

Abstract No. 1.1 Tuesday 5th September 2017 at 12:00-12:45

Title: Deafblindness – Theory-of-mind, cognitive functioning and social network in Alström syndrome

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Main focus: Both research and practice, Acquired deafblindness

Abstract: Purpose: The aim of this presented PhD-project has been to explore the emergence and expression of Theory-of-mind (ToM) in challenging conditions. ToM refers to the ability to understand thoughts and feelings of others. The challenge referred to is acquired deafblindness.

The presentation deals with young adults with Alström syndrome (AS). AS causes a severe progressive combined auditory and visual impairment, in addition to a multi-systemic pathology. To feature general consequences of dual sensory-loss and the impact of health, individuals with Usher syndrome type 2 (USH2) were included in one study. This deafblind-related group exhibits a slower rate of progression of visual loss than the AS group and the syndrome is not multi-systemic, enabling conclusions also about the impact of health. The main focus in this presentation is on the development of ToM, and how this relates to communicative prerequisites, development of some cognitive skills and social circumstances.

Methods: The design was quasi-experimental, with an exploratory focus. 12 individuals with AS, and 13 individuals with USH2 were matched to 24 nondisabled individuals on background variables as age, gender and educational level. Sensory functions were measured. Information about communicative skills and social behaviour was obtained from responses to a questionnaire. Advanced ToM was measured by a multiple task that taxes the ability to understand thoughts and feelings of story characters'. Verbal ability was assessed with a test of vocabulary. Executive functions (EFs) were measured by a test of inhibition and updating. Working memory (WM) was measured by a test of serial recall of non-words. Structured interviews were conducted with a social network inventory, to measure the size of the social network

Results; The group of individuals with AS was outperformed by both the nondisabled individuals and the individuals with USH2, in ToM-tasks. Individuals with AS further displayed a significantly higher degree of heterogeneity in performance in this respect. Some individuals with AS performed on equal level with nondisabled individuals. ToM performance was predicted by verbal ability and EFs, whereas WM proved to be an

indirect predictor. A later onset of visual loss further characterized AS individuals with better ToM. The size of the social network by individuals with AS was smaller relative to that of nondisabled individuals, and many of the acquaintances were professionals working with individuals with AS (mainly health professionals). Amount of friends correlated with ToM performance.

Conclusions: Variability in ToM in the AS group, seem to be highly dependent upon social prerequisites and communicative skills, in which EFs have a mediating role, Training of EFs could support ToM development in children with AS, by improving the prerequisites for social interaction. Implementation of assistive technology for optimal development of verbal ability and to enhance participation in childhood is further required. Assistive technology within different social environments is in addition required to maintain reciprocal social relationships in adulthood.