



## NEWS

### **Vuxendövas Nordiska Råd (VDNR) Nordic Council of Deafened Adults**

*By Linda Drattell*

A path with a raised white line for people who are blind leads from the Hoje Taastrup train station to the Danish House of Disabled People's Organizations (Handicaporganisationernes Hus). We are in a suburb of Copenhagen. The Handicaporganisationernes Hus is a circular building with walls curved inward as if they have been pinched into an asterisk of sorts, rounded edges on the outside and meeting together in the middle. The pinched sides have been designed as wings, each one a different color for the simplicity of finding a particular office. Each wing has its own designated safe space: a fireproof stairwell/elevator that has its own ventilation system and electricity in the event of a disaster. Lights blink slowly so as not to affect those who have epilepsy. This is a building that has been built on the philosophy of equal opportunity accessibility through universal design, and whose designers have learned from the designs of other buildings around the world and from the lessons of 9/11. This is the venue of the VDNR Nordic Council of Deafened People' annual meeting and seminar.

The VDNR Nordic deafened communities held their annual meeting on May 20, 2016 and the seminar on May 21. The purpose of the May 20 meeting was to discuss projects and share information pertaining to those who are late-deafened and hard of hearing in the Scandinavian countries: Denmark, Sweden, Norway, Finland, and Estonia. Saturday's seminar was organized by topic, such as the psychosocial impacts of becoming late-deafened, political perspectives in Denmark, inclusion in society, etc.

VDNR has two members/representatives/delegates from Nordic countries. They are encouraging Latvia, Estonia, Iceland, and the Faroe Islands to join VDNR (it is questionable whether the latter two will join, since their populations are so small that there are few deafened people). Two Estonian guests came this year and provided a report at the annual meeting. Two additional deputies to the Finnish delegates also attended, one of whom was Liisa Sammalpenger, a fellow ALDA member and member of ALDA's international committee.

Liisa had invited me to attend the May 21 seminar, since I was living just under two hours' flight time away in London. I was looking forward to attending it and learning from others, but I was in for a surprise.

I arrived in Hoje Taastrup, a suburb of Copenhagen, on Friday afternoon, May 20, and began receiving messages from Liisa and from the chair of the VDNR, Trine Gaarsdahl, asking when I would be coming to the meeting that day. Instead of just attending Saturday's seminar as I had expected, I was informed that the VDNR would like me to share information about ALDA, DCARA, my new organization BEADHH, and local advocacy efforts at their Friday meeting. I hurried over and was told that I would have 15 minutes to speak. As it turned out, the meeting ran over time and I was asked if I would mind presenting for 15 minutes on Saturday instead—they would find a place in their schedule to add me. Given that I had no expectation to present at all, I was perfectly fine with this. Sure, I said. I especially enjoy sharing what I love about ALDA.

On Saturday morning, at

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breakfast, I was informed that the opening speaker was sick. Would I mind presenting for the hour she was to have spoken, opening the seminar? A bit rattled, I said that was fine, but what would they like for me to talk about? I was told to speak about myself and the topics they mentioned earlier. A full hour? Oh, my.

I started peppering people with questions during breakfast, which they took to be small talk, until they noticed I was jotting down notes on a piece of folded paper. An interpreter/captioner (I'll explain momentarily) asked me if I wanted to follow the conversation or just work on my speech. I was genuinely embarrassed, but explained that if I were to give a speech I would need to know what was of interest to everyone. I put the paper away.

The Norwegian speaker I replaced had planned to speak about the psychological consequences of hearing loss. I was not a specialist in clinical psychology like her, but I did know firsthand the psychological consequences of hearing loss! I was also told that the audience did not expect statistics but were interested in how ALDA, DCARA, BEADHH and local advocacy efforts worked. I explained how we help each other cope and thrive in ALDA. I opened the seminar with a discussion about what it was like to become deafened (stages of grief, feeling isolated, relationships challenged), and how ALDA, with its philosophy of "Lost my hearing, found a family" and its motto of "Whatever works!" rise to meet the needs of those who are deafened.

I shared information about the Cinemark Theatres lawsuit and settlement, in which ALDA was the organizational plaintiff. I shared stories about ALDAcon—how precious newcomers are to us and how we creatively find ways to include them. I told them about ALDA's karaoke night, use of balloons to communicate the rhythm, line dancing, workshops, and using whatever modes of communication work for each individual attendee. I shared ALDA's philosophy of humor, as in our stories for the *ALDA News*. I explained how ALDA started and how captioning began as ALDA Crude. When I finished my presentation, Liisa joined me and gave a presentation about ALDAcon in Arizona last year.

After the presentation, two audience members said that they were inspired by ALDA's use of humor. I had a lot of fun talking about ALDA and enjoyed sharing

the ALDA moments I cherish. ALDA is my favorite subject! I was told after my presentation that it was obvious I had given this speech several times, but I said no, I just loved talking about ALDA. I didn't need to rehearse.

Seminar presenters included Aida Regel Poulsen, Secretary of the European Federation of the Hard of Hearing, who gave an informative speech, providing data about the percentage of deaf/late-deafened/hard of hearing/deaf-blind people in the UK (15.6%) and in Denmark (16%). These figures are comparable to the United States estimates (15%). Aida also reported that while deafened people are included in equality planning by various laws, in practice they are excluded due to lack of proactive planning, emphasis on "reasonable adjustment," and lack of confidence in those needing accessibility. This, too, resonates with what we experience here in the States, where we repeatedly see a lack of accessibility despite the fact that we have moved from, as Aida put it, being "objects of charity" to individuals with human rights.

Other speakers talked about bilateral cochlear implants, training and employability of deafened people, whether work areas should be made accessible, lack of accessibility in government meeting locations, and the greater need for automated speech-to-text and its difficulties in processing dialects.

Strategies were also discussed, such as the Norwegian Hard of Hearing (HLF) focal points at the policy, community, and corporate levels. Decision-makers generally depend on success stories from the media, which create an illusion that being hard of hearing or deaf is not so bad, or that cochlear implants are a miracle cure. As a result much-needed supports are not provided.

How did we understand each other? Here's the fascinating thing about interpreters in the Nordic countries: an interpreter is trained to provide sign language interpreting (whether it is Danish, Finnish, Swedish, or Norwegian Sign Language), but can also take an additional year of training to type on a QWERTY keyboard for captioning (speech-to-text) on the spot or as you go—also in these languages and in English, whatever is preferred. English and German are taught in each of these countries as second languages.\* Some interpreters are only trained to caption.

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One of Liisa's interpreters was trained both in sign language and captioning, but others present were trained just to caption or sign. Liisa's interpreters captioned in English when I was present, for which I was very grateful.

by over-the-shoulder straps so that the interpreter can type while standing and the captions are readable as we walk around. For a large meeting, such as the seminar, a large screen is used.

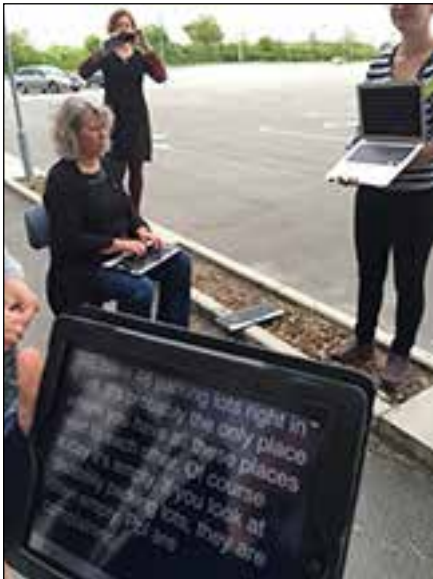
The captioning effort tended to be slow and there were mistakes, but this might have been because more than one person was speaking; more than one language was being used, such as Danish and Finnish, with both being interpreted into English for the captions; or the



Interpreters with portable captioning.



Pair of interpreters.



Portable captioning.

The keyboard is carried around along with a screen such as that of a tablet (even your smartphone will do) and can be propped up anywhere to facilitate conversations or presentations, such as on the table in the restaurant. For a guided tour, or while standing in groups, the interpreter balances the keyboard and tablet on a makeshift pad that is held in place against the abdomen



Linda presenting.

limitations of using a QWERTY keyboard. Or all three. Regardless, having the captions in this portable way enabled conversations that would have been impossible to have otherwise. One exception was the captioning of the seminar and Friday meeting into Swedish by two brothers, one of who would translate and speak the words in Swedish through a makeshift tube into his brother's ear, who then typed the captions in Swedish. I was told that the dual effort by the brothers ensured Swedish captions that were live, with minimal mistakes.

What was I most impressed with at the seminar? First was the interpreter/captioning role, in which the interpreter becomes a captioner

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as the situation warrants, and the fact that captioning could be mobile, using a portable keyboard and tablet.

Second was the government support of interpreters/captioners in Nordic countries. In Finland, the government pays for unlimited communication access in the workplace and other situations such as attending a seminar, volunteering, and participating in social events. Two interpreters/captioners flew to Denmark with Liisa, their expenses paid for by the Finnish government. In Sweden, you have to have documented costs and argue to get this kind of support; communication access is based on fixed employment or seeking a job in order to qualify for 20 hours of interpretation services per week. But this support is still provided by the government. In some instances in Sweden, the employer agreed to pay for the communication access. In Denmark, the situation seems to be better, but the various Danish municipalities offer different levels of support. Still, Trine Gaarsdahl mentioned that in Denmark she has unlimited hours of interpreting at her place of business.

And third, I was impressed with the Handicaporganisationernes Hus itself—from the holes in the plywood barriers to make them see-through and the naturally lit rooms that emphasize the use of daylight and open space, this is a place where all can find the greatest accessibility. Jesper Boesen, the owner and consultant of No Barriers Advice, was heavily involved in the construction of this accessible building and provided a tour. The challenge faced in its design was to provide for all disability groups in the same building. Compromises had to be made so it is not optimized for one particular group, yet it is one of the most—if not the most—accessible office buildings in the world. The reason for its success is that the designers and architects listened to all the disability organizations to make the right compromises and solutions.

The organizations, for their part, focused on articulating their demands and needs, not on the solutions themselves. Jesper emphasized that it is not always easy to agree on solutions, but it is easier to agree on needs. So the architects were provided with the problems to solve and they solved them. Additionally, it was not enough to say that each group wanted accessibility. For example, a ramp may be the ideal image of mobility access, but if you need to make a detour or take the back route to get to it then it isn't right to think of the ramp

as accessible. Therefore, in the design of this building, accessibility had to be equated with equal opportunity. To help the engineers gain insight, they were put into wheelchairs, wore goggles that gave them tunnel vision, wore earplugs and were blindfolded. Then they were taken 200 meters away from the meeting facility and were told to get back into the room. As a result, everything from the fire escape to parking spots was designed to provide equal opportunity, openness, and respect. And it was built at a cost that was a little less than the cost of an average office building.

I want to thank Liisa for inviting me to the VDNR seminar. It is always wonderful to share information and to see how others create solutions for the accessibility issues that face us all.

\* Some of the spoken and written languages are similar and can be understood by the users of each. There are different sign languages in the Nordic countries, and interpreters do not know the signs of the neighboring ones. Swedish and Finnish signs are approximately 50% the same because they have had the same base since the 1800s. Swedish is the second official language in Finland, as Finland was previously East Sweden until 1809, and those from Finland tend to use Swedish when speaking with people from other Nordic countries. This was the second time the VDNR seminar was held in English in order to be accessible to other Europeans; last year, it was held in English in Estonia. Two years ago, the seminar was in Finland, using Finnish and Swedish. Before this, it was only open to the Council members.

*Linda is a former president of ALDA and worked as community relations director and hard of hearing support specialist for DCARA. She served as an advocate in obtaining communication access in BART trains and stations and in her successful settlement with Cinemark Theatres and AMC Theaters for movie captioning. Linda received ALDA's I. King Jordan Award, the Hearing Loss Association of California's Outstanding Service Award, and DCARA's Employee of the Year Award. Contact her at [lindra@comcast.net](mailto:lindra@comcast.net).*

