

# **Children with severe or profound intellectual and multiple disabilities – characteristics and communication interventions**

Akademisk avhandling

Som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentlig försvaras i K Isaksson, Medicinargatan 16, den 21 oktober, klockan 09.00.

av Anna Rensfeldt Flink

Fakultetsopponent: professor Bea Maes, Katholieke Universiteit Leuven, Belgien

## **Avhandlingen baseras på följande delarbeten**

- I. Flink, A. R., Boström, P., Gillberg, C., Lichtenstein, P., Lundström, S., & Johnels, J. Å. (2021). Exploring co-occurrence of sensory, motor and neurodevelopmental problems and epilepsy in children with severe-profound intellectual disability. *Research in developmental disabilities*, 119, 104-114.
- II. Rensfeldt Flink, A., Åsberg Johnels, J., Broberg, M., & Thunberg, G. (2020). Examining perceptions of a communication course for parents of children with profound intellectual and multiple disabilities. *International Journal of Developmental Disabilities*, 68:2, 156-167.
- III. Rensfeldt Flink, A., Broberg, M., Strid, K., Thunberg, G. & Åsberg Johnels, J. (2022) Following children with severe or profound intellectual and multiple disabilities and their mothers through a communication intervention: single-case mixed-methods findings. *International Journal of Developmental Disabilities*.
- IV. Rensfeldt Flink, A., Thunberg, G., Nyman, A., Broberg, M. & Åsberg Johnels, J. Augmentative and Alternative Communication with children with severe/profound intellectual and multiple disabilities – speech language pathologists' clinical practices and reasoning. Submitted manuscript.

**SAHLGRENKA AKADEMIN**  
**INSTITUTIONEN FÖR NEUROVETENSKAP OCH FYSIOLOGI**



# Children with severe or profound intellectual and multiple disabilities – characteristics and communication interventions

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## Abstract

Children with severe or profound intellectual and multiple disabilities (S/PIMD) communicate presymbolically and need support in all aspects of daily life. Communication intervention studies are scarce, and so is research focusing on characterization of S/PIMD. The **overall aim** of the thesis was to contribute knowledge about the prerequisites for communication from the perspectives of the child, the parent and the context by exploring the multiplicity of disorders and problems in S/PIMD (*Study I*) as well as aspects of communication interventions provided by Swedish habilitation services (*Studies II through IV*). Various **methods** were applied with a focus on mixed (quantitative and qualitative) methods. **Findings:** In *Study I*, a sample of children with severe/profound ID was explored. It was found that all children in the sample were affected by added problems or neurodevelopmental disorders (apart from ID) and it seemed difficult to draw a line between “prototypical” S/PIMD and non-S/PIMD cases. Notably, positive screening for autism was prevalent in the sample. *Studies II and III* explored parents’ experiences as well as parent and child outcomes from a parental course on communication (ComAlong). *Study II* utilized survey data from parents’ course evaluations. In *Study III* two parent and child dyads were followed longitudinally, before, during and after the ComAlong course. Video data of parent child interactions and parental interviews were gathered and analyzed in detail. Results from both studies showed that parents found it meaningful to learn about communication and augmentative and alternative communication (AAC), even though a minority of parents in *Study II* struggled with AAC. Several parents from both studies stated that the course affected their communication. However, changes in parents’ or children’s communication were not detected in coded video data in *Study III*, which raises important questions for future research. To gain a broader perspective on AAC in relation to S/PIMD, *Study IV* focused on speech language pathologists’ (SLP) clinical practices and decision making regarding AAC implementation with the target group. According to results from analyzed survey and focus group data, SLPs valued AAC highly and implemented a variety of AAC approaches with children with S/PIMD. Clinical decision making on AAC seemed to be mainly guided by clinical experiences and the circumstances and wishes of the child’s social network. The **conclusions and implications** from this thesis relate to the conceptualization of S/PIMD as a spectrum condition; the complexity of parental learning in parent-mediated communication interventions and relevant outcome measurements; the importance of family centeredness in clinical AAC practices and the insufficient associations between clinical practice and research.

**Keywords:** Severe/profound intellectual disability, multiple disability, parent-mediated communication intervention, augmentative and alternative communication, speech language pathologists

ISBN: 978-91-8009-925-7 (TRYCK)

ISBN: 978-91-8009-926-4 (PDF)