

**Summary of PhD Qualitative study: Investigation into the health, well being and occupations of Victorian mothers of a child with a disability.**

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Please view the accompanying PDF file that explains the methodology used for this study.

Victorian mothers engage in an extraordinary range or relentless and difficult direct and indirect tasks as a result of mothering their child with a disability. Direct caregiving occupations range from semi medical procedures such a gastrostomy feeds, and administration of many daily medications; to night time waking to assist a child with seizures, or to roll an immobile child, unable to roll themselves in bed; to containing violent behaviour; and assisting their child to play on equipment at regular playgrounds. Indirect occupations associated with caregiving included the constant need advocate for a child's inclusion; necessary development of personal skills that help the mother to emotionally manage and care for their individual child; and organization and planning for the many services that the child needs and uses. The needs of the child, and the consequences of the type and extent of disability, resulted in a range of services being required by the child and family. Services included school based assistance, many professional and medical services, and community based respite services. Any challenge to locate, retain, or afford a necessary service caused much time and hardship for the mother. In fact, the mother was challenged by many factors about services; the child themselves and tasks required to care for the child; family factors; and community factors including physical and attitudinal barriers. Similarly, characteristics of these factors may also provide support for the mother, such as having available, suitable and affordable services; a supportive and involved spouse; and an inclusive helpful school community. Another important factor that influenced how well a mother managed her caregiving role, in addition to the other roles in her life, was the characteristics and skills that the mother possessed herself. A mother who possessed personal characteristics that enabled her to organize herself, rally support and advocate for her child was described as being better able to manage the caregiving role. Overall, the sum total of challenges and supports from within the child; the mother herself; family; services and the community either helped or hindered the mother's management of her caregiving role. Another effect from this whole equation of influences was on the mother's health. Physical and mental health effects were described as significant by all participants in the study. Anxiety, depression, suicidal thoughts, back and neck pain and ongoing feelings of distress were reported.