

Paths for Future Research: A Preliminary Conceptual Model of Effective Support for Pregnant Women with Intellectual and Developmental Disabilities

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Introduction

With an increase in fertility rate⁽¹⁾ and uptake of maternity services among women with intellectual and developmental disabilities (IDD)⁽²⁾, improving the quality of support for this high-risk population⁽³⁾ should be a social and clinical priority. However, most prenatal services were developed for the general obstetric population⁽⁴⁾, and very few studies have described support for women with IDD during pregnancy and childbirth.

Objective

To develop a conceptual model which explains factors associated with effective maternity support for women with IDD. This conceptual model will be used to guide the development of a large qualitative study.

Methods

Design: A pilot qualitative study using grounded theory⁽⁵⁾, followed by a descriptive case study⁽⁶⁾, were conducted in 2015 and 2016.

Participants: Adult women with IDD who had given birth in the last five years (n=8) were recruited by convenience sampling through developmental services agencies in Ontario.

Data collection: Semi-structured interviews based on a modified version of the Social Support Self-Report (SSSR)⁽⁷⁾ and a social circles task.

Participant Characteristics

Table 1: Characteristics of participants

Camille^a: 38 years, French, 1 pregnancy; Alexandra^a: 32 years, French, 1 pregnancy;

Catherine^a: 27 years, English, 2 pregnancies; Rose^a: 23 years, English, 3 pregnancies

Results

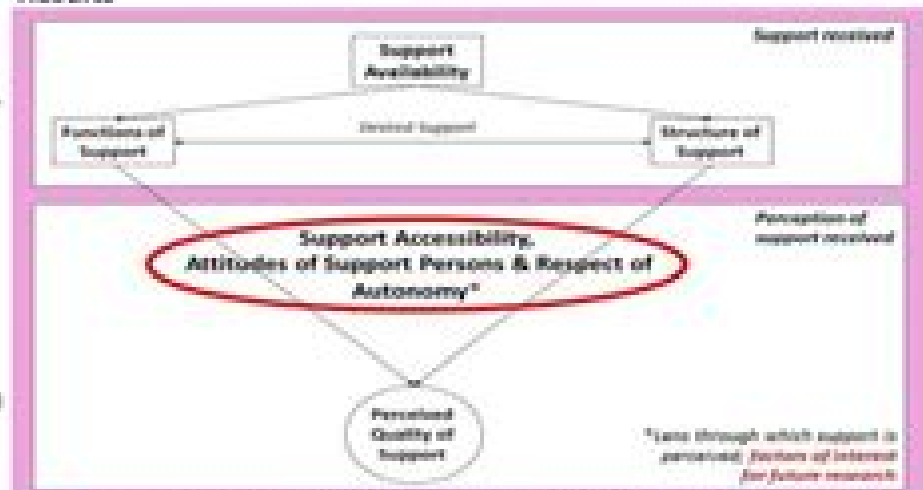


Fig. 1. Preliminary conceptual framework of effective maternity support. Diagrams are created in accordance with the Grounded Theory, J.L. Strauss, M. B. Corbin, in Office from their research on social and structural and developmental disabilities during pregnancy and childbirth, an exploratory qualitative study, University of Ottawa, 2016. Reproduced with permission from the author.

Paths for Future Research

How can we improve prenatal social support to optimize the health of mothers with IDD?

- Support accessibility, caregiver attitudes, and autonomy are identified factors worthy of future investigation.
- Moreover, our research suggested that: (1) a stable relationship with a support person who accompanies women with IDD throughout pregnancy and childbirth may increase satisfaction with and access to prenatal support, and (2) increased contact with this pregnancy population may decrease negative attitudes.
- Based on this knowledge, we plan to develop curricula for healthcare providers and support persons which aim to decrease stereotypes, facilitate contact with and optimize care for pregnant women with IDD.
- This may include (1) developing strategies to match pregnant women with IDD to a key support person to promote autonomy and facilitate support accessibility and uptake, and (2) conducting focus groups with physicians to target attitudes and increase IDD-related knowledge.

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