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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
Massey University

Robyn Munford

1989
...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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# TABLE OF CONTENTS

| ABSTRACT | iii |
| ACKNOWLEDGEMENTS | v |

## PART ONE

### CHAPTER ONE: INTRODUCTION

- The Context: The New Zealand Society for the Intellectually Handicapped (IHC)  
  Page 8
- Women Who Care  
  Page 11
- The Form of the Thesis  
  Page 16

### CHAPTER TWO: THEORETICAL PERSPECTIVES

- Feminist Theory and Research  
  Page 19
- Critique of Economic Explanations of Power  
  Page 22
- Foucault and Irigaray's Understanding of the Nature of Power  
  - Michel Foucault  
    Page 28
  - Luce Irigaray  
    Page 39
- A Framework for Analysing the Experiences of Women Who Care for People with Intellectual Disabilities  
  Page 47
  - The Household - Women's Daily Lives and Experiences of Power  
    Page 49
  - The Observation, Examination and Comparison of Women in the Household  
    Page 51
- The Use of Knowledge to Control Women in the Household  
  Page 53
<table>
<thead>
<tr>
<th>Chapter Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>- The Use of Language to Control Women's Experiences in the Household</td>
<td>55</td>
</tr>
<tr>
<td>- The Technologies of Power Operating in the Organisation</td>
<td>55</td>
</tr>
<tr>
<td>- The Observation, Examination and Comparison of Women in the Organisation</td>
<td>56</td>
</tr>
<tr>
<td>- The Use of Knowledge to Control Women in the Organisation</td>
<td>59</td>
</tr>
<tr>
<td>- The Use of Language to Control Women in the Organisation</td>
<td>60</td>
</tr>
<tr>
<td>- Women's Resistance to the Power Relations</td>
<td>61</td>
</tr>
<tr>
<td>- The Process of Change</td>
<td>62</td>
</tr>
<tr>
<td>- The Role of Change Agents in the Process of Change</td>
<td>67</td>
</tr>
</tbody>
</table>

**CHAPTER THREE: THE RESEARCH PROCESS**

<table>
<thead>
<tr>
<th>Section Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Theory and Research</td>
<td>71</td>
</tr>
<tr>
<td>- The Role of Feminist Methodology in This Study: Factors That Have Influenced the Research Design</td>
<td>73</td>
</tr>
<tr>
<td>- The Process of Carrying Out the Research: Setting the Scene</td>
<td>75</td>
</tr>
<tr>
<td>- The Procedures and Criteria Used to Select the Women</td>
<td>78</td>
</tr>
<tr>
<td>- The Interviews</td>
<td>80</td>
</tr>
<tr>
<td>- The Analysis</td>
<td>85</td>
</tr>
</tbody>
</table>
PART TWO

THE WOMEN'S EXPERIENCES

CHAPTER FOUR: WOMEN'S EXPERIENCES IN THE HOUSEHOLD

- The Major Themes
- The Daily Routines and Relationships Associated with Caregiving
  - A Day in the Life of a Caregiver
  - Morning Routine
  - The Daily Routine
  - The Afternoon and Evening Routines
  - The Women's Feelings About Their Daily Routines
- Health and Well-Being
- Time and Waiting
- Women's Commitment
- Making Sacrifices
- Support
- Feeling Grateful
- Feeling Worthless
- Feeling Ambivalent - The Good and the Bad

CHAPTER FIVE: AN ANALYSIS OF WOMEN'S EXPERIENCE IN THE HOUSEHOLD

- Women's Daily Experience of Power
- Observation, Examination and Comparison
- Knowledge
- Language

CHAPTER SIX: WOMEN'S EXPERIENCES WITH THE ORGANISATION

- The Major Themes
- Work With the Organisation 132
  - Direct Caregiving Positions 134
  - Social Work and Support Positions 134
  - Staff Training and Policy Development 135
  - Management/Service Coordinator Positions 136
  - The Women's Feelings About Paid Work 137
- Voluntary Work 143
- Feeling Worthless 147
- Decision-Making Processes 150
- Exchanging Information About the Organisation 158
- Exchanging Information About Caregiving 163
- Support 166
- Work Without Reward 170
- Community Care 176
- Struggles and Resistances 189
- Feeling Ambivalent - The Good and the Bad 200

CHAPTER SEVEN: AN ANALYSIS OF WOMEN'S EXPERIENCES WITH THE ORGANISATION 202
- Observation, Examination and Comparison 202
- Knowledge 205
- Language 209

CHAPTER EIGHT: WOMEN'S RESPONSES TO THE RELATIONS OF POWER 212
## CHAPTER NINE: CONCLUSIONS

- Major Themes 222
  - Private and Public Worlds 225
  - Mutuality and Conflict 228
  - Bringing About Change 229
  - Community Care 232
- Future Research 234

APPENDIX ONE Personal Characteristics of the Women 237

APPENDIX TWO The Interview Schedule 243

BIBLIOGRAPHY 251