

Abstract No. 6.8

Thursday 7th September 2017 at 14:15-15:00

**Title: Health and people with Usher syndrome, need for biopsychosocial approach**

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Main focus: Mainly research/Both congenital and acquired deafblindness

Abstract: To live with deafblindness can be challenging for several reasons and its implications for interaction with others and with the surrounding environment can be vast. People with Usher syndrome constitute the largest group of individuals under the umbrella term of deafblindness. People with Usher syndrome have a congenital hearing loss to varying degrees and a progressive eye disease, balance is also affected in some persons. Three clinical groups of Usher syndrome have been identified named 1, 2 and 3, and 13 genes have been disclosed. The progression of Usher syndrome means that over the life course there is a need to adjust to new everyday life situations. Clinical knowledge and limited research that exists have shown that people with deafblindness experience difficulties in everyday living, including problems with anxiety, depression, social withdrawal and communication breakdowns. The aim of the presentation is to discuss the importance of a biopsychosocial approach when describing health for people with deafblindness, here with the example of health for people with Usher syndrome.

The empirical material employed was based on an extensive survey in which people with Usher syndrome, all three types included, answered two questionnaires concerning health, anxiety, depression, social trust, work, health-care, financial situation, and alcohol and drug use. The focus was on general health, physical health and psychological health, social trust and financial situation.

The results revealed poor physical and psychological health, a lack of social trust and a strained financial situation regardless of clinical diagnosis and in comparison with a reference, a cross-section of the Swedish population. People with Usher syndrome reported high frequencies of fatigue, headache, different kinds of pain in back, neck and shoulders, suicide thoughts and suicide attempts. Furthermore social problems in terms of being afraid to go out alone, lack of general trust in others, having no one to share innermost feelings and confide in and having no one to ask for help when needed was revealed.

At the workshop different theoretical perspectives of health will be addressed and the discussion will stress the importance of taking a biopsychosocial approach when describing the health of people with USH, in which previous research is lacking. If a biopsychosocial approach is not considered there is a risk of reducing the complexity of living with a progressive condition such as Usher syndrome.