

Experiences of Parenthood and the Child with an Intellectual Disability

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Avhandling för avläggande av filosofie doktorsexamen i psykologi, som med vederbörligt tillstånd av Samhällsvetenskapliga fakulteten vid Göteborgs universitet kommer att offentligens försvaras fredagen den 14 december 2012, kl. 10.00, Sal F1, Psykologiska institutionen, Haraldsgatan 1, Göteborg.

Opponent är professor Eric Emerson från Institute for Health Research, Lancaster University, Storbritannien.

The dissertation is based on the following studies:

- I. Boström, P., Broberg, M., & Hwang, C. P. (2010). Different, difficult or distinct? Mothers' and fathers' perceptions of temperament in children with and without intellectual disabilities. *Journal of Intellectual Disability Research*, 54(9), 806-819.
- II. Boström, P. K., Broberg, M., & Bodin, L. (2011). Child's positive and negative impacts on parents - A person-oriented approach to understanding temperament in preschool children with intellectual disabilities. *Research in Developmental Disabilities*, 32(5), 1860-1871.
- III. Boström, P. K., Broberg, M., & Hwang, P. (2010). Parents' descriptions and experiences of young children recently diagnosed with intellectual disability. *Child Care, Health and Development*, 36, 93-100.
- IV. Boström, P. K., Broberg, M. (Submitted). Openness and Avoidance – A Longitudinal Study of Fathers of Children with Intellectual Disability.



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Abstract

Boström, P. (2012). *Experiences of Parenthood and the Child with an Intellectual Disability*. Department of Psychology, University of Gothenburg, Sweden.

When a child is diagnosed with an intellectual disability (ID) the experience of parenthood is affected and parents' descriptions tend to vary, containing a wide spectrum of emotions that may change over time. In the present thesis, empirically-based knowledge about parents of children with ID and their particular circumstances in Sweden is described within the theoretical framework of Bronfenbrenners' ecological model (1977). The individual children and their closest relationships are at the centre of the ecological model, surrounded by spheres of environmental factors that interact with their development directly and indirectly. Parents are affected by the disability in terms of mental health as increased levels of stress and depression have been found among parents of children with ID. The impairment in parental mental health is not, however, simply explained by the severity of the disability or developmental delay, but is related to a number of risk and protective factors in parents and children. Parents' descriptions and experiences of parenthood are not only of interest from a mental health point of view. They also offer information about the parent's motivational system to provide care and protection for the child described within attachment theory (Mayseless, 2006a).

To explore the diversity of parents' experiences, the four studies presented in this thesis aimed to investigate parents' descriptions and experiences of their child with ID during five years from two different perspectives. In studies I and II, parents' descriptions of child temperament were analysed and explored in relation to positive and negative impact of the child. Results from studies I and II indicated that children with ID differ from typically developing children in terms of temperament. Two unique temperament profiles (disruptive and passive/withdrawn temperament) were found only among children with ID and turned out to predict negative impact on mothers. In studies III and IV, interviews with parents exploring their subjective experiences of the child and the parent-child relationship were analysed. Most parents in study III described their child in both positive (affectionate/loving) and negative terms, indicating a balanced experience of their child. In contrast, a few parents' narratives were more limited, offering a less nuanced picture. Experiences varied between acceptance of and preoccupation with the disability. Parent's narratives varied in time orientation in terms of tense and flexibility. In study IV, fathers explicitly described how receiving the diagnosis of the child had affected them as persons in the theme *an interrupted path - no longer taking things for granted*. Fathers mostly described themselves as *being a good father*. The process of integrating, managing and living with the insight of the child's diagnosis was described in the theme *dealing with the unexpected* containing the subthemes *vulnerable openness*, *contained openness*, and *avoiding the unexpected*.

The four studies show that children with ID constitute a highly heterogeneous group evoking equally diverse reactions from their parents. Results indicate that parents are affected by the variety in child temperament, and also by the support and constraints of their environments. The different perspectives may provide important information about parents' emotions towards and experiences of the child that may affect parents' well-being and parenting behaviour.

Key words: Intellectual disability, parents, fathers, family impact, temperament, risk and protective factors