

Avhandling för avläggande av filosofie doktorsexamen i psykologi som med vederbörligt tillstånd av samhällsvetenskapliga fakulteten vid Göteborgs Universitet kommer att offentligt försvaras fredagen den 29 september 2017, kl. 10:00, Sal F1, Psykologiska institutionen, Haraldsgatan 1, Göteborg.

Fakultetsopponent: Dr. Kitty-Rose Foley, Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW Sydney), Australia.

This thesis is based on a summary and the following papers:

- I. Nowak H.I., Broberg, M. & Starke, M. (2013). Parents' experience of support in Sweden: Its availability, accessibility, and quality. *Journal of Intellectual Disabilities*, 17 (2), 134-144. DOI: 10.1177/1744629513486229
- II. Nowak H., Starke, M., and Broberg, M. The Availability of Formal Parenting and Emotional Support to Parents of Children with Disabilities in Sweden. Manuscript submitted.
- III. Nowak H., Broberg, M., and Starke, M. The opportunity for children with disabilities to participate in planning and evaluation of support: Parents' and professionals' perceptions. *Journal of Intellectual Disabilities*.
- IV. Nowak H., Broberg, M., and Starke, M. Now what? Parents' experiences of parenthood and formal support during and after a special upper secondary school program for their young adult children with severe physical disabilities. Manuscript submitted.



Abstract

Nowak, H.I. (2017). Parents of Children with Developmental Disabilities and Their Experiences of Formal Support. Department of Psychology, University of Gothenburg, Sweden.

The aim of this thesis was to investigate how UN conventions, national laws, regulations, and policies are manifested in everyday experiences of parents of children with disabilities. The specific aims of this thesis are to 1) investigate how parents of children with developmental disabilities experience their parenthood and received formal support, 2) investigate how parents and professionals experience the opportunity for children with disabilities to participate in decision-making process, 3) describe how individual factors (parental gender and country of origin as well as the child's diagnosis and age) contribute to parents' experience of their subjective need and experience of support during the course of childhood (age span in all the studies 1-20 years). **Study I** explored parents' experience of the received support through a semi-structured interview with six parents of children with intellectual disabilities in the Western region of Sweden. Parents reported difficulty in finding and obtaining information about and accessing available support. **In Study II and III**, parents of children with disabilities participated in a structured telephone interview. **Study II** aimed to explore the perception of needs for formal support and the actual received support in parents of children with disabilities in Sweden. The focus of the study concerns parenting and emotional support and factors related to parents' perception of support needs. Parents experienced that they had not received the support that they needed regarding information about their child's rights and available existing support. Parents also reported that their need for support for stress management and for individual counselling had not been fulfilled. Parents' needs for formal parenting and emotional support were related to the gender of the parent and their country of origin. **Study III** investigated professionals' and parents' ratings of the opportunities available to children with disabilities to participate in planning, decision-making, and evaluation of support, and parental satisfaction with current level of such child-participation. Most professionals indicated that they were able to meet with children directly, but relied more on parents' descriptions of the child's needs and opinions of support services than on direct communication with the child. Both parents and professionals rated children's opportunities to participate as limited, but the participation increased with age. **Study IV** investigated parents' who have young adult children with severe physical disabilities and attended a special upper secondary school program. The study specifically looked at their reflections of everyday life and their experience of parenthood during and after their young adult child attended the special upper secondary school program. Parents' experiences of parenthood were related to their youth's capacities and environment. The environmental factors, however, played a significant role in the ways parents perceived their young adult children's future.

Overall results from the studies show norms, rules, and regulations in regard to support services provide children with disabilities and their parents opportunities to apply for support services, giving them a chance to participate in the community, and to live as others in accordance with the UNCRC and UNCRPD. However, these support services are not equally accessible by all children with disabilities and their parents. Laws, regulations, and policies governing the right to support do not provide assurance that parents would be receiving the support that they need. The studies also show that plenty of work still needs to be done in implementing disability policy in Sweden.

Keywords: children, disabilities, experience, parents, participation, policy, support.

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