

Implementing a Program for Parents with Intellectual Disability in Sweden: A Feasibility Study

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Department of Psychology, 2016

Avhandling för avläggande av filosofie doktorsexamen i psykologi som med vederbörligt tillstånd av Samhällsvetenskapliga fakulteten vid Göteborgs Universitet kommer att offentligt försvaras fredagen den 16 december 2016, kl 10:00, Sal F1, Psykologiska institutionen, Haraldsgatan 1, Göteborg.

Fakultetsopponent: Professor Mats Granlund, Department of Behavioural Science and Social work, Jönköping University, Sweden

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

- I. Mc Hugh, E., & Starke, M. (2015). Understanding support workers' competence development in working with parents with intellectual disability. *Journal of Intellectual Disabilities*, 19(4), 326-341. doi: 10.1177/1744629515576045.
- II. Mc Hugh, E., & Starke, M. (2016). *Supporting implementation of an Evidence-Informed Program using peer support groups: Area Coordinators' perceptions and experiences*. Manuscript submitted for publication.
- III. Mc Hugh, E., & Starke, M. (2016). *Investigating feasibility and fidelity of the Parenting Young Children program in Sweden*. Manuscript submitted for publication.
- IV. Mc Hugh, E., & Starke, M. (2016). *Measuring program fidelity: Including the perspective of parents with intellectual disability*. Manuscript in preparation.



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Abstract

Mc Hugh, E. (2015). *Implementing a program for parents with intellectual disability in Sweden: A feasibility study*. Department of Psychology, University of Gothenburg, Sweden.

This thesis examines implementation of an evidence-informed parent education program for parents with intellectual disability, called Parenting Young Children (PYC), in the Swedish social services. The empirical studies on which the thesis is based aimed to evaluate how feasible and successful implementation of PYC has been to date, examining program fidelity, and the provision of program support. **Study I** explored perceptions of competence development and the training process for Swedish program users (support workers) who participated in monthly peer support groups. Focus groups discussed experiences of PYC and completed a competency questionnaire on two occasions. Perceived competence was high and increased over time. PYC peer support groups were thought to be beneficial for performance evaluation, exchange of information and coping with problems. However, many reported few opportunities to implement the program. **Study II** investigated peer group facilitators' (Area Coordinators) perceptions of working in peer support groups. Area Coordinators completed diaries each month after meetings, recording topics covered, difficulties experienced by the group and general reflections about peer support. Area Coordinators also attended a focus group. Several opportunities and barriers to program implementation were perceived within the groups. Interaction between the peer support groups and the organization/managers was thought to be particularly important, but difficult to achieve. In **Study III** fidelity was examined by tracking frequency of implementation of program activities and teaching approaches in support workers. Feasibility was explored through questionnaires addressing perceived program complexity and compatibility in support workers and their managers. Implementation of PYC was reported to be highly feasible, with overall positive attitudes to Evidence-Based Practice, good program compatibility and low perceived program complexity, as well as high satisfaction with implementation support. However, some behavioural aspects of PYC were rarely reported to be used in practice. Low implementation intensity was also reported. **Study IV** aimed to develop a PYC fidelity measure that included the perspective of program recipients. Two questionnaires were developed; one measured parents' perceptions of support workers' fidelity, the other was a self-report questionnaire for support workers. Items from the support worker and parent versions were compared for inter-rater reliability. Parents and support workers both reported very high fidelity. Scores were consistent over a three month period. Inter-rater reliability between parents and support workers was, however, only fair. Taken together, these results highlight enthusiasm and perceived need for PYC in the social services. Further work is needed in order to assist implementation of PYC and to develop both the program itself and program support

Keywords: evidence-informed programs, intellectual disability, implementation, program fidelity, Parenting Young Children, feasibility

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