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SUPPORT NEEDS AND SERVICE PATHWAYS OF PARENTS WITH INTELLECTUAL IMPAIRMENTS

A SSHRC Partnership Development Project

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SUPPORT NEEDS AND SERVICE PATHWAYS OF PARENTS WITH INTELLECTUAL IMPAIRMENTS: A SSHRC PARTNERSHIP DEVELOPMENT PROJECT

BACKGROUND

- Building capacity in human service systems to render appropriate assistance to parents with intellectual impairments is critical to a sound investment in the future of their children. Without appropriate support, their children face a heightened risk of developmental deprivation and are ten to fifteen times more likely than their peers to be apprehended by child and youth protection authorities: On any given night in Canada, approximately five out of every 1000 children aged 14 and under are in foster care, and of these five children at least one will have been taken from a parent with intellectual impairments.

PURPOSE

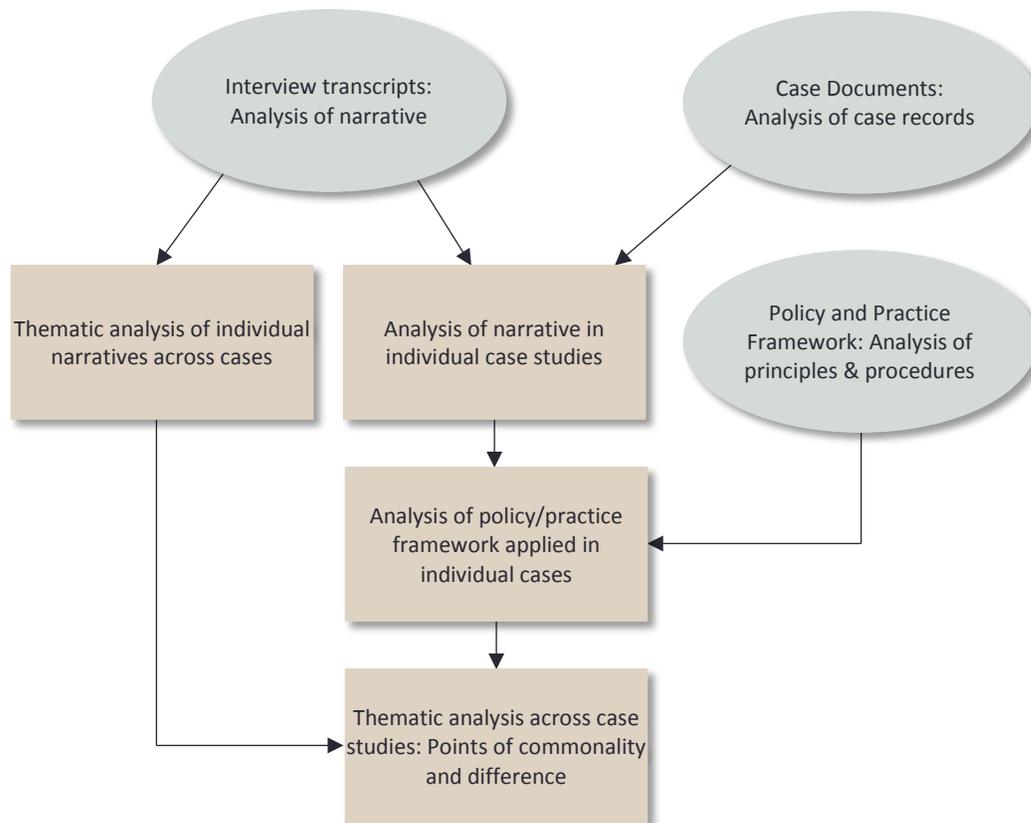
- **The purpose of this study is to determine a strategy to build systems' capacity to accommodate the support and learning needs of parents with intellectual impairment and, in turn, improve the life chances of their children.** One objective is to investigate the support needs and service utilisation patterns of parents with intellectual impairment. Another objective is to examine the pathways of parents with intellectual impairment into and within the child and youth protection system. The study will highlight strengths upon which to build (e.g., established inter-agency working relationships), as well as service gaps and other systems' capacity building needs.

METHODS

- Reference groups of parents with intellectual impairment will be established and appropriately supported. The parent reference groups will advise on all aspects of the project (e.g., procedures and instrumentation) and participate in the process of interpreting and communicating the project findings.
- **To achieve breadth and depth of understanding, and to connect this understanding to a clear course of action, a multi-stage, multi-method study is proposed.** Stage 1 (S1) will involve semi-structured interviews with a sample of approximately ninety parents with intellectual impairment and their key support workers. Stage 2 (S2) comprises a collective case study to investigate parent experiences and worker decision-making in the context of child and youth protection processes. A series of in-depth interviews will be conducted and case records and relevant policies will be analysed. A series of composite case narratives will then be constructed. Stage 3 (S3) will involve multidisciplinary working groups of professionals. Using the data from S1 and the composite case narratives developed in S2, the working groups will map systems' capacity building needs and determine a strategy to build systems' capacity to support parents with intellectual impairment and promote a positive start to life for their children.

- S1 interviews will be conducted in the family home, audio-recorded and later transcribed. Informed by ecological-transactional theory, and modeled on the now classic Life Events and Difficulties Schedule, the semi-structured interview will assess parent stressors/supports needs and service utilisation across four broad, inter-related domains: family relationships and routine/s (e.g., cohesion, chaos); family resources and constraints (e.g., financial hardship, neighborhood safety and services, social support); parent-child health and wellbeing; and, parenting knowledge and skills. To obtain the worker perspective on the parent's support needs (and worker training needs) phone interviews will be conducted with parent nominated key workers.
- The collective case study (S2) will investigate the service pathways and experiences of parents with intellectual impairment, including pathways into and within the child and youth protection system, from multiple vantage points. Parents and workers will be interviewed, case records will be reviewed, and policy documents will be analyzed to generate insight into (a) how problem-situations are defined, decisions made and services negotiated, and (b) factors influencing or shaping these processes and, in turn, parent and child 'outcomes'. Interviews with parents and workers will elicit their narratives of what has taken place, covering topics such as first contact (e.g., circumstances leading up to the child maltreatment investigation), critical incidents/ turning points in the case, parent and worker understandings (e.g., problem definitions) and decision-making, and services/referrals. Based on a careful analysis of all of the data, a series of composite case narratives will be developed. Each of these will be constructed from multiple, individual case narratives to protect participant confidentiality.
- The study will culminate in S3, *determining a capacity building solution*. **The aim is to engage users of research in the process of interpreting the research findings and translating these into a plan of action.** Professionals, including decision-makers and experienced frontline service providers will be recruited to participate in S3. The participants will be divided into working groups. Each group will work independently. This multi-group strategy may be viewed as a form of investigator triangulation, strengthening the rigor of the process. A series of three focus groups will be conducted with each group.

Figure. Model of data analysis



S3. DEVELOPING A CAPACITY BUILDING STRATEGY

- In the first focus group, participants will be invited to share their perspectives on services for parents with intellectual impairment, including perceived systems' strengths and deficiencies. Findings from S1 and the composite narratives developed in S2 will then be presented to each working group.
- In the second focus group, participants will come together to discuss the composite case narratives. The overarching question for group discussion is, "what do these cases reveal about systems' capacity to support parents with intellectual impairment and their children (e.g., service gaps, continuing professional education needs, etc)?" Qualitative descriptive methods will be employed to analyse and summarise Focus Group 1 and Focus Group 2 discussions, and summaries will be distributed to participants.
- In the third focus group, participants will use all of the available data, S1 - S3, to map systems' capacity building needs and together design a systems' capacity building strategy. The work of the groups will then be integrated, with input from the parent reference groups.

PROJECTED OUTCOMES

- One outcome of the project is the creation of policy and practice relevant knowledge about the support needs and service pathways of parents with intellectual impairment. There is now a substantial literature on parents and parenting with intellectual impairment. However, there remain significant gaps in knowledge which this project will address including, for example, knowledge about the service pathways of parents with intellectual impairment. **The primary outcome will be a research-informed strategy to build system's capacity for evidence-based practice, delivered by well trained, properly resourced and joined-up service providers.** The strategy will include the specification of goals and a comprehensive plan of action that is ready for implementation and evaluation. This strategy and plan of action will not be developed by the researchers in isolation. Rather, users of research, including decision-makers and frontline practitioners will be actively involved in its development. The purpose of engaging users of research in this process is to facilitate knowledge translation: people responsible for implementing the strategy will have had a hand in creating it.
- One of the potential impacts of the project is changed thinking about the support needs of families headed by parents with intellectual impairment. The project may for instance foster a more contextual and holistic understanding of their support needs *vis a vis* the current focus on parenting skill deficiencies. A more holistic approach will consider hitherto neglected support needs, including but not limited to the need for trauma, grief and/or relationship counseling; quality health care (e.g., mental health and addictions); safe housing and financial assistance; and, positive social relationships. Ultimately, the impact of the project, or more specifically, the capacity building work it gives rise to, will be measured by its impact on the developmental health and life chances of children. We anticipate that building system's capacity to accommodate the support and learning needs of parents with intellectual impairment will result in a substantial reduction in the risk of child developmental delay, child behaviour problems, and child accidents and injuries; and, a substantial reduction in the number of children entering the out-of-home care system.