Aarne's life with deafblindness

I am Aarne Pirkola and language user person with deaflindness. I have Usher's syndrome. Usher's syndrome is hearing and visual impairment. Hearing and vision weaken according to the ageing. I act as vice president in the Finnish Deafblind Association. My professionals are custom service in the business enocomy and massage. My hobbies are chess, gym, swimming, to read books, to watch films and to hike in the nature. Now here I talk for my experiences and everyday with deafblindness.

As chlid I saw normally signs and I walked without aids and guide. I thought being deaf. I didn't understand that I have problems with vision. I walked and fell chair and items. I learned to see always floor in walking. I didn't dump into items. As 9-year old I get know that I have Usher's syhndrome when I was on the special vision doctor.

I went at deaf school and at deaf high-school. During of school and high-school I played with deaf children, I taked many sport and exerice, I played cards and board games and computer games. I was in deaf and deafblind youth summer camps. I travelled to many places in Finland and in aboard. I have a happy life but weakening of vision took challenges to me. I had a difficult to think for coming professionals. I was 12-year old and thought that I cannot play my favorite speice ice hockey whrn I would want. As 15-year-old I thought that I cannot get driving card. I have acclimatized change of life.

I was in the youth course of of the Finnish Deafblind Association. Threre was other youths who have same Usher's sydrome. Adult coursedirector drew peer support conversation whick subject is Usher's syndrome. I get new informations for Usher and we youths turned own experiences.

When I was 18 year old my vision begined weaken badly. I had a difficult to see the signs of the deaf friends. I despressed and I was thining. At beginning I was exctiing I decided what do I do. I said bravely to deaf friend that my vision is bad and I need use a tactile-sign. He said that it is good promise. admit. I begun use tactile sign. At same stey by stey I realized to being deafblind. I was ashamed to use a white stick but later I accustomed to use it. I noticed that walking with white stick is safety. I don't fall and not smash to

items. At street people give space to me what it is esay to walk. They open a door me and they help me to walk over a car street.

I went at deaf school and at deaf high-school. Sign laugeaging school enviroment is familiar to me. After high-school I went to special vocational school to student firstly custom service of the business economy and late second professional massage. At first time I was in class where is not other deaf students not sign laugeage skilled teacher only they are hearing and talk. In the study I had interpreter of the sign laugeage. I see signs of the interpreter on the narrow field of vision and a distande of three meters. Also I use a tactile-signs from hand to hand if class room is cramped and light is not enought. Help of interpreter I was going very in the study.

I acted as self-employed masseur support of enterprice allowance. Support period of the 1,5 years ended. I didn't be to able continue a massage company because of unprofitable.

I had a swimming hobby and I was in the training of the para swimming team. I partipicated in the para swimming of finnish champion. I had interpreter and assistant in the swimming training and competition.

I am experied interpreter user. I use sign language interpreter in hobby, in study, in work life, in meeting, in doctor, in relativie party, in trips and in ice hockey match in areena, etc.Interpreters have special education of deafblindness. Interpreters of the deafblind can sign tactile hands by hands, guide, give touch messages and describe me. I use one interpreter when interpretation time is short and work is not much. Usually interpretation time on over two hour and deafblind get two interpreters.

Also I use personal assistant. Assistant's meaning is help me at home and outside of the home. Assistant can not interpret me at long only help me at cleaning at home, at hobby and at shopping in the shops. Assistant can interpret shorily at cash desk in shop of cafe.

I travel by taxi of the transportservice for disableds at leisure, at school- and worktravellings. Also I use a publish traffic example by bus and by train. I go to travel with white stick or with interpreter / assistant.

My aid are white stick, sunglasses, magnifying device, display screen, pocket shaker, alarm clock, etc. They make easier everyday of the deafblnds. I have a difficult to read the small texts in magazine and book. Help of magnifying

device I read text better. There is white big text and black back in screen of magnifying device. I use with magnifying programme or display screen a computer and smartphone. Deafblinds can read and write message. They are at contact with family, relatives and friends. They do things at email, buy train ticket, book a time of the doctor and pay bills. Deafblinds see not lights of door- and firealarm once they feel a pocket shaker. Help of services and aid I am able to participate to events of the deafblind, deaf and society. Example to youth summercamp and conference in Finland and in aboard.

I am proud for deafblndess. My deafblindnessculture and - identity have grown bigger and stronger. My vision has weakened slowly. I have acclimatized to change of life easier. I am prepared to study Braille and practise tactile signs. I want not life with roadblock because of blinding. Deafblind have to enjoy for life at same way that others.