

ISAAC2014

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MY LIFE SO FAR- LET'S HEAR IT FROM ELINA!

Dear listeners

In the beginning of my presentation I would like to clarify that I am mentioning brand names for the sole purpose of providing clarity and examples. These are my experiences and no one should draw conclusions from endorsement or criticism of my use of brand names in this speech.

My name is Elina Ino. I am twenty-two years old. I live in Helsinki, Finland on my own with my assistance dog Jopo in an apartment with 24/7 possibility for assistance. My family consists of my parents, sister, half-brother, nephew who is still a baby and my dog Jopo. I went to a Ruskeasuo, a state owned special school for my primary education which took twelve years and then to Jarvenpaa Training Center. I graduated this spring but I still have the student exam to pass. Well, I can take the exam again when I'm a grandmother if it still bothers me then.

When I was a child I used to go to the candy store even without any functional communication system. I still got the candy I wanted. I have always been able to make myself understood, with out without AAC. I can not recall any occasion where I was not able to make myself heard. My sister was the best to interpret my messages and gestures. I guess I thought that I am speaking *through* my sister. But when I saw someone with a speech generating device, I knew I wanted one, too.

When I think back, I do not miss any of the old methods I used to have.

In kindergarten I had a communication book with Bliss symbols, if my memory serves me right. I had letters glued on the table on my wheelchair and I would point to them one at a time. I had to repeat myself several times when people kept forgetting my message, especially when it was a long one. To me and to others around me that was really frustrating.

My mom wants me to be able to communicate more and bring out my thoughts and ideas.

At home we managed mostly without any assistive technology. When I wanted to tell a long story, we had to bring out AAC. But when I started school in Ruskeasuo, a whole new world opened up to me when we started to practise using AAC regularly.

In Ruskeasuo we started to seek for different options for my communication. We must have tried every possible option there is. But I was so demanding that I would not take just any device, it had to be good enough for me. In the lower grades I used my Bliss book and the letters on my table. When I started the higher education, that is classes from seven to twelve, I got a Lightwriter. I had an assistant, who remembers that my friend used to turn the pages on my Bliss book in a speedy manner and only she would be able to keep up with my stories. Generally I was annoyed that my messages were always late. All the others had already moved to the next subject when I had finished my message to be printed out aloud.

I used my text-to-speech-device with my nose. For more complicated and longer messages I got a portable eye-controlled compute MyTobii. I mainly used MyTobii for school work and surfing the internet, talking with my friends and writing my blog. Outside and for faster communication I used the Lightwriter. Tobii is still too big to take out on the bars. My wheelchair would look like an armored car if I took Tobii out with me. I like the fact that I can use my device with eye gaze. I do not need any more buttons or levers to deal with.

I have a few reasons not to like my Lightwriter. When I type fast it takes like hundred years for the message to appear. Or it does no show up at all. I need to answer the question "do you want to save a

new word” on almost every word and it takes me forever to be able to continue my message. My assistant used to laugh that I make so many mistakes until she tried the device and wrote a bunch of non-sense. I might want to type the letter A and a L shows up and they are not even close on the keyboard. The Lightwriter is not made for Finnish weather. If there is even a slight below zero temperature the speech is really behind or does not work at all. Me and my friend have been laughing and cursing that Lightwriter does not stand Finland. I need my voice especially with my dog and with groups and everything. Sometimes when the Lightwriter has been unused for a while it turns off and I have to wait for it to start again before I can say what I need to say.

As you see, I have now a new computer. I just got it a month ago and I have to say.....

In Finland people with speech disorders are entitled to use interpret service but I have decided not to use this service. I do not want to have a third person between me and my communication partner. If someone does not understand me when I am running errands, I will find another person that will. When asked to describe a voice output device of my dreams it would be a lot like Tobii, but the size of a tablet. Something that is light and portable but yet firmly attached to my electric wheelchair. I could take it with me to bed or to a regular table. And it would be lovely if it endured Finland! If one can make a cell phone that operates in rain and freezing temperatures then why not all-important communication devices? Water-proof features, for example. But still I am lucky to have been given all the assistive technology I have wanted, or almost.

I have some advice to the people who are talking with a person who uses voice output device or other AAC system. Be patient and wait. I am annoyed when people talk to my assistant and to to me. Sometimes it feels like I am invisible. Sometimes I would just like to shout out that “Hey, I’m here, too!”. I have noticed that nowadays when I am running errands independently with my dog Jopo people see and hear me better. But there are always those people who make me invisible and run away when I ask for help. It is easier to talk with children, because they are curious. I get so mad when parents tell their children not to stare, not to ask anything. The child does not learn if she is not able to look, ask and try the voice output device.

If I was given the choice to talk to just anyone in the world, I would choose to talk to people in the media. I would like to bring out the people with speech impairment. There are so many stereotypes about if you communicate differently than others, you must have something wrong with your understanding or hearing.

I have now a few minutes to answer your questions, if you have any. I will answer in Finnish to make its faster and Paula here will translate my answers in English. Thank you for your time and that you came to listen to me.