

Abstract No. 4.6

Wednesday 6th September 2017 at 12:00-12:45

Title: The support needs of family members of persons with Usher type 2

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Co-presenters: Saskia Damen

Main focus: Both research and practice/Acquired deafblindness

Abstract: When someone suffers from progressive deafblindness, this will not only influence the person with deafblindness, it will also have a great impact on his or her family members. However, there are no support programs for family members of people with acquired deafblindness in the Netherlands. This is a shortcoming, because family relationships are subject to change because of the impact of the progressive syndrome. For instance, people with Usher type 2 are known to have more stress (Högner, 2015), which has a negative influence upon the family dynamics.

There are currently several support programs available for people with Usher syndrome, but in order to have an optimal outcome of a certain treatment, involvement of direct family members is essential. Family members who receive support, are better able to provide more effective support and assistance themselves. Furthermore, it is an important aim of the government to shift the responsibility for increasing participation in society to the individual and his or her social network (Vreugdenhil, 2012).

The aim of this project, in which the target audience is involved in the design of the study, is to gain more insight into the support needs of families of persons with Usher type 2. By means of questionnaires and in-depth interviews information relating to, among other things, individual quality of life, the interpersonal aspects of the relationships of the participants and quality of family life will be gathered from the data. These findings will form the basis for an advice regarding the development of a support program for spouses and children of persons with acquired deafblindness .

During the workshop, information will be given about the results of the project so far. Furthermore, the way in which a target group can be involved in the different stages of setting up and conducting qualitative research will be a central topic of the presentation. After the presentation there will be time for discussion with the participants of the workshop on the question if and how support of family members is constituted in their home countries and what the role of family members is in the support of clients. Participants will also be asked if they can give suggestions on the content of a support program for family members on the basis of their own experiences.