

ABSTRACT

Olsson, B. Malin (2004) *Parents of Children with Intellectual Disabilities*. Department of Psychology, Göteborg University, Sweden

The thesis focuses on the psychological adaptation of parents with children with intellectual disabilities (ID). Questions that have guided the research are: What is the life situation of parents with children with ID like? What facilitates parents' lives and what are the greatest difficulties? Why do some parents of children with ID manage to cope well, while others do not?

Three theoretical perspectives are used to understand individual differences in adaptation in parents of children with ID. The relational stress-processing model (Lazarus & Folkman, 1984; Lazarus, 1999) provides a general understanding of individual differences in the experience of and reactions to different stress factors. The risk and resistance model of Wallander & Varni (1998) provides an understanding of risk and resistance factors that are specific to the life situation of parents of children with disease/disability. The theory of sense of coherence (Antonovsky, 1987) provides understanding of how personality factors are important for stress processing.

226 families with children with intellectual disabilities (ID) (51 children with Down syndrome (DS), 107 children with mental retardation (MR) of other origin than DS and 68 children with autism) and 234 control families, with children ranging from 0-16 years of age, answered postal questionnaires. Families of children with ID were recruited from community-based programs providing services to families of children with disabilities. The control group was comprised of families of randomly selected children, living in the same geographical area and having the same age and gender distribution as the study group.

The aim of **study 1** was to investigate the prevalence and severity of parental depression in families of children with ID and in control families.

The aim of **study 2** was to test whether Antonovsky's theory of sense of coherence (SoC) (1987) can contribute to an understanding of: (1) the individual differences in psychological adaptation in parents of children with ID; and (2) why parents with children with ID generally experience higher levels of stress and depression than parents of normally developing children.

The aim of **study 3** was: to explore if families in Sweden experience the stressors and life situations described in previous studies from other countries.

The aim of **study 4** was to use existing literature and qualitative examples to illustrate how Antonovsky's concept of sense of coherence (SoC) (Antonovsky, 1987) can form a conceptual framework for understanding both dimensions of personal strengths as well as possible situational threats to these strengths in parents of children with intellectual disabilities.

From the results it can be concluded that: (a) mothers of children with ID are at markedly increased risk for depression compared to their spouses and control parents, (b) parents of children with ID experience many different stressors of which time restrictions and restricted social life seem to be the two most severe (c) most parents described some positive aspects of having a child with ID such as having adopted new views in life (c) the formal support system is perceived as difficult to navigate and sometimes unfair (d) the theory of sense of coherence (SoC) can form a conceptual framework for understanding both dimensions of personal strengths as well as possible situational threats to these strengths in parents of children with intellectual disabilities and (e) parents of children with mental retardation and autism described a more difficult life situation and more depressive symptoms than parents of children with DS.

Key words: Intellectual disabilities, parents, depression, sense of coherence, risk and resistance factors