

RESEARCH PROGRAMME

COMMUNICATIVE DISABILITIES AND HANDICAPS: INDIVIDUAL AND SOCIAL ASPECTS

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The programme is funded by the Swedish Council for Working Life and Social Sciences for the period 2003-2008. A short report in Swedish of the first three years is available at www. The main research focus of the programme is the development of communication and language abilities when specific disabilities and constraints are at hand. The study of functional impairments is in itself important in the sense that it lays a solid basis of knowledge yielding directives for meaningful remedial and compensatory interventions. However, this type of study has also the potential of gaining deeper theoretical insights into general conditions for human communication and language development. The theoretical underpinning encompasses explanations of impairments in terms of biological as well as environmental variables. We propose that there is a range of disabilities which represents a variation in the way early individual preconditions interact with environmental

circumstances in a wide sense; social and communicative, where the family context is crucial, and institutional ones, where education, remediation, habilitation and compensation are of paramount importance.

The natural habitat for the development of language and communication is the face-to-face communication between a child and adults, and other children. However, a variety of circumstances can interfere with the ideal possibilities for interplay between the interlocutors. The programme focuses on a number of these obstacles and in certain respects suggests interventions.

Of interest are questions concerning development of language and communication when the expected means of communication are not at hand as is the case for deaf children and children with cerebral palsy. We also focus on conditions when the child's interest in communication and social relationships is limited or deviant, being the case of autism spectrum disorders. Yet another challenging area is when specific aspects of language processing seem to malfunction, resulting in dyslexia. Furthermore, we include the family context, coping and life situation of parents with children with intellectual disabilities.

Our aim is to reach a deeper theoretical understanding of the ways the resulting communication skills are related to the different preconditions and also to further develop remedial interventions and teaching and learning guidance. To accomplish this, we apply a variety of approaches, ranging from longitudinal research, experimental and quasi-experimental design, to case studies.

Specific issues addressed in the programme

1) Mentalizing: language, interaction, and cognition

The child's development of mentalizing or of a "theory of mind" implies a growing insight into the thoughts and feelings of other people. It is a sine qua non for relationships, cooperation and interaction in general with other people. It has been established that there is a marked step in its development around 4 to 5 years, when children start to demonstrate knowledge of the way other persons' actions are governed by their private thoughts and feelings. At the same time it has been shown that children with certain diagnoses, in particular encompassing the autism spectrum disorders, have problems with this kind of mind-reading. It was also suggested that such problems might be a core deficit of autism related to a neurodevelopmental disorder. However, there are indications in the research literature that there is no such core deficit in autism and Asperger syndrome. Our contention is though that a case could be made for a combination of different deficits that explain the behaviour in autism and Asperger syndrome, i.e. deficits in theory of mind, executive functions, central coherence, language competence, cognitive style and memory functions. These different deficits contribute to different degrees and kinds of problems depending on the tasks and depending on the context when performing a task. One aim within the research programme is to address these issues.

Among non-speaking children with cerebral palsy, a low performance on certain mentalizing tasks has been found (Falkman, Dahlgren Sandberg, & Hjelmquist, 2005). Compared to children with autism, the explanation must be different. It is suggested that the limited possibilities for own-initiated communication and language use among these children could be a crucial factor. The major interpretative work and responsibility for the communicative

exchange in a conversation reside in the speaking and able-bodied person. This could foster talk about simple, concrete matters, not abstract mental states. The lack of appropriate conversational experience is therefore hypothesized to be a circumstance of importance. The explanation is essentially the same as of the delay of mind-reading skills among deaf children from hearing families. These deaf children meet a conversational context where they have no signing models and thus get a, relatively speaking, limited input. Common to deaf children and non-speaking children with cerebral palsy is that they have conversational experiences very different from typically developing children, experiences that are not fostering of mentalizing abilities. However, the number of studies of these groups, in particular children with cerebral palsy, is still limited and motivates further investigations where one paramount question would be the character of the delayed or deviant mentalizing abilities. We have just finished a three-year study of deaf children aged 6-13 years at a special school for deaf children (Falkman & Hjelmquist, in press). The programme offers an ideal context for further studies of deaf children.

In a new project, reading/writing skills and mentalizing among children with autism are studied.

2) Characteristics of dyslexia as a functional impairment with serious individual and societal consequences in a world of text

Poor reading ability is certainly a serious functional impairment in current society with severe consequences for the affected individual in working life with reduced possibility of getting a job or of promotion and even maintaining a position in a rapidly changing organization. Furthermore, poor reading is a critical obstacle for continuing education. Also as a citizen in a democratic society poor readers most often have a lower level of participation.

One common cause of poor reading is developmental dyslexia, a neurobiological disturbance often with a genetic basis (Høien & Lundberg, 2000). A full genome scan of a family with a history of dyslexia is to be completed as a part of the programme. However, within the programme we have a broader perspective on reading disability and also recognize social, educational, cultural and linguistic factors. We also want to explore various conditions seemingly related to reading problems, such as ADHD or problems with mathematics.

In one study (Samuelsson, Lundberg, & Herkner, 2004) we have demonstrated that there is a low degree of comorbidity between dyslexia and ADHD among male adults. Although many adults with ADHD are poor readers in the sense that they have difficulties comprehending connected narrative or expository prose, they do not show typical dyslexia symptoms like phonological problems or poor word decoding. In a further study within this programme we examine the corresponding relation among female students from the age of 8 to 16.

Children with reading difficulties often have problems with arithmetic. In one study we carefully analyse this relationship. A group of 60 nine-year olds are followed over one year. A broad spectrum of their functioning is assessed including several aspects of reading and arithmetic. A special focus is directed on task orientation including attention, persistence, and intrinsic motivation. The longitudinal design permits a proper test of a causal model. The next step is to investigate the basis of poor task orientation which leads us to socio-economic and cultural factors early in life.

3) Communication, language and cognition in children with Rett syndrome (RS) and in children with severe speech and physical impairments (SSPI)

Children with Rett syndrome

Rett syndrome (RS) represents a biologically complex neurodevelopmental disorder of uncertain pathogenesis, featuring severe loss of function between late infancy and the fourth year of life. A diagnosis of RS is based on clinical consensus criteria and its course divided into four characteristic stages: (I) early developmental stagnation; (II) severe psychomotor disintegration and regression; (III) partial cognitive and communicative recovery, but prominent deficit in motor planning; (IV) late gross motor deterioration. Along with medical symptoms severe linguistic and communicative difficulties are always present, and are necessary criteria for the diagnosis. The specific aim of the studies on children with Rett syndrome is to evaluate linguistic and communicative development at the time of stagnation in development, the developmental course: loss and regain of verbal speech abilities, and the actual use of communicative functions, especially joint attention and intentional communication. A problem in earlier studies has been to find assessment methods adapted to the low developmental level and the extraordinary impairment characteristics of RS girls. Therefore, development of methods for the study of this group of very disabled individuals must go hand in hand with further investigation of their cognitive, communicative and linguistic functioning.

Children with SSPI, severe speech and physical impairments, mostly cerebral palsy

A range of issues are raised in the studies on children with SSPI, more specifically children who rely upon Augmentative and Alternative Communication (AAC) to express themselves. AAC refers to communication modes like graphic symbols such as Bliss, sign language, manual signs and gestures. Common modes of communication beside the linguistic one are eye gaze, facial expressions and vocalisations. We investigate how the children code incoming information, and their pre-linguistic and linguistic expressive modes. Furthermore, we examine the transition from non-linguistic to linguistic communication, how early the child could start to use other means for communication, and analyze the early interaction pattern between the parent and the child (Dahlgren Sandberg, 2005).

Another purpose is to study the strategies that children with SSPI use during reading and spelling acquisition and the problems they meet. Based on this knowledge, the long-term aim will be to find methods to help the children acquire reading and spelling skills, e.g. through other strategies than the alphabetic or through developing methods for use of speech synthesis as a support during the reading and spelling process. Specific questions concern how phonological awareness and short-term memory develop in children with SSPI (Dahlgren Sandberg, in press).

4) Early communicative processes and their relation to cognitive development in children with developmental disorders

Several studies have shown that infants are able to establish and remember inner representations at least at six months of age and at nine months of age start to participate in interaction requiring joint attention together with adults. The hypothesis is that these two abilities are correlated and that these crucial developmental processes share a basic

communicative platform, but the characteristics of this relationship are still unclear. However, we have demonstrated (Heimann, Strid, Smith, Tjus, Ulvund & Meltzoff, in press) that episodic memory measured by deferred imitation, visual recognition memory, and joint attention in typically developing children in infancy is related to later communicative development. Therefore a main question is if children with communicative and developmental disorders show the same pattern as typically developing children. More specifically relationships between non-verbal long-term memory, joint attention, and preference for novelty stimuli are examined in children with autism and Down syndrome and compared with typically developing children. Another aim of the study is to find if there might be developmental trajectories that predict later outcome of intelligence, language development and the ability to understand tasks that include theory-of-mind.

5) Multimedia intervention of children with dyslexia or at risk for developing reading problems

On the basis of several field studies it is concluded that a focused multimedia strategy might boost literacy and communicative development in children with different learning and language problems e.g. autism, Down Syndrome and ADHD. An educational strategy that combines motivating multimedia material in combination with good teacher support and recasting technique leads to both better language and communication skills (Tjus, Heiman, & Nelson, 2004). The aim of this strategy was to maximise the opportunities for exploring literacy and language structures through different modes (text, speech and animations). All children used the program in addition to their ordinary reading and language training. In studies focusing on school children suffering from dyslexia and pre-school children at risk for developing reading problems this multimedia intervention is implemented and comparisons are made to other training strategies.

6) Ordinary parents under extraordinary circumstances – individual differences in the psychological adaptation of parents with children with intellectual disabilities (ID)

In our previous studies, with more than 200 families with children with intellectual disabilities and as many control families, we have confirmed results from studies in other countries by showing that mothers of those children experience increased risk of depression compared to control mothers (Olsson & Hwang, 2001). The stressors described by parents in Sweden, for example having to fight for once own and the child's rights, having a reduced social life, and experiencing time restraints due to care-taking demands, resemble those described in previous research (Olsson & Hwang, 2003). In our studies we found large individual differences between parents. Moreover, we have found that differences in personality factors, like the parents sense of coherence, play a major role for parental adaptation.

Selected references

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