Mothers and fathers of children with developmental disabilities: Co-parenting, well-being and empowerment

David Norlin Department of Psychology 2017

Avhandling för avläggande av filosofie doktorsexamen i psykologi som med vederbörligt tillstånd av Samhällsvetenskapliga fakulteten vid Göteborgs Universitet kommer att offentligt försvaras torsdagen den 9 november 2017, kl. 13.00, Sal F1, Psykologiska institutionen, Haraldsgatan 1, Göteborg.

Fakultetsopponent: Professor Jan Tøssebro, Norges teknisk-naturvitenskapelige universitet, Trondheim

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

- I. Norlin, D., & Broberg, M. (2013). Parents of children with and without intellectual disability: couple relationship and individual well-being. Couple relationship and individual well-being. *Journal of Intellectual Disability Research*, 57, 552–566.
- II. Norlin, D., Axberg, U., & Broberg, M. (2014). Predictors of harsh parenting practices in parents of children with disabilities. *Early Child Development and Care*, 184, 1472–1484.
- III. Norlin, D., Starke, M., & Broberg, M. (2017). A brief intensive intervention for families of children with rare diseases. Manuscript.



Abstract

Norlin, D. (2017). Mothers and fathers of children with developmental disabilities: Co-parenting, well-being and empowerment. Department of Psychology, University of Gothenburg, Sweden.

Parents of children with developmental disabilities (DD) generally experience more stress and poorer well-being than other parents. However, there is considerable individual variation in parental adaptation. The general aim of this thesis was to further the understanding of the adaptation of Swedish parents of children with DD. It investigated factors regarding the individual and the couple that may affect parents of children with DD and evaluated an intervention for families of children with rare diseases. Study I focused on couple relationship and individual well-being in parents of children with DD. Parents of children with intellectual disabilities (ID) (N = 83) and control parents (N = 319)responded to surveys including questions about their well-being and relation with the child's other parent. Data was collected on two occasions 12 months apart. Well-being was predicted by marital quality, economic risk, parent gender and child ID status. Prospective well-being was most strongly predicted by baseline well-being, followed by co-parenting quality. Mothers of children with ID reported poorer well-being than control mothers. Parents of children with ID reported more severe child behaviour problems than controls. Study II investigated parents' propensity to use harsh parenting practices (HPP; e.g. hitting, slapping or yelling). Both parents (N = 44) of children with a wide range of DD, and who were entitled to special support services, and control parents (N = 170)responded to a web survey examining the prevalence of HPP. Parents of children with DD did not indicate higher HPP propensity than controls after controlling for parent sex and child age. The parents of children with DD reported more child behaviour problems than controls. Within the group of parents of children with DD, child behavioural problems positively predicted HPP propensity. Study III evaluated parent outcomes of a brief intensive intervention for families of children with rare diseases aimed to increase parent competence. Parents (N = 124) answered self-report surveys prior to and three months after participation in the intervention. At baseline, mothers reported higher levels of parenting stress, depressive symptoms and anxiety, relative to fathers. Only fathers' responses indicated a change over time: reports by fathers of empowerment and child-related marital stress increased slightly between baseline and follow-up. Additionally, parents found the intervention beneficial, especially through sharing experiences with other parents, meeting other children with the same diagnosis and increasing their knowledge about the diagnosis. Taken together, the results indicate that parents of children with DD experience additional strain compared with the general parent population. The risk for negative outcomes is higher for mothers than fathers. Although the presence of a child with DD does not imply a poorer couple relationship for parents, there is an association between relationship quality and individual parental well-being. In addition, parents of children with DD are more exposed to child behaviours that may be difficult to handle, and those behaviours are associated with a higher risk of harsh parenting practices. Finally, parents of children with DD value other parents in the same situation as a source of support and knowledge.

Keywords: parental well-being, child disability, intellectual disability, developmental disability, couple relations, harsh parenting, rare diseases

ISBN 978-91-984178-6-9 (Print) ISBN 978-91-984178-7-6 (Pdf) ISSN 1101.718X Avhandling/Göteborgs universitet, Psykologiska inst. ISRN GU/PSYK/AVH--368—SE

David Norlin, Department of Psychology, University of Gothenburg, P.O. Box 500, 405 30 Gothenburg, Sweden. Phone: +46 735 69 48 10, E-mail: david.norlin@psy.gu.se