

**ALDAcon2017**  
**Hearing Loss: A Global Condition**  
**Gerard de Vijlder and Georgia van der Gen**  
**October 13, 2017**

**GERARD DE VIJLDER:**

Today, Georgia and I will share information about sudden deafness in Europe. We have visited you before, in 2011 and 2013, to gather tips for organizing our own convention to celebrate our foundation's 25<sup>th</sup> anniversary in 2014. It was attended by sudden and late deafened people from throughout Europe – Denmark, Belgium, Norway, and Estonia, to name a few. Even five ALDAnS came from America. We would like to zoom in on a few countries first, then present facts from research performed by the European Federation. Organizations for hard of hearing and sudden and/or late deafened adults are part of this federation.

In England, there is a group for sudden and/or late deafened adults that meets annually for a national convention. Smaller groups meet locally. The main group sets policy and is made up of volunteers. Most of the members use speech-to-text and sign language. Of the sudden and/or late deafened in England, 120,000 have cochlear implants.

Belgium does not have a national organization, but the region of Ghent has a group that meets to exchange information about hearing aids, cochlear implants, and the latest technologies. There are about 30 people in the group. They communicate mainly through lip reading; hardly anyone signs. When they meet, they use speech-to-text. Belgium contains about 10,000 sudden and/or late deafened people and about 2,000 have cochlear implants.

Norway has no special organization for sudden and/or late deafened people. There is an "umbrella organization" for the hearing impaired, with a section for those with sudden onset hearing loss. This group holds summer camps every two years. Other gatherings usually are handled by the umbrella organization. They communicate through sign and speech-to-text. The cost of interpreters is covered by the country's social system. Norway has about 4500 sudden and/or late deafened people of which 2,000 have implants.

Denmark also has no special organization for sudden and/or late deafened people, but there is a special committee devoted to them. They gather in small groups several times during the year and once a year on a national level for a discussion of communication and social topics. There are around 300 interpreters and speech-to-text transcriptionists available. Denmark has an estimated 8,000 deafened people of which 2,150 have cochlear implants.

In January of this year, the European Federation for the Hard of Hearing (EFHOH) led an investigation into the experiences of this specific group of people within Europe. EFHOH represents over 52 million people with hearing loss. It strives for equal rights.

Its members are hearing impaired, including those with tinnitus, hyperacusis, cochlear implants, and Meniere's disease.

In 2013, EFHOH set up a task force to look into the European situation concerning hard of hearing and sudden and/or late deafened people. The main goal was to look into the lives of these people in different countries. (Questioning centered on whether they have the same problems, what is the government policy, and does a social plan exist.) Questions focused on whether individuals shared common problems; what government policies existed; and whether social plans were in place. In 2014, a survey was created and put online during 2016; it was concluded this past February. Responses came from 334 persons in 21 countries. Most respondents were from England, Denmark, Estonia, France, Germany, Finland, Greece and Sweden. Some of the EFHOH research showed that when 37 percent of the respondents were diagnosed as deafened, they received no treatment at all.

You will notice in the slide that over 60 percent of those who became sudden and/or late deafened became depressed or experienced anxiety. Only 28 percent of those were offered support. And, as with most of you, the most frustrating element was listed as communication with friends and family.

In the area of employment and education, only 21 percent had access to speech-to-text captioning. For 67 percent, the response was "not available."

A surprising response was that 44.6 percent stayed with their current job without support. Equally surprising was the 23 percent that had no difficulty finding another job.

This next slide shows what methods of communication people use. It lists hearing aids as the most used and cochlear implants at 47 per cent. Speech-to-text stands at 44 percent while lip reading registers at 61.5. Very few, about 13.3 percent, use sign supported speech with lip reading. A bare one percent use a mouth/hand method. Finger spelling is used by only 8.2 percent, but is used a lot in England. Unspecified "other means" were reported by 10.3 percent, and 13.8 percent responded that they still found it very difficult to communicate.

Last, but not least, we would like to tell you some things about the Dutch deaf and hard of hearing, and about the foundation.

There are an estimated 10,000 sudden and/or late deafened people in The Netherlands. About 60 to 70 become sudden deafened every year. Approximately 6,000 have cochlear implants.

The Netherlands has legislation that takes care of facilitating accommodation needs, such as speech-to-text and sign language interpreters. Each deafened person has the right to 30 hours of either in private domain situations. For working or educational purposes, a person must apply and the government will decide whether to grant assistance and for how many hours. People have free choice regarding the interpreter.

The Foundation of Sudden and/or Late-Deafened has over 500 members. We meet several times a year on an international level. We have weekend activities every weekend with a different theme for each one. Besides the national gatherings, we have five regional divisions that organize their own activities. On average, there are three activities every month. Our signing choir, with which people with various types of impairments sign along, is very successful. There are 38 women and four men and they travel all over the country.

**AUDIENCE MEMBER:**

I have a question about when people come together from different countries in Europe, all speak different languages. Is one universal sign language, like ASL, used?

**GEORGIA van der GEN:**

We all use our own language. Wherever a language is born, it's a natural language just as spoken language is. Every country has its own sign language.

**AUDIENCE MEMBER:**

Do you have the equivalent of the ADA in Europe? Is there a movement to do that?

**GEORGIA van der GEN:**

Just recently. In 2016, the United Nations acquired a ratification of a policy that in all of Europe, everything should be accessible to people with disabilities.

**AUDIENCE MEMBER:**

It appears that an awful lot of people in Europe rely on lip reading to a considerable extent, just like here in America. It seems that lip reading might be more difficult in some languages as opposed to others. Are you aware of any research on that?

**GEORGIA van der GEN:**

I don't know of any official research. I can tell you from my own experience that depending on the country you are in, you might be able to lip read if you know the native language. I know for a fact that English is very hard to lip read for foreigners because they keep a stiff upper lip.

**AUDIENCE MEMBER:**

I guess it's just cultural. I find French impossible to lip read because it seems to me that they don't move their mouth at all. But I suppose if you were born in France, it would be easy.

**AUDIENCE MEMBER:**

I speak Spanish and I find it easier to read than English, unless it's too fast. Anything too fast is harder to read.

**AUDIENCE MEMBER:**

Have you seen a deafened experience in the United States that you would like to see copied in Europe?

**GEORGIA van der GEN:**

That would be accessibility. In The Netherlands, we have a right to an interpreter but here, if you go to a museum, it is responsible for providing the interpreter. It is ethics, I think. It says something to society. So, we would like to bring that to Europe.

**AUDIENCE MEMBER:**

For those 37% you mentioned who were not treated when their hearing loss was diagnosed, why not?

**GEORGIA van der GEN:**

There were many different reasons, but not everyone stated a reason, so we do not know why not. One reason was lack of services.

**AUDIENCE MEMBER:**

If we were going to visit a country in Europe, how would we get an interpreter or captioning? Where would we go?

**GEORGIA van der GEN:**

Preferably, people bring their own interpreters. You would have access to captioning through the Internet.

**GERARD DE VIJLDER:**

Thank you, thank you so much.

**Gerard de Vijlder** lives in the Netherlands. He became deafened in 1975. In 1989, he co-founded the Stichting Plotsdoven Foundation for Sudden- and Late-deafened Adults in the Netherlands. He still gives a lot of time and energy to the group, serving as vice-president of its board. In 2014, he was honored with knighthood for his level of service.

**Georgia van der Gen** works as a sign language interpreter. She was born in America and lived here into her young adult years. This allows her to interpret for deaf people who travel abroad and thus experience the differences in attitude and opportunities for deaf people in several countries across the globe.