishes of the deafblind (and vision and hearing impaired) persons. The instruction takes place in the regional vision centers and hearing institutes. In the Danish social legislation it is stipulated that a specific effort is to be made for adults with a physical or mental impairment to prevent the individual's problems from becoming worse and to maximize the individual's functioning and potential for development.

### **Services in the US**

#### **Commissions on the Blind**

Every state has specialized services to people who are legally blind. In New York State this is the Commission on the Blind and Visually Handicapped (CBVH). These state groups provide the funds for services like rehabilitation training and equipment, generally equipment that will enhance a person's ability to obtain and hold employment. Therefore there is no provision in many states, for example, to provide a computer with Braille output for someone who is



not going to be working. If people move between states, they may be asked to return the equipment. The counselor from the Commission has a narrower focus than the deafblind consultant in Denmark because the emphasis is on employment. Deafblind people find their cases are opened for services and then closed; if further services are needed, a new application is made. If a deafblind person wishes to go to the Helen Keller National Center, it is the State Commission on the Blind that provides the funds. Some states now prefer to keep their students closer to home.

At this moment one of the interviewees is fighting to have her case re-opened for equipment needs and mobility services. The request at first was denied. In another situation, a different interviewee requested a CCTV which he can use for reading, but the request is denied because he will not be working.

#### **Helen Keller National Center**

The Helen Keller National Center (HKNC) is a center based on New York's Long Island about 25 miles from the heart of Manhattan. HKNC provides rehabilitation services to deafblind people from around the entire country. Students come from around the US to learn a variety of skills to enhance independence and vocational choices in their home states. Some of these skills include orientation and mobility, Braille instruction, independent living skills, and a vocational experience while they are at the Center but which does not always translate into a competitive job at home. From their annual report for 2005-2006 92 students went to the center, only 22 of whom had vocational goals, and at the end, 6 students were working at competitive jobs. Seven additional students did not complete the program, but it is not known if these students were vocationally oriented (7).

#### **Helen Keller Community Service Program for New York City area in concert with the NYS Commission on the Blind**

The Community Service Program (CSP) provides rehabilitation, vocational, and support services to eligible persons who are deafblind, in their homes, work sites and communities. During the fiscal year 2006, CSP served 56 deafblind individuals delivering a variety of services including: rehabilitation assessment, rehabilitation teaching, orientation and mobility training, and casework services (7). The program does not

include Support and Service Providers (SSP) services.

#### **Helen Keller regional representatives**

While the Helen Keller National Center (HKNC) in New York has regional representatives working around the United States, they do not work for the government or municipality; they are employed by HKNC. Not every deafblind person has contact with Helen Keller National Center. While there is some similarity to the Danish deafblind consultants the Helen Keller regional representatives are more narrowly focused. They do not have an ongoing counseling role with deafblind clients, except periodically. They also can consult to local authorities and schools, if asked. They can make recommendations and troubleshoot and refer clients to the National Center, but the impact is more limited in terms of securing services, which are paid for by each state. They do not have a legal mandate to make sure services are in place. Each regional representative covers several states. In 2005-2006, the ten regional representatives met with 1554 deafblind people (7).

#### **Support Services Providers**

The Support Services Providers' (SSP) role is similar to the role of the contact person in Denmark. Cities like Seattle in Washington State, Minneapolis, Minnesota and Boston, Massachusetts, have well established SSP programs wherein deafblind people have the services of an SSP for several hours a week. Some SSP programs rely on volunteers and some are paid. Being an SSP often is not a job by which one can support oneself; it is not a full time job unless an agency hires the SSP to work for several clients.

There are 17 established programs around the country serving anywhere between 8 and 55 deafblind people with SSP services from one hour a week to 20 hours a week. Most offer about 3 hours a week. (8) These are funded by a combination of funding sources including grants, city and state governments.

Few states or municipalities have SSP programs, and there is none for the US at large. There is no SSP program in New York City or Long Island where the Helen Keller National Center is based, despite New York City being only 20 miles away from the Center. Helen Keller National Center only provides SSP services



to their own students. There is no legal right to have an SSP in the US comparable to having a contact person.

#### **American Association of the Deafblind**

American Association of the Deafblind (AADB) is a national consumer organization of, by, and for deafblind Americans and their supporters. "Deafblind" includes all types and degrees of dual vision and hearing loss. The membership consists of deafblind people from diverse backgrounds, as well as family members, professionals, interpreters, and other interested supporters. AADB receives funding from grants, membership fees, and tax-deductible donations. AADB's mission is to ensure that all deafblind persons achieve their maximum potential through increased independence, productivity, and integration into the community". (9)

Currently, because of financial constraints, there has not been enough money to support a national conference in two years, and none is planned before 2011. Historically, deafblind people have to pay for transportation to and from the conference, a conference fee, and all their own expenses while at the conference; SSPs pay for their own transportation but eat and sleep without charge. However, they are not paid for their services and attend as volunteers. The costs are prohibitive for many people, and there is no overall government or public support for conferences, although individual groups within states or municipalities may provide some support.

#### **Mental Health services**

Deafblind people can see mental health counselors at their own request if they have some sort of health insurance, either private or public, and if they can find a program that has counselors who know sign language. Theoretically under the Americans with Disabilities Act, they should be able to secure services in any mental health program that would then secure the services of a sign language interpreter. In reality, this does not happen much.

While a city like New York has both non-profit and private programs serving deafblind, deaf, and hard of hearing people, many states and cities have no mental health services that are accessible to deaf and deafblind people.

#### **In summary**

Just by reviewing the ability of deafblind people to participate in activities and in the world at large, one can see that the lives of deafblind people in the US and Denmark are very different. For instance, in the US services are not a guaranteed right under the law. Some communities, like Seattle Washington, more approach the services in Denmark, than, for example, New York City. There is no established system of ERFA groups and no system of social interpreting in the US. Setting up groups is prohibitively expensive because there is no way for interpreters to be paid.



## Securing services in different communities

### Securing Services – the US

In the US services and contact with other deafblind people were often delayed because there is no systematic way in which these are initiated; the people who took part in the interviews experienced that they had to find the services and initiate contact on their own. This is especially true for those who were hard of hearing. Ophthalmologists are required to report legal blindness to the state services for the blind, but the reality is that this often does not happen. Two of the Americans interviewed in this project were only referred to the Commission on the Blind when I contacted their ophthalmologists and requested they file the reports. This was 10-15 years after the diagnosis of legal blindness! Until they are registered as blind, they have no contact with or access to any support services. In both of these situations, there was substantial anxiety and depression about what was happening until these contacts were established.

Once contact is made with the Commission on the Blind, deafblind people can receive mobility instruction, education related to their deafblindness, low vision services, and vocational services. But they still might not find out anything about deafblind groups or communities, other deafblind people, or even the Helen Keller National Center's regional representatives until their vision loss is very significant or they find out information on their own.

In the US, seven adults, long diagnosed with Usher 2 or 3 or other conditions, still have no regular contact with anyone else with Usher. None of these people self-identifies as deafblind.

In the US community of culturally Deaf people many know those with Usher syndrome, so there is the possibility of exposure and contact with others. It may not be regular contact depending on where they live and whether or not there are SSP (Support Services Providers) services available. Many people with Usher 2 and 3 (i.e. who are not culturally Deaf) don't have contact with others who have Usher. There are three places to meet. These are the conventions of the American Association of Deafblind which currently doesn't have money to mount a convention,

deafblind camps held in some places around the country, such as Seattle, and State deafblind associations of which only 17 are listed on the AADB website. (9)

In the US therefore, some states offer more opportunity for deafblind people to be with each other than other states.

In select places in the US there are deafblind communities, but New York City is not one of them, although there is a current attempt underway now to have some organized social activities. There is no support system, there are no contact persons, no ERFA groups; there is isolation. People do well when they still have a lot of vision and travel independently, but when both vision and hearing are gone, there is no organized system of SSPs to contribute to independence. There is no place to go to, no community of welcoming others. Even though Helen Keller National Center has SSP services for its students, this SSP service does not extend the 20 miles to the center of New York City.

### Securing Services – Denmark

Those people with acquired deafblindness in Denmark who were interviewed lose as much emotionally and concretely in their lives as their counterparts in the US, but they have so much more to move toward, at least when compared to New York City.

In Denmark deafblind consultants contact the person immediately upon referral. Deafblind people from FDDB reach out, contact person services are secured, people join ERFA groups and suddenly there is the possibility of regular exposure to deafblind people, activities, social events, meetings and the ability to travel. It is important to note that every deafblind person receives this kind of contact whether or not they later decide to use a particular service. They feel welcomed and have a place to go, the beginnings of a new identity, and role models to move toward. These all provide access to life, to involvement in the political life of deafblind people working to secure services.



The deafblind people interviewed repeatedly mentioned the importance of their deafblind consultant in their lives. “When I don’t understand things, I ask my deafblind consultant.” “If I have a problem with my contact person, I talk to my deafblind consultant.” If I need services or need hearing or vision attention, I ask my deafblind consultant.” “When I had some court papers to attend to, my deafblind consultant helped me sort them out.”

The most common statement is that it is only the deafblind consultant who understands the complexity of vision and hearing loss, who can communicate easily, and also understands the laws and the rules for securing services. This role is crucial, and is viewed as providing continuity of appropriate services.

In the US most services come through programs for the blind who may not understand the issues of hearing loss and its impact on a person with vision impairment. The crucial role of a deafblind consultant eases the way in a multitude of situations and it is utterly dependable.

Because of having a contact person, people interviewed in Denmark can participate in the lives of others who are deaf, hard of hearing, visually impaired, and deafblind, and they can participate in the hearing-sighted world as well. Among the cohort, some taught Danish Sign Language in a variety of settings, taught in an interpreting program, were involved with FDDB, went into schools to teach about deafblindness, and were co-leaders of monthly ERFA group meetings.

Deafblind people in Denmark can also participate in the hearing world activities by taking classes, attending religious services or local meetings, because they have access to contact persons and social interpreting. (As mentioned earlier, this program is under change.)



## 2: RESULTS

### Reactions to diagnosis and process starting

#### **Denmark – predominant self-identification as deafblind**

Of the 14 people interviewed in Denmark, 11 of them self-identify as deafblind. This includes people who are both sign language users and spoken language users. A number also identifies as culturally Deaf, either as an equal identity or secondary to the deafblind identification. Three people do not identify as deafblind: one self-identifies as blind and hard of hearing, one as “I have a number of disabilities”, and one as hard of hearing with vision impairment.

Identifying oneself as deafblind seems to be well connected to participation with other deafblind people. All of those who self-identify as deafblind are active in FDDDB (The Danish Association of the DeafBlind) and participate in ERFA groups. Eleven of the 14 people use the services of a contact person; of the three who do not use a contact person, one is involved with a rehabilitation center for the blind; one is a person with Usher who still has a lot of vision, and one said, “I use my spouse for now but probably should apply for some contact person hours”.

#### **US – little if any self-identification as deafblind**

Of the US group of 13 people, 2 self-identify as deafblind, considering deafblind to be a kind of identity. The ones who do identify as deafblind have contact with other deafblind people. Three others identify as deafblind only to describe their disability: For example, “I only identify myself as deafblind when describing my disability and accommodation needs, for example for an airplane flight”. Two people live in housing where other deafblind people live but only one of them identifies as deafblind. However, even in this housing, there are mostly deaf people and there is no sense of a deafblind community.

In fact, none of the American deafblind people interviewed lives in a place with a strong deafblind community, so there is less opportunity to socialize with others or participate in community events; there are none in New York City, although there has been an attempt to start a deafblind association. Answers might well have been different in a place like Seattle, Washington, where there are more services available similar to services in Denmark and where there is a deafblind community.

#### **Starting point – time of diagnosis**

All the deafblind people were very open and willing to talk about themselves, their lives and the issues that affected them and continue to impact their lives. They were very open about their struggles, including their struggles with depression. They also discussed positive aspects of their lives.

Despite the different environment, many of those interviewed followed a similar internal process although their self-identification might be different as time went on.

When looking at how people start to define themselves as deafblind, it is important to look at the time of diagnosis, because at that moment no one self-identified as deafblind. The time of diagnosis is the starting point, although people may have suspected problems before diagnosis.

A variety of issues that were raised related to the definitive problem of vision loss in both countries. The examples below are from both cohorts and are virtually interchangeable. It was a poignant realization to review the interviews and see that deafblind people from two countries who had no contact with each other had such similar thoughts and feelings.



### **The importance of other deafblind people**

How do people start to think of themselves as deafblind? Of course, this is a process. As people in both countries spoke about their losses and their depressions, they referred to the importance of other deafblind people in pulling them out of their depression.

Many people spoke of initial meetings with deafblind people, even before they were involved with FDDB (The Danish Association of the DeafBlind) or had a deafblind consultant in Denmark or were involved with the AADB (American Association of the Deafblind) and the deafblind activities in the US, and many said: "I didn't think that I was like them". But when their own lives were impacted by their vision and hearing loss, they did make contact with others.

A woman in Denmark contacted a resource and said: "Remember you told me about deafblind people some time ago? Well, now I am one and I need information". In general, people who are culturally Deaf had some knowledge at least of the existence of others with hearing and vision loss, even if they didn't socialize with any of them. There are always people with Usher syndrome in the Deaf Community.

It is different for people who are hard of hearing and then lose vision because they often don't know anyone else who is hard of hearing, much less who also has a vision impairment. "All my friends are hearing and have good vision", said both a woman in Denmark and a woman in New York.

### **Denial and reaching out**

Those interviewed mentioned the suspicion that something was wrong for a long time prior to di-

### **Marginalized from friends and community**

The interviewees describe shame about their vision loss, significant depression and self-isolation for a year, drinking to excess, tremendous anxiety, suicidal ideation, fears of the future for themselves and for their families.

As vision loss progresses, deafblind people report losing friends. Culturally Deaf people who use sign language in both countries report losing friends because tactile communication was difficult and time-consuming and they felt marginalized from the Deaf Community.

agnosis, and they mentioned the shock of diagnosis coupled with the relief of finally knowing.

There were two groups of responses to diagnoses: One group responded immediately to the news, perhaps because these were already symptomatic and having problems at work and in social life. They started reaching out and making changes in their lives.

The other group found out the diagnosis and then did not follow through on any recommendations made by medical providers. One American and one Dane both mentioned that they continued to drive, for example, till several car accidents forced them finally to confront what was happening.

### **Giving up the expected life**

People were very open in their responses about their process and talked about "having a nervous breakdown" or resorting to alcohol as an escape, getting into bed for a year with significant depression, and having fears of the future.

There were concerns about what would happen to their families, what would happen to work and their ability to earn a living. Some people had already lost jobs because they couldn't see well even before their diagnosis. At least one person whose relative had been diagnosed with Usher put off going to an eye doctor despite having problems. The reason for delay was the expected significant repercussions for work and education that would ensue once a diagnosis was definite.

People lost jobs, had to give up their goal of pursuing a particular career, had to leave their educational setting and embark on a different path. They had to give up their expected life. Some of those interviewed knew of others who were deafblind or knew others themselves, and they spoke about the importance of these contacts.

### **Issues of loss**

People with acquired deafblindness experience losses, both large and small, both concrete and abstract – losses of work, of friends, of education, of family relationships and roles, activities, of security, loss of their place in the world and community, and loss of who they thought they were, their identity, their expected life, and a future they had imagined.



People in both countries reported losses of friends and changes in family roles, loss of vocation and shame about not being able to do what they used to do to provide for themselves and for their families. Everyone who ever drove missed driving and the independence it brought, and reported not liking to be dependent on others. Parenting roles were impacted and there were concerns about the impact on their children of having a deafblind parent. Deafblind people had to give up careers and dreams of careers, had to leave school or work. Some lost partners who thought dealing with a deafblind person would just be too much to handle.

In short, they had to give up the lives they expected and hoped to live, and as seen by their reactions of depression, alcohol abuse, and anxiety, they did not know where to turn.

#### **Impact on mental health: depression and anxiety**

People cannot imagine a life they have never been exposed to. Without exposure and without contacts, and without a mental image of what their lives can be, people with deteriorating vision and hearing are, of course, in a fragile and vulnerable position. There is no context for their diagnosis of deafblindness, no ability to master the situation and no ability to problem solve because they have not yet been exposed to anyone with their problem or learned about the possible solutions. They cannot learn what they have to learn because they don't yet even know the questions to ask. They cannot find meaning in this diagnosis, and may feel utterly bereft and adrift. To have this diagnosis without information, without contacts and without context is truly frightening, and accounts for some of the reactions of significant depression and withdrawal from others.

Some of the people in NYC sought mental health services for dealing with their uncertain futures and lack of long-term supports. Anxiety and depression were not related to a new diagnosis but were a response as vision and hearing diminished. When I facilitated a weekly group of people with Usher 1 some years ago, three of seven members had attempted suicide in the past. Two of the current NY group had significant suicide attempts.

In Denmark fewer people sought mental health services, although depression and anxiety were reported, both in the past and in the present. Some people used antidepressant medication for some time, and felt they could go back to their physician to discuss re-emergence of depression or anxiety. But few people were seen in long term psychotherapy, probably because they were not so isolated. As one woman with Usher 1 said:

“If you have a contact person, you don't need a psychologist”.

It would be interesting to look at rates of depression and anxiety in these populations, and how this correlates with available services.

#### **From loss to loss all over again**

Vision and hearing loss can involve an ongoing process of change and deterioration, especially for those with Usher, who may adapt to one loss and then find that the losses start all over again with visual deterioration.

In Denmark two people mentioned that they considered asking their physician for medication again because of stress, anxiety, and depression, and two considered asking to see a psychologist. In the NY group four were receiving psychotherapy and some were using antidepressant medication.



## A new identity added or an old one reconstructed

### Process available in a deafblind community

There is no doubt that one cannot self-identify as deafblind without the contact and context of other deafblind people. One can describe one's disability as in "I am deafblind" as an explanation of one's problem or needs, but this is not a deafblind identity. This is different from saying: "I belong to this group and we ascribe to certain norms, values, and ways of behaving".

Several people spoke of the importance of the impact of other deafblind people on their lives. In both countries, deafblind people described feeling "normal with other deafblind people", "feeling relieved when meeting others early on to see that deafblind people could lead regular lives, and a feeling of 'coming home'".

An American psychologist with Usher 2, Wendy Williams, writes about the identities of deafblind people and exploring the deafblind community leading to a new identity added to one's sense of self. (10)

"Because of a need for a sense of belonging and being a part of a group, some people may decide to explore the deafblind community. ... This exposure may validate one's being and experiences and may normalize life. ... There may come a perception of oneself as a capable human being who cannot hear and see well and / or an identity as a unique individual with deafblindness. ...

Some people may discard their previous identity and become deafblind. Other individuals may maintain their initial identity. Still others may fluctuate between their primary / secondary heritage and the deafblind identity."

This is a wonderful description of a process available in a place where there is a deafblind community to go to, explore, receive validation, and in which to be welcomed.

### Danish interviewees – "I am deafblind"

All of the interviewed people who participate in ERFA groups and Fddb identify themselves as deafblind, while the three who do not participate in ERFA groups and Fddb do not self-identify as deafblind. Nearly everyone had the services of a contact person. One man had the same contact person for 16 years! Their sense of identity could not grow in the absence of a community.

When asked to describe their identities and communities, deafblind people in Denmark mostly responded "I am deafblind". Both sign language users and spoken language users described themselves as deafblind. Some added that they were also Deaf, and one woman with Usher 2 said she sees herself as hard of hearing and sighted.

Again, they described the difficulties of trying to hold on to their previous identity in quite poignant terms: "I will hold on to the Deaf World as long as possible".

They described issues with using tactile sign language slowing down communication. They also talked about losing Deaf friends and how painful that was. Everyone spoke of all kinds of losses and of the importance of Fddb and ERFA groups in their lives, deafblind consultants, and, of course, the importance of contact persons in keeping them connected to the world.

People said:

"Contact persons are very much a part of us and can translate or repeat when I miss things."

"I would be alone in total darkness without my contact person."

"Before there were contact persons, I was afraid and lonely."

"If one has a contact person, psychological problems are lessened. If deaf-



blind people can get out of the house, they don't need psychologists."

"With my contact person and my deafblind consultant I have a productive life."

One woman spoke about the transition from one identity to another as a deafblind person and said:

"The first time I said 'I am deafblind', it was very hard, but now I have formed strong relationships within Fddb. I get a lot of support from Fddb, which is why I am training to become an Fddb consultant. I want to give back to the organization".

Another interviewee described the deafblind world as being a place where people are more open about problems, more frank about issues and more willing to talk about their feelings, adding that deaf people do talk about feelings but they hold back at the same time.

A woman described deafblind culture as very different from hearing-sighted culture.

"We care about each other, one person talks at a time, we are aware of each other's needs, we check on communication, we don't pass judgment, there is a lot of touch, and a strong sense of belongingness, and among each other we don't have to explain ourselves. It's hard to be deafblind; it can be exhausting because you have to use so many resources just to communicate, and hearing people just don't understand."

#### **American interviewees – "I am Deaf with a vision problem" or...**

The Americans present a different picture. Again, these Americans were mostly New York-

ers, and those in other parts of the country where there are deafblind communities and services may present a very different picture, one closer to the responses of Denmark.

Those people interviewed with Usher 2 and 3 do not socialize with any others with Usher and only identify as deafblind if there were no other choices available, although they might meet at an RP (Retinitis Pigmentosa) convention. They identify as deafblind to make their need for accommodations known. Several people had no services and didn't know there were any services to be had, despite being legally blind for years, and they didn't know others with Usher or who were deafblind. One woman with Usher 2 or 3 who had a cochlear implant said: "Now I feel myself to be blind-hearing".

Several people who grew up in the Deaf Community with Usher 1 and other deafblind conditions and use tactile American Sign Language quite adamantly self-identify as Deaf with a vision problem, and never as deafblind. This includes people who use dog guides and canes to travel. Only two people in the whole group self-identified as deafblind.

There are rare social meetings in New York, and they are rare because there are no SSP services which would make them possible. Attempts to form social groups have been made but they have not been successful. An attempt is once again underway. Some people visit Helen Keller National Center on occasion but there is no sense of community that carries back to NYC.

Again, these are the responses of interviewees from New York. For instance, no one from Seattle was interviewed but with their active community one would hypothesize that responses would be quite different than the answers of New Yorkers.



## Rights and services make the difference – and the identity

### Comparison of two communities with different rights

Although this comparison is of deafblind people from two countries, it seems that self-identification is more related to having a community to move toward, with service availability and access to the world, than to the country of origin. This project has thus become a comparison of two communities with different rights to a variety of services. The project may also be seen to make a statement about how two governments provide for people with disabilities.

In Denmark many more services and opportunities are available for regular contact with other deafblind people than are available in the US, at least in New York City. However, many Danish deafblind people do not participate in ERFA groups and FDDB, although it is offered to all. Therefore one might speculate that answers about identity from a non-involved group of deafblind people in Denmark might more closely match the New York City group. One might also speculate that a group of deafblind people from, for example, Seattle, Washington, might answer more like the Danish cohort.

What makes the situation so different in the US and Denmark is that the Danish government support for services, as a right, as a given. While there are problems, such as having enough contact person hours, the service is written into the law; it is a right. The ERFA group is a long established tradition, now being used by deafblind people. Because of these rights and services people identify as deafblind; it is an important part of who they are. There is no law guaranteeing these kinds of activity in the US, although there are 17 SSP programs around the country. Without a right to SSP services, people cannot come together to form a community. People in the US therefore have no access and do not identify as deafblind because they are not part of a community of deafblind people.

The two countries are very different in size, population, attitude and services. Denmark has 5,5 million people; New York City alone has more than 8 million people. Programs in the US have to be administered locally; the country is

just too big. But the establishment of SSP programs could be legislated. That hasn't happened, except on a limited basis.

### Deafblind culture and community

There is no doubt though that in Denmark where people have a variety of options for being with people and being involved in a community and they exercise those options, they can develop an identity that says "Yes, I am deafblind". They describe being very involved in a community of people who belong to the deafblind association, attend camps and events, help other deafblind people who are recently diagnosed, attend ERFA group meetings biweekly or once a month. They use the services of a contact person, which allow them to be active and direct their own lives, as a right. This is a service available to all in Denmark.

The identification as deafblind did *not* depend on degree of hearing loss and vision loss. People who self-identified as deafblind have Usher syndrome, Type 1 (ie. they are profoundly deaf and use sign language), Usher syndrome, Type 2 (ie. they are hard of hearing), and other different kinds of acquired deafblindness. The common thread is that they all belong to FDDB, attend ERFA groups, participate in the life of the deafblind community and use the services of contact persons.

The Danish interviewees report taking care of each other and attending to communication because that is what deafblind people do. One woman said, "...at meetings of FDDB, it doesn't matter if we use sign language or spoken language, we are all together."

The services provided in Denmark allow people to be with each other and have a community. And when there is access to a vibrant community, people feel a sense of belongingness and identify with it. They feel themselves to be deafblind.



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