

Abstract No. 2.4 Tuesday 5th September 2017 at 14:15-15:00

**Title: CHARGE and working on social connectedness-
a big challenge**

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Main focus: Mainly practice, Congenital deafblindness

Abstract: Based on our daily working experience with children and teenagers with CHARGE- syndrome we will consider the question why people with CHARGE regardless of their intellectual, cognitive and communicative skills come to limits in their social-emotional connectedness and get often in a social off because of going ballistic without transparent reasons. Examples are often change of school, dismiss of school, problems in finding a good job.

In this workshop we will discuss what this means for the qualification of the special assistance staff and the tutoring of the families, since there the basis for the `touch of closeness` and the `maintaining of social connectedness` is laid.

Besides teaching in the “Deutsches Taubblindenwerk” we care for early intervention. Since there is an increasing number of pupils with CHARGE we also advise teachers who work in regular schools. But we not only advise about the ordinary care for deaf-blind people but try to point out the special needs for CHARGE children. For two reasons this is not easy. First: for most colleagues the use of some technical gear (e.g. FM, enlarging seeing aids) and supporting communication systems (e.g. gestures, symbol cards, reference objects) is uncommon. Dealing with these aids leads to insecurity and extra time and makes our colleagues feel that they have to climb on a high mountain of new tasks. Second: when entering school the pupils show no or only few behavioral disorder (stronger need for physical activities, necessary breaks, constant questioning) and this behavior is not a problem to deal with. In the consequence the way of special support of these pupils is seen in teaching basic reading, writing, calculating.

It is to say that even our profession regarded communication support as a guarantor to minimize behavioral disorder. The idée was: if my counterpart can talk to me about uprising problems, these problems can be solved with the help of speech on a cognitive level. Especially when we had to deal with older students we learnt how wrong this approach was. These students had to leave regular schools not because of cognitive problems but because of their massive behavioral disorder.

In this period Nafstad, Rodbroe, Janssen and Souriau published their scientific studies which led to establish the Co- Creating- Communication Model. “Successful Communication” was then newly defined.

From our point of view this brings a great chance for children with CHARGE. Their lack of social self-regulation can now be faced at an earlier state. Since these children normally can't judge their present emotional level and don't know how to come from one level to another, we do have to keep in mind not only to name things and circumstances. We as well have to regard enough the emotional status of these children and their counterparts and have to develop alternative strategies. This needs sensitiveness, empathy, experience, competence and all the TIME it takes to deal with all aspects of our task to enable our pupils to live a content life in social connectedness.