Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.
“In our house we’re not terribly sexual”:
Exploring the Barriers to Supporting Intellectually Disabled People in the Area of Sexuality and Intimacy

Carol Anne Hamilton

A thesis presented in fulfilment of the requirement for the degree of Doctor of Philosophy
Sociology, Social Policy and Social Work
Massey University, Palmerston North
New Zealand

2008
Abstract

How support workers enable, regulate or constrain the sexual expression of intellectually disabled people who live in service agency group homes is the subject of this thesis. A general literature search of what intellectually disabled people currently experience in their lives, including their experiences in the area of sexuality and intimacy, begins this investigation. Secondly, an extensive literature review of the support role, incorporating an appraisal of past and current issues related to the support position in general and to the area of sexuality support in particular, was completed. What intellectually disabled people themselves would like in relation to sexuality and intimacy support was included in this section. Thirdly, a review of research studies focussing on the operation of the support position within service agency systems was undertaken.

These explorations revealed a high degree of reluctance on the part of workers to provide assistance in the sexuality area, despite a proven necessity for support to be made available to the intellectually disabled people they worked with. Review research studies suggested a variety of causal factors in explanation of this reluctance. These suggestions link to two meta-reason positions. Failure to prove support either stemmed from individual worker’s inactions due to ignorance and/or incompetence, or from wider systemic failures on the part of agency services to positively value and support this key service role in this area. However, little if any analysis of the possible influence of the broader social, emotional and cultural contexts, in which the concepts ‘sexuality’ and ‘(intellectual) disability’ are located, could be found in the studies reviewed.

Eleven in-depth interviews were conducted with front-line support workers about their sexuality support practice. Preliminary readings of the interview texts revealed a similar reluctance on the part of the workers concerned to assist those they worked with in this area. Interview texts were then subjected to a post-modernist inspired, interpretive discursive analysis. This analysis uncovered and tracked how key power/knowledge effects inherent in the terms ‘(intellectual) disability’, ‘sexuality’,
‘gender’ and ‘desire’ inhering in the concept of an ‘ideal (sexual) couple’ interweave to shape the ‘no support necessary’ practice responses held in worker’s interview talk.

From this exploration it is suggested that research studies of workers’ practices as an aspect of the promotion of change in support outcomes in the sexuality support area need to go beyond the parameters of recommendations that stem from considerations of either individual or systemic limitation alone. It remains a convincing point to suggest that poorly performing workers need retraining in this area and the overall value of the support role within service organizations needs reshaping. However, future research recommendations also need to engage more directly and effectively with the effects of the wider social and emotional “ideal (sexual) couple” ambiguities that also influence worker’s lack of assistance in this complex and sensitive support area. The use of a post-modern perspective as a helpful conceptual tool in unpacking the power these ambiguities hold within the support position is offered as a productive way forward for future research and practice development.
Acknowledgements

While my name is on the title page of this thesis, I could not have done what I did by myself. I acknowledge, with aroha, the input of the following people.

My three supervisors: Dr Martin Sullivan, Prof. Robyn Munford, and Dr Michelle Lunn, who critiqued draft after draft of this thesis and who stuck with this project to the end. I could not have been in better hands.

My family and friends: Lise Claiborne, Miraz Jordan, Deb Moran, Heather Carrell and Maureen King, whose timely offerings of love, time, emotional support, food, transport and finance when I needed it most got me through.

The discourse group: Sue Cornforth, Jeanie Douche, Sue Sewell, Shirley Robinson and Margret Westwater, whose enthusiasm for the conceptual challenges of a post-modern approach kept me believing that this methodology had merit when it all seemed too hard to grasp.

People in the intellectual disability service field: Vicki Stewart, Donna Mitchell, Sue Smart and the workers I interviewed, whose assistance made the practical aspect of the project possible.

… and the others who, as they say, are too numerous to mention, but whose comments and actions have helped make this dream a reality

Carol Hamilton
Wellington
New Zealand

Summer 2008
# Table of Contents

Prologue ........................................................................................................ 11

CHAPTER 1 .................................................................................................. 13

Background, Research Question, Rationale and Context .......................... 13
  Introduction .................................................................................................. 13
  Intellectual Disability .................................................................................. 14
  History ........................................................................................................ 15

SECTION 1: .................................................................................................. 16

Intellectually Disabled People and Quality of Life .................................... 16
  Quality of Life in Domestic Environments ................................................ 16
  Difficulties with Service Systems .............................................................. 17
  Quality of Life in Community Settings ..................................................... 17
  Job Participation ......................................................................................... 18
  Income ...................................................................................................... 18
  Participation in Community Life .............................................................. 18
  Socio/Emotional Conditions .................................................................... 19
  How Intellectually Disabled People View their Lives ................................ 20
  The Supported Independent Living Option ............................................ 20
  Discussion ................................................................................................ 21

Sexuality and Quality of Life ...................................................................... 22
  The Problem of Material Environments ................................................... 22
  The Problem of Inadequate Knowledge ................................................... 23
  Problems for Intellectually Disabled Women .......................................... 24
  Problems for Intellectually Disabled Men ............................................... 25
  What Intellectually Disabled People Think ............................................. 26
  Gay, Lesbian and Bisexual Issues ............................................................. 27

Section 2: The Research Question ................................................................. 28
  Why the Support Position? ....................................................................... 28
  Why Sexuality Support? ........................................................................... 30

Sexuality and the Theoretical Context ......................................................... 31

Section 3: Support in the Wider Context ..................................................... 33
  Three Social Beliefs .................................................................................. 33
CHAPTER 2 ........................................................................................................................................ 39

Profiling the Support Position ..................................................................................................... 39
  Introduction .............................................................................................................................. 39
  Definition of a Support Worker ................................................................................................. 39
  Support in New Zealand ........................................................................................................... 40
  Individual Worker Performance on the Job ............................................................................. 41
  Isolating a Discrepancy ........................................................................................................... 41
  Review ........................................................................................................................................ 43
  Problems in the Worker Position ............................................................................................ 44
  The Retention Problem ............................................................................................................ 44
  The Stress Problem .................................................................................................................. 45
  Solutions to these Problems ..................................................................................................... 46
  Problems in the Organisational Structure ............................................................................. 46
  Difficulties for New Workers .................................................................................................... 46
  Differing Consequences for Workers ..................................................................................... 47
  Communication with Managers ............................................................................................... 47
  Differing Audiences and the Support Role ............................................................................ 48
  Summary .................................................................................................................................... 48

Intangible Factors in the Support Position .................................................................................... 49
  Factoring in the Emotional Aspect of the Role ...................................................................... 49
  A Positive View ....................................................................................................................... 50
  Worker Reticence .................................................................................................................... 51
  Emotion in the Support Position .............................................................................................. 52
  Emotional Ambivalence ............................................................................................................ 53
  Example 1 .................................................................................................................................. 54
  Example 2 .................................................................................................................................. 54
  Example 3 .................................................................................................................................. 55
  Summary .................................................................................................................................... 57
  Connecting Workers to Those They Support ....................................................................... 58
  Workers and “Being Known” ..................................................................................................... 58
  Emotional Blandness ................................................................................................................. 59
  Further Discussion ..................................................................................................................... 60
CHAPTER 3

Human Service Agencies, Workers and Sexuality Support

Introduction

Part 1: Documenting Sexuality And Worker Support Practice

Consequences of Sexual Behaviour
Variations in Worker Response
1983–1994
Research Studies from 1994
Isolating Troubling Sexual Behaviour
Gender and Support Practice
Summary

Human Service Agencies and Sexuality Support

The Dual Obligation Conflict
Promoting Ability/Protecting From Harm
The Impact of Gender Neutrality on Service Provision
Sexual Abuse and Gender Neutrality
Service Agency Provision in Mitigation of Abuse
Sexuality Education and People who use Services
Agencies Concentrate on Socio-Material Change
Summary

Developing a Safe Work Environment

The Value of Training
Support and Policy Initiatives
Summary

Part 2: The Gap between Organisational Systems and Worker Difficulties

Organisational Systems and Abuse Support
Support for Workers and the Interplay between Gender and Sexuality
An Ethos of Female Care
Worker Distance
The Effects of a Group Staffed Home Model
Summary
The Manager Role
Support for Managers
Research and Practical Solutions to the Problems

Further Discussion

Further Discussion
CHAPTER 4 ......................................................................................................................... 92

Theoretical Perspectives and Support Provision 92

Concept 1: The Individual/Medical Framework 92
  Difficulties with an Individual/Medicalised Approach 93
  Cure Defines the Limits of the Support Role 94
  Intellectual Disability and Individual/Medicalised Approaches 95
  Two Kinds of Support Principles 95
  The Value of Normalisation Principles 96
  Social Role Valourisation and the Role of ‘The Other’ 96
  Social Role Valourisation and the Role of Support 97
  Social Role Valourisation and Normalising the Social Body 98
  Why the Pre-Eminence of Social Role Valourisation Principles? 98
  What Does Community Mean? 99
  Normalisation/Social Role Valourisation and Support in New Zealand 100
  Consequences of Normalisation for Intellectually Disabled People 101
  Normalisation Principles and Support Practice 102
  Normalisation/Social Role Valourisation and Sexuality Support Practice 103
  Summary 104

Concept 2: Social Model Principles Framework 104
  Disability as a Lack of Resources 105
  Disability as Unequal Social Relationships 106
  The Influence of Social Model Principles 106
  Difficulties Relating to Social Model Principles 107
  The Value of the Model when Impairment is Mind rather than Body 108
  The Inclusion of Larger Social Issues 108
  Social Model Perspectives and Intellectually Disabled People 110
  The Distinction between Ability and Advantage 110
  Social Model Principles and Notions of Support 111
  Investigating the Flipside of the Coin 112
  Summary 113

Concept 3: Rights Based Frameworks 113
  Allowing the Right – How much does it enable? 114
  Rights Based Principles and Sexuality Support 115
  Rights, Support and Wider Social Processes 116
  Summary 117

Further Discussion 117
## Dissolving the Binary

- Research Recommendations 120
- Recommendation Difficulties 121
- Changing the Focus 123
- Challenging the Notion of (Worker) Autonomy 124
- De-Centering the Individual 126
- Re-Visioning Disability Support 127

## Developing a Post-Modern Context

- Disability and the Notion of Cartesian Dualism 129
- Disability as a Material Reality of Inter-Relationship 130
- Disability as a Cultural Orientation 131
- The Standpoint Position for the Data Analysis 131
- Disability and Support Interconnections 132
- Developing a Post-Modern Position 132
- Ontology: The Material Body 133
- Epistemology: The Body of Knowledge 134

## Positions of Power and Support Frameworks

- Reworking Power Dynamics 135
- Foucault and Power Dynamics 136
- Three Aspects of Power 136
- Linking Power/Knowledge 137

## The Influence of the Normative

- Normative Codes 138
- The Problem with Normative Codes 139
- The Power/Knowledge/Language Nexus 140
- Language and Normative Positions 141
- Language and Discourse 141
- Discursive Power, Language and Making Choices 141
- Re-Framing Sexuality 142
- Sexuality as Discursive Formations 143
- Sexuality and Binary Codes 144
- Sexuality Power/Knowledge Effects and Support Work 146
- Power as Repressive and Enabling 147
- The Difficulty With Revisioning Disability 147
- Why Re-Focusing is Important 149
- Footnotes 149
CHAPTER 8

Sexuality Support: Positioning Women

Introduction

Discursive Assumptions and Support Positions

Helen: ‘She’s Too Old For It’

Exploring the Knowing Worker Position
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information For Participants</td>
<td>322</td>
</tr>
<tr>
<td>Who is doing the research?</td>
<td>322</td>
</tr>
<tr>
<td>Ethical Approval</td>
<td>325</td>
</tr>
<tr>
<td><strong>Appendix Two: Group Confidentiality Agreement Form</strong></td>
<td>326</td>
</tr>
<tr>
<td>Group Confidentiality Agreement</td>
<td>326</td>
</tr>
<tr>
<td><strong>Appendix Three: Worker’s Consent Form</strong></td>
<td>327</td>
</tr>
<tr>
<td>Consent Form for Support Workers</td>
<td>327</td>
</tr>
<tr>
<td><strong>Appendix Four: Letter to General Manager</strong></td>
<td>330</td>
</tr>
<tr>
<td><strong>Appendix 5: Interview Trigger Questions</strong></td>
<td>333</td>
</tr>
<tr>
<td>Trigger Question Format</td>
<td>333</td>
</tr>
<tr>
<td>General Questions</td>
<td>333</td>
</tr>
<tr>
<td>General Sexuality Questions</td>
<td>333</td>
</tr>
<tr>
<td>Support Work and Personal Care</td>
<td>333</td>
</tr>
<tr>
<td>Responses to Sexualised Behaviour</td>
<td>334</td>
</tr>
<tr>
<td>Training and Information</td>
<td>334</td>
</tr>
<tr>
<td>Sexuality Policy</td>
<td>335</td>
</tr>
<tr>
<td>Change</td>
<td>335</td>
</tr>
</tbody>
</table>