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THE HIDDEN COSTS OF CARING:  
WOMEN WHO CARE FOR PEOPLE WITH  
INTELLECTUAL DISABILITIES

A thesis presented in partial fulfilment  
of the requirements for the degree  
of Doctor of Philosophy at  
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...the mother is really the one that looks after the handicapped children because the husband has to work. And then when he comes home tired from work he doesn't want to know how many times that day \_\_\_\_\_ wet on the floor or was sick or she had a row with the neighbour because of the kid or something else...

(Quote from a mother)

They're always in the caregiving roles. Direct hands on caregiving roles....I think it goes back to the traditional myth of women as being primary caregivers. The men in positions of power.

...I think mainly the men I've come into contact with within the IHC have been administrators or managers or executive staff, something like that, and it's the women who do all the hands on, all the middle management - not usually top management...

(Quote from a mother)

ABSTRACT

This dissertation examines the ways in which patriarchal systems structure and control the lives of women who care for people with intellectual disabilities. It is argued that the power relations which derive from these systems have remained hidden and that the richness and diversity of the experiences of these women have not been adequately portrayed.

In an attempt to authentically capture the lived experiences of women who cared for people with intellectual disabilities this dissertation provides an account of the perceptions of thirty women. These women were mothers of people with intellectual disabilities and/or paid workers employed by the New Zealand Society for the Intellectually Handicapped, a large voluntary Organisation providing services for people with intellectual disabilities in New Zealand, hereafter designated the Organisation.

Certain key principles of feminist theory and research are used to develop an analysis which seeks to not only reveal pertinent relations of power, but to examine and critique them. This process contributed to the development of a means for transforming both the practices that control the women's lived experiences and the meanings used to interpret these experiences.

The analysis of the relations of power that controlled women who care for people with intellectual disabilities was advanced in relation to two key sites: the household and the Organisation. The explanatory framework developed to explore the lived experiences of the women was derived from certain intellectual strands in the French tradition. Irigaray's writings were used to elucidate the ways in which patriarchal systems operate to control the women's lives. Foucault's theoretical concepts contributed to the development of certain technologies of power that operated in the household and the Organisation. These technologies of power which pervaded the daily

lives of women relate to both the material conditions of their existence and to the social meanings used to define their lives.

Several significant themes emerged from the analysis of the women's experiences. One of the most important of these related to the women's views on the policies of community care. In examining these the women's ambivalent feelings about the implications of these changes are articulated.

Associated with this finding the themes also clearly supported the view that new ways of explaining women's lived experience must be developed. A definitive example of this was the way in which feminist theory must continue to re-examine the explanatory usefulness of the now familiar private and public dichotomy as a concept for describing women's experiences. The present research identifies some alternatives for explaining and understanding women's experiences in the private and public realm. Some possibilities for extending this process further are also addressed.

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