“Conditionally Sexual”:
Constructing the sexual health needs of men and teenage boys with a moderate to profound intellectual disability

Nathan J. Wilson
MSc *Birm (UK)* BSocSc *CSU* DipHealthSc *UWS*

Centre for Developmental Disability Studies
Faculty of Medicine
University of Sydney
Australia

Submitted in fulfilment of the requirements for the degree
Doctor of Philosophy (Medicine)
March, 2009

CERTIFICATION

I certify that this thesis and the research reported in it are original. It contains no material which has been submitted for the award of any other degree or graduate diploma in any other university, and that to the best of my knowledge and belief this thesis contains no copy or paraphrase of material previously published or written by another person, except where due reference is made in the text of the thesis.

Nathan J. Wilson
MSc *Birm (UK)* BSocSc *CSU* Dip. Health Sc *UWS*

CONTENTS

CERTIFICATION **i**

CONTENTS **ii**

ACKNOWLEDGEMENTS **vi**

STYLE KEY **vii**

PUBLICATIONS AND PRESENTATIONS **viii**

LIST OF TABLES **x**

LIST OF FIGURES **xii**

LIST OF APPENDICES **xiv**

ABSTRACT **xv**

CHAPTER 1 – Introduction: Sexual health as a biopsychosocial perspective **1**

CHAPTER 2 – People with an intellectual disability being sexual: The historical and philosophical context **6**

Some Historical Context of Intellectual Disability *7*
Pre-Christian Era *10*
    Summary of pre-Christian Era *12*
Christian Era *13*
    Christianity and Political Power *13*
    Christian Dualism *14*
    The Middle Ages (500-1300 AD) *15*
    The Renaissance (1300-1520 AD) *17*
    The Reformation (1520-1700 AD) *17*
    The Age of Enlightenment (1700-1820 AD) *19*
    Summary of Christian Era *19*
The Scientific Era *21*
    Eugenics *25*
    The War Years *26*
    Sexology *27*
    Summary of Scientific Era *29*

Sexual Sociology 29
    Structuralist Accounts 30
    Deconstructionist Accounts 31
    Interactionist Perspectives 31
    Feminist Approaches 33
    Discursive Perspective 34
    Summary of Sexual Sociology 35
The Current Intellectual Disability Discourse 36
    Involuntary Sterilisation and Reproductive Rights 42
    Sexual Abuse 44
    Masturbation 47
    Summary of Current Intellectual Disability Discourse 48
Sexual Health and well-Being 48
    Summary of Sexual Health and Well-Being 52
Summary 53

CHAPTER 3 – Sexual health for men and boys with an intellectual disability 54
Introduction 54
Men and Boys with an Intellectual Disability 58
    Sex Differences in Literature Relating to Intellectual Disability 61
Pathologising men and boys with an intellectual disability 72
Theories of Masculinity 77
    Direct Gender Hierarchy: The Gender–Power Quandary 82
    Structural Inequality: Gender as a System of Meaning 84
    Masculinity and Intellectual Disability 86
Male Sexual Health and Intellectual Disability 88
    An Emerging Male Sexual Health Agenda 90
Male Health as Defined by the Mainstream 91
    A Definition of Male Health 94
    A Feminised Health Environment? 95
    A Masculine Health Environment? 96
    A Salutogenic Approach to Male Health 98
    The Potential of the Male Carer 102
Summary 105

CHAPTER 4 – Ethnography as a research methodology 106
The Research Question 107
The Choice of method 108
A definition of Ethnography 111
Ethnography as Methodology 111
Bias in method Selection 114
My Theoretical Perspective 115
Ethnographic Techniques to Understand the Lives of People with an Intellectual Disability 118
Sensitive Research of the Vulnerable 121
Masculine Ethnography as Research Method 124
Summary 126

CHAPTER 5 – Procedure: understanding sexual health 127
Ethical Research 129
    Ethics Application 132
    Ethical Concessions 133
Access to the Field 136
    Setting: The Australian Context 137
    Interview Participants 139
Data Collection 140
    Design of Interview Schedule and Pilot Interviews 140
    Interviewing 142
    Observation 146
    Exiting the Field 148
Data Analysis 149
    Transcription of Interviews 149
    Transcription of Participant Observation 151
    Constant Comparative Analysis 152
Summary 158

CHAPTER 6 – Conditionally Sexual 159
Snapshot of Peter's Day 161
The Three Themes of Conditionally Sexual 164
    1) Sexual development 164
    2) Conditionally Masculine 165
    3) Gendered Service Delivery 166
Summary 167

CHAPTER 7 – Sexual development of men and teenage boys with a moderate to profound intellectual disability 168
The Individual 170
    1) Self-discovery 170
    2) Hormonal Influence 176
    3) Reinforcement 178
    4) Insight 181
    5) Self-care 184
Staff Influence 185
    1) Staff belief-system 186
    2) Duty of care 191
    3) Staff as interactional gatekeeper 193
Summary and Conclusions 194

CHAPTER 8 – Constructing the concept of *conditionally masculine* 197
A Positive Construct 199
    1) Being male 199
    2) Male mutuality 203
A mutable Construct 207
    1) Limited masculinity 207
    2) Shapes masculinity 213

Unique: Maleness is different from femaleness 215
    1) Motherly interaction 216
    2) Masculine sexual control 217
Summary and Conclusions 218

CHAPTER 9 – Gendered service delivery 222

A Gender Continuum 224
    1) Gender Less Important 224
    2) Gender Important to Role 226
Gendered Caring Roles 227
    A Feminine Perspective 227
    1) Femaleness is different from maleness 228
    2) Minimising male temptation 236
    A Masculine Perspective 238
    1) Maleness is different from femaleness 239
    2) Males as carers 241
    3) Males as a conduit to male well-being 245
    Promoting Maleness 246
The Built Environment and Staffing 249
    Staff training 252
    Policy 252
Summary and Conclusions 253

CHAPTER 10 – A review of the study, and future impact on policy, practice, research and theory 256

Purpose of the study 256
The Findings 257
    1) Sexual Development 258
    2) Masculinity 258
    3) Service Delivery 259
    Summary of Findings 259
Methodology 260
    Review of the Literature 260
    Ethnography 262
    Scientific Rigour 263
    Ethics 265
    Reflexivity 266
Implications of the Study 267
    Ethnographic Implications 268
    Toward a Masculine Ethnography? 271
    Implications on Practice 272
    Implications for Theory 278
Toward a Masculine Health environment 284
Conclusion 288

REFERENCES 289

APPENDICES 321

ACKNOWLEDGEMENTS

The completion of this thesis would not have been possible without the support of a number of people over the last five years, none more so than the participants.

I am honoured to have been supported by my three supervisors whose patience, encouragement, and knowledge have expertly guided me toward completion of this project. The supervisory team was: Professor Trevor R. Parmenter, Associate Professor Roger J. Stancliffe, and Dr Russell, P. Shuttleworth.

The support of my employer, Disability Enterprises, for allowing me a flexible working arrangement. In particular, sincere thanks to a wonderful mentor, Mr. Bob Weaver. Also, thanks to Deb Brown and Deb Andrews for their unwavering patience.

In particular, thanks to my wife, Sandra, and our three beautiful children; Skye Victoria, Rory Johnathan Gord, and Saffi Violet; for their unconditional love and support, their endurance, and for the many sacrifices they have made over these years.

I would also like to acknowledge Dr Chris Atkins for her frequent intellectual support, Desrae Parker for her clarity of vision, and my good friend Tony Green for his reliable sense of humour and regular intellectual debate. In addition, Kathy Thorncraft at the University of Sydney Medical Library.

This project was supported by a University of Sydney Postgraduate Award, support from Disability Enterprises, plus a small textbook grant from the Blue Mountains Health Trust, and a conference grant from the NSW Nurses and Midwives Board.

STYLE KEY

Italics	are used to introduce a technical or key term
“Italics”	refer to direct quotes from participants
“Double quotation”	not in a quote represents a title, slang, or coined expression
Bold	represents my emphasis

PUBLICATIONS AND PRESENTATIONS

Publications –

Wilson, N. J. (2005). Men, health and intellectual disability: The current status. *The Journal of the Association for Practitioners in Learning Disabilities, 21*(3), 6-13.

Wilson, N. J., Cumella, S., Parmenter, T. R., Stancliffe, R. J., & Shuttleworth, R. P. (2009). Penile hygiene: Puberty, paraphimosis, and personal care for men and boys with an intellectual disability. *Journal of Intellectual Disability Research, 53*(2), 106-114.

Wilson, N. J., Parmenter, T. R., Stancliffe, R. J., & Shuttleworth, R. P. (2009). From diminished men to conditionally masculine: toward a salutogenic construct of masculinity for men and boys with an intellectual disability. *Manuscript submitted for publication*.

Wilson, N. J., Parmenter, T. R., Stancliffe, R. J., Shuttleworth, R. P., & Parker, D. (in press). A masculine perspective of gendered topics in the research literature on males and females with intellectual disability. Journal of Intellectual and Developmental Disability.

Presentations at conferences –

Wilson, N. J. (2006). Men with an intellectual disability and gender equity in health: A recognition of difference before equity, *Paper presented at the 17th Annual Conference of the Professional Association of Nurses in Developmental Disability Areas (Aust) Inc*. Epping: NSW.

Wilson, N. J. (2007). Sexual health and men with an intellectual disability: A population health approach drawing upon masculinity theory, *Oral poster presented at the World Association for Sexual Health 1st World Congress for Sexual Health: Achieving Health, Pleasure and Respect*. Sydney: NSW.

Wilson, N. J. (2007). Defining the sexual health needs of men with an intellectual disability: A salutogenic approach, *Paper presented at the 42nd annual conference of the Australasian Society for the Study of Intellectual Disability (ASSID): Active citizenship, community engagement.* Fremantle: Western Australia.

Wilson, N. J. (2007). Constructing a salutogenic framework for the sexual health needs of men with an intellectual disability, *Paper presented at the Annual conference for the Association of Psychologists in Developmental Disability Services (PSYCHDD)*. Mercure Hotel, Parramatta: NSW

Wilson, N. J. (2007). Restraining passion: male sexual health at the crossroads, *Paper presented at the 18th Annual Conference of the Professional Association of Nurses in Developmental Disability Areas (Aust) Inc*. Epping: NSW.

Wilson, N. J. (2007). *A forgotten and vulnerable population: men with profound and severe intellectual disabilities.* Paper presented at the 7th National Men's Health Conference; Debate and invigorate: challenges in men's health, Adelaide convention centre.

Wilson, N. J., Parmenter, T. R., Stancliffe, R. J., & Shuttleworth, R. P. (2008). Constructing the sexual health needs of men and boys with a moderate to profound intellectual disability, *Poster presented at The University of Sydney Biennial Faculties of Health Research Conference: "From Cell to Society 6"*. Leura, NSW.

Wilson, N. J., Parmenter, T. R., Stancliffe, R. J., & Shuttleworth, R. P. (2008). Conditionally sexual: Constructing the sexual health needs of men and boy's with a moderate to profound intellectual disability, *Paper presented at the NSW Department of Ageing Disability and Homecare Behaviour Support Conference for Metro South: „Disability and Sexuality; A Clinical Perspective'*. Thomas and Rachael Moore Education Centre, Liverpool Hospital, NSW.

LIST OF TABLES AND BOXES

Table 2.1
Summary of Christian era 20

Table 2.2
List of life behaviours of a sexually health adult 51

Table 2.3
Summary of human sexual health concerns 52

Table 2.4
Categories of human sexual health problems 52

Table3.1
Estimates of the prevalence of intellectual disability by sex and age, total number (in 1000s) and as a percentage of the Australian population of that sex and age, 1998. 59

Table 3.2
Distribution of males and females with an intellectual disability using government-funded services in NSW during 2005-2006. 61

Table3.3
Summary of article titles in JIDR (1996 +), JARID, AJMR and JIDD with the word male, man, boy or men in title since the year 2000 64

Table 3.4
Summary of article titles in JIDR (1996 +), JARID, AJMR and JIDD with the word female, woman, girl or women in title since the year 2000 67

Table3.5
Summary of known book titles or book sections from a sex-specific perspective 70

Table3.6
Number of journal articles in JIDR (1996+), JARID, AJMR and JIDD related to family issues whose title mentioned gender since the year 2000 71

Box 3.1
Articles in JIDR (1996 +), JARID, AJMR and JIDD from 2000 whose focus was sex, or gender, differences 72

Table 3.8
Connell's framework for understanding masculinities 79

Box 3.2
Summary of the literature concerning male sexual health and intellectual disability 89

Box 3.3
Key findings from men's health education needs assessment 92

Table 5.1
Thematic Summary of Semi-Structured Interview schedule *141*

Table 5.2
Semi-Structured Interview Schedule *142*

Table 5.3
Example of formation of open codes *154*

Table 5.4.
Example of formation of axial codes *155*

Box 7.1
Field notes: Controlling Physicality *187*

Box 7.2
Excerpt from human relations and sexuality policy *191*

Box 7.3
Field notes: Staff role as Interactional Gatekeeper *194*

Box 8.1
Field notes: The release of male energy *200*

Box 8.2
Field notes: male banter *206*

Box 8.3
Field notes: The interactional context of limited cognition *211*

Box 9.1
Field notes: The built environment, community group home 3 *251*

Table 10.1
Preliminary factors for a masculine health environment *285*

LIST OF FIGURES

Figure 3.1
The health promotion/reaction continuum 76

Figure3.2
Two perspectives of gender formation 81

Figure3.3
The pathological fortress of male sexual health 88

Figure 3.4
A problematised paradigm of male health 99

Figure 3.5
Salutogenesis 101

Figure 4.1
The research Process 110

Figure 5.1
Process of Enquiry 128

Figure 5.2.
Core constructs and hypothesised links between them 143

Figure 5.3
Emergent access-limit-deny continuum 153

Figure 5.4
Individual Sexual Development, Draft 157

Figure 6.1
Conditionally Sexual 160

Figure 7.1
Sexual Development: The First Theme of Conditionally Sexual 161

Figure 7.2
Axial codes for individual sexual development 170

Figure 7.3
Axial codes for staff influence 185

Figure 8.1
Conditionally Masculine: the second theme of Conditionally Sexual 198

Figure 8.2
Axial codes for a positive masculinity 199

Figure 8.3
Axial codes for mutable masculinity *207*

Figure 8.4
Staff perspective of masculinity, limited by disability *209*

Figure 8.5
Axial codes for unique: maleness is different to femaleness *216*

Figure 9.1
Gendered service delivery: The third theme of Conditionally Sexual *223*

Figure 9.2
Axial codes for a feminine perspective *228*

Figure 9.3
Amended core constructs of staff behaviour and performance *235*

Figure 9.4
Axial codes for a masculine perspective *238*

Figure 9.5
Promoting male well-being *248*

Figure 9.6
Performance of gendered caring roles *254*

Figure 10.1.
Theoretical Implication of Conditionally Sexual *280*

Figure 10.2.
Propositional concept for male health outcome *287*

LIST OF APPENDICES

Appendix 1. **322**

Ethics approval

Appendix 2. **324**

Consent form

Appendix 3. **325**

Participant information sheet

Appendix 4. **326**

Recruitment letter

Appendix 5. **327**

Interview Schedule

Appendix 6. **328**

Additional consent form for photograph

Appendix 7. **329**

Conditionally Masculine book chapter submitted for review with Vanderbilt Press

Appendix 8. **358**

Tabular example of codes using constant comparative method

ABSTRACT

This thesis reports on a study which explored the sexual health needs of men and teenage boys with a moderate to profound intellectual disability. Qualitative in design, this study was exploratory in nature as it sought to develop theoretical knowledge in male sexual health as a broad concept as opposed to testing a theory or hypothesis related to sexual health.

Literature on sexuality and intellectual disability was reviewed in addition to male-specific literature on intellectual disability. In addition, mainstream literature on sexuality, sexual health, masculinity and men's health was also reviewed. The literature review highlighted that the intellectual disability specific literature had largely ignored mainstream literature and had failed to acknowledge emerging work in men's health and masculinities. Moreover, the literature identified a problematised focus toward sexual matters and males with an intellectual disability.

The topic of enquiry was explored via an ethnomethodological design. Data consisted of interviews with 17 paid support staff, over 100 hours participant observation in community group homes, and triangulated with relevant artefacts from the field. The *constant comparative method* was used to analyse the data.

Participants described the notion of men and teenage boys with a moderate to profound intellectual disability as being *Conditionally Sexual.* Conditionally Sexual was framed by three interconnected themes: 1) sexual development, 2) conditionally masculine, and 3) gendered service delivery.

Through consideration of the implications to theory, practice, research, and policy, a propositional framework for a masculine health environment has been outlined. This framework is based on a salutogenic notion of male sexual health and the development of a healthy masculinity.

CHAPTER ONE

INTRODUCTION: SEXUAL HEALTH AS A BIOPSYCHOSOCIAL PERSPECTIVE

This thesis will report on a study which explored the sexual health needs of men and teenage boys with a moderate to profound intellectual disability. The primary research question asked was: what are the sexual health needs of men and teenage boys with a moderate to profound intellectual disability? Qualitative in design, this study was exploratory in nature as it sought to develop theoretical knowledge in male sexual health as a broad concept, as opposed to testing a theory or hypothesis related to sexual health. The aim of the study was to provide a conceptual framework of male sexual health which might enable families, accommodation, community support, and advocacy services to enhance the sexual health and well-being of the males with an intellectual disability they provide care and support to. Primarily, this chapter will present a synopsis of the thesis. In addition, it will introduce some key terms and definitions, plus a short summary of the impetus for the study.

People with an intellectual disability[1] are those who experience limitations in both intellectual and adaptive functioning, the origins of which occur before the age of 18, and whose limitations are expressed in conceptual, social and adaptive skills (World Health Organisation (WHO), 2001). Importantly, like all humans, people with an intellectual disability are a heterogeneous group. While unique differences between people with an intellectual disability are often articulated, for example, via diagnosis, IQ, or syndrome, this study will differentiate primarily by gender. In includes men and teenage boys with a moderate to profound intellectual disability as a sub-group, excluding younger boys with

---

[1] Intellectual disability is the terminology used in Australia, other countries may use terms such as learning disability, mental retardation, or mental handicap.

an intellectual disability and males with a borderline to mild intellectual disability. A person with a moderate intellectual disability typically has limited language skills and needs assistance with self-care; a person with a profound intellectual disability typically cannot understand requests, has very limited communication, no self-care skills, and is usually incontinent (Clarke, 2006). This study is based on the premise that men and teenage boys with a moderate to profound intellectual disability are human beings and are therefore sexual beings. As sexual beings, they also have sexual health needs.

The impetus for this study largely arose from my experiences over 20 years as a male specialist developmental disability nurse. I was troubled by many issues relating to the sexual needs of the men and boys with an intellectual disability I had supported, and indeed continue to support. Furthermore, the issues were also compounded by my location as often the only male staff member within a work setting and the desire not to appear overly interested in sexual matters to my female peers. In one of my recent roles, I engaged with the local women's health centre to identify how the centre might work with our organisation toward meeting the health needs of the women and girls with an intellectual disability our organisation supported. At the same time I had many staff approach me seeking advice regarding male health issues to which, in the absence of a model for men's health, I could only offer limited advice. The problems staff tended to identify related to penile and/or sexual problems and were typically constructed negatively; a pathological construction of male sexuality and sexual health. Therefore, the impetus behind this study was to endeavour to explore male sexual health from the positive perspective that as a man, and as a nurse, I knew it to be. That is, sexual health was an issue far greater than the penis, testosterone, and their alleged influence over the male brain.

While human sexuality as a concept is almost impossible to define (Pan American Health Organisation & World Health Organisation, 2000; Wheeler, 2001), the literature which seeks to explore sexuality and intellectual disability rarely seeks to attempt a definition. Accepted contemporary analysis suggested that in the past the sexuality of people with an intellectual disability was characterised by a denial of sexual rights, treatment as "eternal children", a perception of being either asexual or deviant, viewed as morally corrupt, and were thought to engage in profligate breeding of more people with intellectual disabilities (Dupras, 1976; Judge, 1987; Katz, Mutters, Norley, Sporken, & Stockmann, 1975; Kempton & Kahn, 1991; Rhodes, 1993). This analysis asserted that with a renewed and emancipatory focus on sexual rights, people with an intellectual disability should be as free as any other citizen to express their sexuality. However, the argument behind this analysis, past repressive – present empowering, seemed too simplistic to me as it overlooked the true complexity of human sexuality. The issue of rights is only one component of a much broader set of issues. Furthermore, given that laws relating to mental capacity are unequivocal about capacity and sexual consent[2], rights seemed more of a theoretical notion than a practical reality for males with more severe intellectual disability.

As a nurse, my undergraduate training taught me that health, including sexual health, was a biopsychosocial construct that could incorporate issues such as restrictions of rights due to mental capacity and still work toward supporting a person attain an optimal state of health and well-being. Based upon this biopsychosocial perspective, I believed sexual health to be a far more useful construct in supporting the sexuality of

---

[2] Generally, capacity to consent is reflected by a persons' ability to comprehend and retain information concerning the risks and benefits of the said matter plus use this information in weighing up their decision (Department of Health, 2001a). An essential prerequisite for consent relating to sexual matters must also consider the legal age for sexual consent which may differ from one jurisdiction to another (Roy, 2006).

people with an intellectual disability than an analysis hinging on the symbol of rights. When I turned again to the literature focussed on sexuality and intellectual disability it seemed I was misguided; sexuality as a social construct with rights as the fulcrum seemed to be the accepted theoretical perspective, sexual health a secondary bio-reproductive issue. Encouraged to explore the mainstream[3] literature by my primary PhD supervisor, I was overwhelmed with the quantity and theoretical breadth of literature, some of which supported my biopsychosocial “article of faith”, some of which did not. Significantly, the mainstream literature illustrated that the intellectual disability specific literature had overlooked two pivotal points by: 1) largely ignoring the mainstream sexual health literature and, 2) failing to acknowledge the emerging, but vital, body of work in men’s health and masculinities.

Therefore, this thesis began with both the sexual health needs of men and teenage boys with a moderate to profound intellectual disability and my own professional and personal convictions. These issues have been interrogated via an appraisal of the literature which spans the theoretical intersection of disability, sexuality and masculinity. Although a biopsychosocial paradigm has been declared as the starting point, this study has addressed the research aims via an ethno-methodological dissection of the sociological and bio-medical theoretical extremes. Central to this study are sexual health needs of men and teenage boys with a moderate to profound intellectual disability. I hope in a small way they may benefit from a renewed focus on their sexual health that will enable them to experience and enjoy a healthy and masculine sexuality.

---

[3] Mainstream refers to the wider body of literature that is concerned with all humans. The word “mainstream” is used throughout this thesis to reflect this wider body of work.

Literature exploring the sexual nature of humans will be reviewed in Chapter 2. This will situate the contemporary theoretical positions based upon an historical analysis of the intersection of sexuality and disability. Chapter 3 will then place a focus on men and boys with an intellectual disability and their sexual health needs as reported in the literature. Significantly, Chapter 3 will also examine the emerging theoretical development of masculinity studies and men's health. Chapter 4 considers why ethnography was the best approach to answer the research question and also articulates a review of my own bias within this study. Chapter 5 then procedurally unpacks the progress of the study ending with a summary of the *constant comparative method* and how it was used to analyse the data.

The study's findings are presented in Chapters 6 to 9 using a model to depict the three key themes. Chapter 6 introduces the model, *Conditionally Sexual*, and explains how this model represents an analysis of the data based upon my perception and the literature review. Chapter 7 deconstructs the first theme in detail, *sexual development*, and explains how this theme is an interchange between the individual, the staff and the environment. Chapter 8 unpacks the second theme, *conditionally masculine*, which offers a new insight into the effect impaired cognition has on masculinity. Chapter 9 contextualises the findings in Chapters 7 and 8, through an analysis of the third theme, *gendered service delivery*. Chapter 10, the final chapter, summarises what this study has found. In addition, Chapter 10 explores the implications of the study and presents an appraisal of the methodology including limitations. Lastly, Chapter 10 provides a propositional framework for a focus on male sexual health together with some suggestions for future research.

CHAPTER TWO

PEOPLE WITH AN INTELLECTUAL DISABILITY BEING SEXUAL: THE HISTORICAL AND PHILOSOPHICAL CONTEXT

> *In contemporary Western societies sexuality is often understood as a private, universal, and natural aspect of social life. However, sexual expression is also a public and a political concern that has great significance in terms of morality, social order, and identity. Historically, sexual conduct has been associated with polar extremes of good and evil, normality and abnormality, purity and danger, and order and disorder* (Hawkes & Scott, 2005b, p. xvii).

The sexual nature of humans has interested scholars in disciplines from theology and anthropology through to contemporary theoretical perspectives. Ancient texts such as the *Karma Sutra* remain relevant as humans continually endeavour to understand their individual and collective sexualities. In ancient Egypt, sexuality traversed the living and the afterlife, while in pagan Greek and Roman society even the Gods had unique non-human sexualities. Christianity then offered a different perspective of human sexuality which is still influential today. This chapter will provide a brief linear[4] account of human sexuality and how this account may have intersected with the lives of people with an intellectual disability. Further, this chapter will draw on contemporary philosophical perspectives of human sexuality to suggest how the current perspective on sexual health for men and boys with an intellectual disability has evolved.

Starting with a review of the pre-Christian era, this chapter chronologically progresses through summaries of the Christian and scientific eras, toward the social focus in the 20th century. Importantly, these summaries will consider the sexuality and intellectual disability-specific literatures and identify instances of their union in order to

---

[4] Several critiques, mostly post-modern, suggested that the development of human sexuality was far from a singular unilinear progression, but was a much more complex developmental concept (Gillis, 1987; Hawkes, 1996). Notwithstanding such critiques, Chapter 2 will pursue a brief linear narrative for ease of explanation.

accurately locate contemporary perspectives. That is, how is the current sexual discourse for people with an intellectual disability historically constructed[5] and what are the strengths and limitations of this discourse? To locate the current discourse, different theoretical approaches to sexual matters will be interrogated concluding with a summary of how bio-medical and sociological perspectives are frequently purported to represent an oppositional dichotomy. The major sections of Chapter 2 therefore are: 1) pre-Christian era, 2) Christian era, 3) scientific era, 4) sexual sociology, 5) the current sexual discourse and, 6) sexual health and well-being. To conclude, this chapter will suggest that a biopsychosocial perspective of sexual health and well-being offers a more useful framework; a framework which understands promotion of health and well-being as the positive interaction between a person and their environment. Firstly however, some potential pitfalls to the historical interpretation of disability will be summarised to set the scene for how the wider discussion has been approached.

SOME HISTORICAL CONTEXT OF INTELLECTUAL DISABILITY

Several problems in the interpretation of historical events relate specifically to intellectual disability. While they can be presented as differences of opinion, problems or critiques, they are nonetheless significant for the novice historian and therefore need to be acknowledged. Concerning the historical interpretation of disability, M. L. Rose (2003) felt little in-depth historical analysis actually takes place within modern literature and "…too often, anachronistic assumptions about modern standards of normalcy have been applied to very thin evidence and have resulted in sweeping conclusions" (p.31). These assumptions are: 1) differing interpretations of disability-specific treatment across time,

---

[5] Use of the work "construct" or "constructed" throughout this thesis does not refer to social constructionism or a social constructionist perspective. Construct simply means to build, erect, or create. References to social constructionism however do occur throughout the thesis and will be made explicit.

often with the benefit of hindsight, 2), the use of historical events to represent philosophical dogma, 3) the use of the written word over other artefacts and, 4) the misinterpretation of history. These four pertinent issues will now be summarised.

1) A review of some literature on the history of disability points to the understanding of different contexts of disability, different nomenclature and different perspectives across history (Berkson, 2006; Braddock & Parish, 2001; Bragg, 1997; Bredberg, 1999; Judge, 1987; Kanner, 1964; Parmenter, 2001). Problems and criticisms have started to emerge within analysis of some historical events partly because of such differing perspectives (Gleeson, 1997). Principal to this critique is the historically recent differentiation between impairment, a medically defined construct and disability, a socially defined construct. Such differentiation in constructs, argued Metzler (2006), were not at all relevant in the past. For example, certain impairments which disable in a modern and industrialised society may not have presented such a problem in previous historical periods. Therefore, to examine history with the language, ethics and concepts of today may impose a certain distortion on what life was truly like for the person with an intellectual disability. That is, each historical event needs to be interpreted based upon the tools and understanding each society had at its disposal, together with an appreciation of the variety of medical, social and economic factors. A pertinent example relates to the different ethical interpretations modern society places on the practice of infanticide in Greco-Roman times, as compared with the current practice of foetal screening and elective termination for certain genetic defects (e.g. Bauer, 2008; Little, 2009).

2) A key point of focus in the historical interpretation of sexual matters and intellectual disability are the use of asylums and/or the practice of eugenics in the 19th and

20th centuries as “symbolic” starting points for analysis (e.g. Aylott, 2001; Griffiths, 2007; Griffiths, Watson, Lewis, & Stoner, 2004; Katz et al., 1975; Kempton & Kahn, 1991; Roy, 2006; Savarimuthu & Bunnell, 2003; Servais, 2006). While asylums and eugenics are within themselves worthy topics for analysis, it is the manner of their historical interpretation together with limited recognition of events prior to this that problems arise. For example, contemporary discussion of sterilisation for those living in asylums around the turn of the 19th century is rarely contextualised by an appreciation in hindsight of the limited range of contraceptive and anti-libidinal options that might have been available 100 years ago. In addition, while the social control thesis relating to the growth of asylums has been successfully contested within literature relating to mental health (e.g. Coleborne, 2006), commentaries relating to intellectual disability still adhere to the edict of social control. For instance, McCarthy (1999) stated early institutions, run by lay superintendants, were taken charge of by doctors who “… became concerned that a whole field of work was slipping away from them” (p. 43). Therefore, an accurate and historically located analysis is required when navigating such divergent perspectives in search of a realistic interpretation on the influence of historically important events such as eugenics and asylums.

3) The source of historical material presents an additional consideration. Bredberg (1999) stated that at different points in history varying institutions which were responsible for managing disability, would have been in a much better position to document the processes of their institution than perhaps the majority of people in that society who may have been largely illiterate. To illustrate this point, the medicalised documentation of treatments on patients in asylums provided a rich and abundant source of written material. In the absence of any other records, such information is at risk of being generalised to the

treatment of all people with an intellectual disability and hence to that historical period. The management of sexual matters within asylums via exclusion and segregation provide one salient example of how generalisations can be made from one historical source.

4) A further problem relates to the misinterpretation of events which subsequently become accepted as truth. A very specific example of this relates to the *ship of fools* which Foucault, the French philosopher, described as an institutional practice to deal with the mentally ill (Maher & Maher, 1982; Metzler, 2006). The ship of fools was in fact "…a literary conceit that was part of a vernacular tradition regarding, not even madness, but folly" (Bredberg, 1999, p. 195). Foucault's error has since been used by other authors to describe a particular part of historical institutional life and hence enhancing and contributing to the reporting of the dehumanisation of all people with an intellectual disability during a defined period.

Notwithstanding the existence of the above pitfalls to historical analysis, an attempt follows to provide a meaningful summary that navigates the identified contextual pitfalls. That is, there is more to the story of people with an intellectual disability being sexual beyond the 19th century when literary records concerning asylum development, eugenics, and bio-medical interest swelled.

PRE-CHRISTIAN ERA

Ancient Greek society underpinned European civilization with various European countries later colonizing the rest of the World; Greek cultural norms, including those to do with sexuality, hence help explain the early evolution of modern society. In ancient Greece, and indeed pre-Christian Rome, hierarchical power relations in sexual culture reflected those of the political sphere; free adult males held the power over boys, slaves, women and foreigners (Wilton, 2000). Free males had the right to choose and to penetrate any person on the other side of the power divide; to penetrate with your penis was a mark of status, being penetrated was shameful. Wilton described how the concept of homosexuality, bisexuality, or heterosexuality was not relevant to Greeks. Same-sex intimacy was just a matter of personal preference, not a defining difference in personality or sexual identity such as how society describes homo, hetero and bisexual orientation today.

Cognitively impaired people were present in Greco-Roman times. Evidence exists in classical Greece of defined and hierarchical levels of intelligence which separated intellectual disability from curable mental illness (Berkson, 2006). M. L. Rose (2003) pointed out that large proportions of the peasant population during this time would have had a mild intellectual disability as defined today, in particular due to poor nourishment during the developmental years. Rose's historical thesis, and the chapter by Braddock and Parish (2001), also contradict the modern belief that infanticide was widespread during these times. However, while the prevalence of infanticide is open to conjecture, infanticide did take place and some cited examples include leaving an obviously disabled newborn on a hillside to die from exposure (Judge, 1987), dropping them into a chasm (McCutchen, 2000), or as Berkson stated, leaving them on your doorstep to either perish or to be taken away as in Roman times. Infanticide was legally supported by *The Twelve Tables*[6] stated Berkson, Gracer (2003) and Judge, which suggested to "…kill quickly … a dreadfully deformed child".

---

[6] The Twelve Tables was the first legislation that formed the centrepiece of the constitution of the Roman Republic.

At the height of the Roman empire, some wealthy Romans apparently did “keep” some people with a disability, physical and/or intellectual, as “fools” to entertain guests (Edgerton, 1984) with some faring quite well and even acquiring fame (Kanner, 1964). It was also considered to bring good luck if a wealthy male “kept” a person with a disability (Braddock & Parish, 2001). However, for the bulk of those with a disability who did survive to adulthood, the adult male of the family was responsible for their care often looking after the person in their own homes (Berkson, 2006). What this inferred in relation to sexual matters for those with an intellectual disability is unclear. However, the suggestion that some people with a disability were used to entertain guests may have also extended to sexual entertaining as it did for slaves. Certainly, mild intellectual disability did not preclude participation in society relative to one’s status, and this included conjugal union and parenthood. However, marriage and other legal acts, were not permitted for people with hearing impairment as well as those who cared not to speak, as it was for those who had a significant mental illness or more severe intellectual disability (Braddock & Parish, 2001). The participation of people with a disability in Norse and Celtic culture was also recorded; tales of disabled people (physical, sensory, intellectual) as integrated citizens exist which, according to Bragg (1997), was reflected in a level of social integration perhaps far greater than at any time since.

Summary of pre-Christian Era

Concerning people with an intellectual disability, the main conclusion to be drawn from the pre-Christian era are the challenge to the modern belief that widespread infanticide occurred, and the level of integration and participation of people with a mild intellectual disability. Furthermore, the establishment of laws directly affecting people with more severe intellectual disability had set a precedent for future law-making.

CHRISTIAN ERA

Christianity is relevant to a discussion of human sexuality as it became the dominant religion across Europe after the fall of the Roman empire and also in the Americas following colonisation (Hill, 2008). Christian values were hence institutionalised into the majority of western society. Contemporary constructs of sexual ethics, legality, and consent are steeped in a Christian understanding between the rational mind and Christian moral ethics. Within the intellectual disability literature, references to Christianity and its influence on rationality and ethics related to sexual matters are scant. McCarthy (1999) referred to Christianity in terms of the "evil impulse of the flesh" which needed controlling. Stinson (2004) suggested the Judeo-Christian view of heterosexuality is used as the valued norm against a backdrop of repression and conservatism. Fegan, Rauch and McCarthy (1993) stated sexual matters and intellectual disability are "…entangled in misinformation and mythology, not to mention religious and cultural beliefs, and personal anxieties" (p.1). Azzopardi (1975), a Catholic Priest, reminded us that a Christian perspective sees people with an intellectual disability as humans and therefore their acts, including sexual, are fully human acts.

Christianity and Political Power

Contemporary western political dialogue remains attached to traditional and family values with reference to what are considered "right" and "wrong" sexual practices (Wilton, 2000). Christianity first became part of the political fabric of society when it was embraced by the Roman empire in the 4th century AD (Horrocks, 1997). Horrocks described how this political shift resulted in Christianity becoming a multi-level political institution and saw the banning of infanticide and exposure of babies under Christian law. By the 6th century, Roman laws were formulated into *The Justinian Code* which recognised people who were “deficient of understanding”, precluding them from certain activities such as making a will and marrying (Berkson, 2006; Braddock & Parish, 2001). Berkson also stated Curators were appointed to oversee the affairs of some people with “deficient understanding” who required special protection. The ethical and moral basis of *The Justinian Code*, asserted Braddock and Parish, was reflected in most European laws from the 6th through to the 18th century. Modern statute law-making concerning sexual matters remain heavily influenced by Christianity in areas such as gay marriage, abortion, embryonic stem cell research, sexual offences law, pornography, sterilisation, and guardianship law.

Christian Dualism

The concept of Christian dualism refers to the burgeoning split between human reason and human emotion which came to represent the emergence of the modern world; the move from mystical and magical notions toward conscious rationality (Horrocks, 1997). Sexual matters, stated Horrocks, were caught between the tension of the animal-like sensuality of the body, and the rational mind yearning for reunion with their sensuality. This gradual shift, represented as the conflict between impulse and reason, had great significance for people with an intellectual disability. Berkson (2006) stated historical examples show people with an intellectual disability were not held responsible for their wrongdoings; they lacked the rationality to be able to deny or confess the consequences of their impulses. Impulsive bodily lust, in the absence of a rational mind, began to define sexual issues toward the ascetic Christian tradition of abstinence and avowed celibacy; sexual renunciation over promiscuity (Connell & Dowsett, 1992).

St. Augustine (354-430 AD) influenced Christian thinking through his writings that stated sexual intercourse outside of marriage was a sin (Westheimer & Lopater, 2005). St. Augustine taught that the only justification for sexual intercourse was to conceive a child (Potts & Short, 1999). As people who were significantly deficient in understanding were precluded from marriage, their range of options for sexual expression would have been similarly curtailed. Augustinian thinking also led to a shift from seeing disability as punishment for sin, or displeasure from the Gods, toward understanding disability as a natural phenomenon (Berkson, 2006). Augustinian thinking also reinforced Christianity as a political power. The church bolstered the notion that sex belonged to marriage hence the Christian state used religion to control its citizens and in turn their sexual lives where procreative, not pleasurable, sex via the mission position was the standard (Hill, 2008). Ironically though, prostitution was tolerated during these times and into the Middle Ages as it evidently avoided the overthrowing of society by “careless lust” (Connell & Dowsett, 1992).

The Middle Ages (500-1300 AD)

Humanity was dealt serious blows in the Middle Ages through various plagues, wars and epidemics which decimated populations and in turn changed the political and social landscape (Cocks & Stehlik, 1996). Disability was but one feature of widespread misery and suffering where the ill, poor and unfortunate became social classifications to define large groups (Stiker, 1999). The Middle Ages saw the classification of sexual “sins against nature” such as anal intercourse, oral sex, masturbation, interfemoral sex, sex during Lent, sex on the Sabbath, and positions of intercourse other than the missionary (Hawkes, 2005). The view that people without understanding should not be held accountable for their actions was made into law together with the expectation that relatives would care for their afflicted (*sic*) family (Berkson, 2006). After the implementation of the *Prerogativa Regis*, a law which entitled the Crown to take custody and profits from land owned by idiots (*sic*), British Court records from the latter part of the 13th century show idiocy, or intellectual disability, was determined through "…tests of literacy, numerical ability, reasoning, knowledge as to place of kin, and so on" (Neugebauer, as cited in Braddock & Parish, 2001, p. 19).

During this time, Europe was becoming more secular. Schools dedicated to law and medicine gradually replaced monasteries as places of learning. Custodial facilities, for those unable to care for themselves, started to emerge, wherein Berkson (2006) suggested care was evidently more humane than it was later to become. Bethlem asylum, later known as "Bedlam", was established in 1247 first as a priory for the Order of the Star of Bethlehem, which not long after provided custodial shelter for fewer than 10 patients (Shorter, 1997). Most people with an intellectual disability at this time either lived with their feudal communities and played a relatively active part in that community, were mendicants whose presence was perhaps welcomed (Gleeson, 1997), or were abandoned and provided with custodial care in such small shelters, assuming they were not completely hidden in the family home or smothered by their parents (Stiker, 1999). Compared to living standards of today, these shelters would have been extremely primitive. However, the formation of these shelters, particularly for foundlings, was not socially condoned as most abandoned children were born out of wedlock and to condone these shelters was to condone the immorality of sexual intercourse out of wedlock (Judge, 1987).

The Renaissance (1300-1520 AD)

Civic morality was the cornerstone of sexual matters during the Renaissance. Traditional Augustinian thinking was used to solidify the focus on marriage and procreative sexual intercourse as the pivotal force in the creation of a stable moral society (Hill, 2008). That is, sexual expression within the confines of marriage, as opposed to the unstructured nature of sexual expression for pleasure, regulated society. Importantly, argued Hill, this social structure viewed amoral behaviour, which was apparently widespread, as an explanation for not only the birth of a disabled child, but also for some of the wider problems of society. Violations of moral Christian values, such as homosexual sexual conduct and masturbation, started to be viewed more as social heinous transgressions as opposed to a simple violation of Christian values as in the Middle Ages. Conformity to civic morality was cemented into public sentiment which had sown the seed toward the societal treatment of “difference” in the Reformation.

The Reformation (1520-1700 AD)

Hill (2008) stated that the Reformation was shaped by the protest against some of the teachings of the Catholic church which subsequently led to the formation of new Christian churches and massive wars. Starting from the ideas of Martin Luther in 1517 and aligned to the religious protest, this period saw the split between vicars who married and those who did not: contrasting the Protestant picture of legitimate lust versus the Catholic perspective of ascetic priesthood (Horrocks, 1997). The reformation continued to shape the way society thought about itself, gradually moving toward a more secular understanding. For example, sexual reproduction began to be understood from a biological perspective as opposed to a moral framework; scientific inquiry proceeded without authority from the Pope. The 17th century marked the beginning of political control over social order, one method was through internment of the poor and insane, the disabled were just a part of the social poor (Stiker, 1999). Stiker described this pivotal shift during the Reformation as a progression from care of the vulnerable due to moral ethics toward social internment of the poor and insane in later centuries. This shift was enabled in the UK, for example, through mechanisms such as Elizabethan poor laws (Tewari, 2006).

For those with a disability who were cared for by their families or communities during this time, life was perhaps far from pleasant. Shorter (1997) described examples of people with a disability living in a hole dug through the floor of a cabin, laying for years in a pig pen, chained to walls, laid on straw in stables covered in faeces, chained and manacled, and locked in cages. Increasing urbanisation, toward the industrial age, and concurrent poverty also resulted in an increase in the number of abandoned children, particularly those who would be socially unproductive such as some children with an intellectual disability (Judge, 1987).

Despite the gradual shift toward a more secular society, this period also represented a contradictory time of terrible demonisation for people with an intellectual disability (Braddock & Parish, 2001; Kanner, 1964). Kanner transcribed one of Martin Luther's table-talks which epitomise this notion of demonic possession:

> Eight years ago, there was one at Dessau whom I, Martinus Luther, saw and grappled with. He was twelve years old, had the use of his eyes and all his senses, so that one might think that he was a normal child … He defecated and drooled and, if anyone tackled him, he screamed. So I said to the Prince of Anhalt: „If I were the Prince, I should take this child to the Moldau River which flows near Dessau and drown him". Luther … was firmly of the opinion that such changelings were a mass of flesh with no soul. For it is in the Devil's power that he corrupts people who have reason and souls when he possesses them. The devil sits in such changelings where their soul should have been! (p. 7).

Sinful sexual promiscuity was suggested as one rationale for the birth of babies with an intellectual and/or visible disability. With no cure at this time for syphilis, maternal syphilis would have purportedly accounted for a number of these sinful births (Judge, 1987). The effects of foetal alcohol syndrome on the unborn brain, unknown at this time, would have also provided a further connection between behaviour deemed as immoral and intellectual disability.

The Age of Enlightenment (1700-1820 AD)

Hawkes (1996) suggested sexual matters in the Enlightenment were a juxtaposition of negative emotions related to sin and the positive promotion of sexual pleasure. In the UK, the Marriage Act in 1753 established monogamous marriage and the nuclear family as the standard (Gillis, 1987). The Enlightenment permitted men and women to develop relationships based on likes and dislikes but this did not extend to same-gender relations (Hill, 2008). *Aristotles Master Piece*, perhaps the first western manual advising married couples on the best methods to ensure procreation, reinforced the view that the practise of sex within marriage was not only morally civilised but also “happy”, “pleasant” and “delightful” (R. Porter, 1987). Despite the shifting perspective on sexual matters, the focus was still firmly centred on marriage which, for people with more severe intellectual disability, remained unlawful.

Summary of Christian Era

Since pre-Roman times, people with an intellectual disability were differentiated due to cognitive impairment, with some experiencing protection, and others seclusion, a theme not too unfamiliar today. Legal structures, from the *Twelve Tables* in ancient Rome (450 BC), *Justinian Code* (529 CE), *Prerogativa Regis* (1322) to Elizabethan poor laws

(Act for the relief of the poor, 1597; Poor law Act 1601), reinforced this differentiation and provided legislated support. Berkson (2006) stated throughout history, protection was a far more probable outcome for those who could afford it (probably the minority). The generation of social taxes were made possible through Elizabethan poor laws. People with an intellectual disability presumably were recipients of the full range of positive and negative individual and societal treatment: love, kindness, ridicule, pity, and abuse. We know marriage, and other legal activities, were not permitted for those with more severe intellectual disability. Based upon the modern classification of borderline to mild intellectual disability, being illiterate, more than likely, did not place one under the scope of such laws. As this era spanned many centuries, Table 2.1 presents a condensed summary in order to illustrate a clear progression to the next section in Chapter 2.

Table 2.1

Summary of Christian era

Topic	Time frame	Key issues
Political Power	300 AD - onwards	Christianity embraced by Roman empire. Formation of Justinian Code. Banning of Infanticide.
Christian Dualism	300 AD onwards	St. Augustine influenced thinking toward appreciation of rational consciousness. Reinforced the social role of the church.
The Middle Ages	500-1300 AD	Disability one feature of widespread misery. Prerogatavia Regis further differentiated intellectual disability in law.
The Renaissance	1300-1520 AD	Reinforcement of civic morality.
The Reformation	1520-1700 AD	Christian split from Catholic church. Ongoing contradiction between church and secular thought.
The Age of Enlightenment	1700-1820 AD	Recognition of sexual matters as pleasurable but within the confines of marriage.

THE SCIENTIFIC ERA

The scientific era is a combination of the Victorian Age[7] (1820-1919), also referred to as the industrial age (Hill, 2008), and the modern scientific age from the end of the 18th century. According to the French philosopher Foucault, *sexuality* as a concept was invented during this era; sexuality equating to an autonomous force, a key that unlocks a person's identity not controlled by the Church (Horrocks, 1997). Darwin's *Descent of Man* (published 1871) provided the culmination of many ideas that had been brewing and also spawned the sexual scientific era as opposed to the religious sexual era (Connell & Dowsett, 1992). While still accepting that human sexuality was intrinsically natural, or pre-social, Darwin changed human understanding toward the notion of evolutionary sexual selection. Not long after, Krafft-Ebing produced *Psycopathia Sexualis* (published 1896) which catalogued forms of human sexual degeneracy. Importantly, argued Hawkes and Scott (2005b), Krafft-Ebing successfully challenged the view of sexual deviance from moral degeneracy toward what is legally understood today as diminished responsibility and insanity defence; themes very relevant in relation to mental incapacity and consent. Intellectual capacity, as the basis of legal culpability and consent to marriage, is also laid out very clearly in a legal treatise[8] on "idiocy" and "lunacy" from this era (Highmore, 1822).

Horrocks (1997) stated the ideas of Freud and Ellis marked the coming together of over two hundred years of secular thought. Freud's theory of sexuality described normal developmental stages (oral, anal, phallic) together with a presentation of sexual perversions and their possible aetiology (Hawkes & Scott, 2005b). Hawkes and Scott

---

[7] Some sexuality historians refer to this era as the "Victorian Age" as the long reign of Queen Victoria was reflected by sexual phobias and straight-laced attitudes to sexual matters (Westheimer & Lopater, 2005).

[8] While I state diminished capacity is laid out very clearly in this treatise, although not impenetrable, it is still a very dense tome for the reader without some legal insight. There are of course clauses and sub-clauses to fully understanding the legal interpretation of diminished capacity in the legal domain. The same principles of the Preregetova Regis can also be found within this document.

pointed out while Freud is often perceived as being stuck in a purely “essentialist” paradigm, his ideas also took social factors into account (e.g. the importance of family) on the development of human sexuality although he never did abandon his belief in the biological basis of sexual instinct. In 1897, Ellis published *Studies in the Psychology of Sex* which Connell and Dowsett (1992) suggested was evidently more sympathetic than Freud to the range of human sexual practices. Hawkes and Scott also stated that Ellis placed more emphases on social issues than Freud; one example relates to same-sex attraction which for some cultures outside Europe was not considered a form of sexual degeneracy.

This era also saw the birth of modern ethnography (chapter 4 will discuss ethnography further). Connell and Dowsett (1992) stated Malinowski, a pioneer of early ethnography, produced the first serious ethnographic study of sexuality; Ellis evidently praised this work and methodology as it placed human sexuality within a social context. While Ellis’ work has been roundly criticised by feminists as it allegedly normalised male violence against females (McCarthy, 1999), the contribution of Ellis and his contemporaries has significantly influenced the way human sexuality is understood today.

Institutions for people with an intellectual disability also developed during this era. In 1842 the Swiss physician Guggenbühl opened the first dedicated institution, the Abendberg, to treat cretinism[9] through a healthy diet, care of the body, mineral preparations, and sensory programmes to awaken the soul within (Kanner, 1964). Hailed internationally, similar models were set up in the USA and across Europe. Kanner argued (even though the Abendberg was closed after 16 years due to the scandal of

---

[9] Cretinism was a term used to describe a group of people with similar characteristics; stunted mental and physical developmental due to hypothyroidism; one cause of hypothyroidism is dietary iodine deficiency (Boyages et al., 1987).

mistreatment, a lack of qualified instructional and medical supervision, and the paucity of the facilities) that Guggenbühl should be acknowledged as the originator of the institutional idea to educate, care for, and therapeutically treat people with an intellectual disability. While other settings had a purely educational focus, Guggenbühl's venture focussed on both medical and educational outcomes.

In 1847, the first Government-sponsored institution was opened in Germany with Dr. Heinrich Rösch as its Director. Dr. Rösch also founded what is though to be the first ever periodical[10] dedicated to intellectual disability (called "mental deficiency" at that time) (Kanner, 1964). Only three issues were published and the content focussed on case studies, treatment, cure, the anatomy of cretinism, biological analysis of blood and body fluids, institutional progress reports, and book reviews. Howe's (1848) report to the legislature of Massachusetts included an extensive empirical summary of the causes of intellectual disability, some of which included a discussion of familial intermarriage and unsuccessful abortion[11]. It also contains a passage on masturbation by people with an intellectual disability which, while full of hyperbole, perhaps aptly reflects the tension between the historical development of scientific reason from moralistic demonisation:

> There is another vice, a monster so hideous in mien, so disgusting in feature, altogether so beastly and loathsome, that, in very shame and cowardice, it hides its head by day, and, vampyre-like, sticks the very life-blood from its victims by night; and it may perhaps commit more direct ravages upon the strength and reason of those victims than even intemperance; and that vice is SELF-ABUSE (pp. 83-84).

---

[10] Kanner stated the next journal was started in 1874, another German effort which had similar aims, interestingly the journal and associated conferences were not dominated by medicine but by educators and theologians and included the idea that not all "feebleminded" children should be institutionalised. A third journal was commenced, also in Germany, from 1909 whose preamble called for a multidisciplinary approach to pull together the scattered efforts of care; topics included speech development, epilepsy, children's suicide, dyslexia, and sex education.

[11] This report contains an extraordinarily detailed series of tables over 40 pages long summarising the unique qualities of 574 individuals with an intellectual disability. It possibly represents the first empirical compilation of its kind; the entire digital reference is available from Google books as it is no longer subject to copyright, yet it's citation in reviews of the history of intellectual disability is not common.

In America, an association of medical officers was formed in 1876, the association now known as the *American Association on Intellectual and Developmental Disabilities* (AAIDD). While their annual proceedings were documented from 1886, *The Journal of Pscyho-Asthenics* represented the first known non-European western journal for intellectual disability and was published from 1896. The first locatable passage in the journal which referred to sexual matters was in 1897:

> There are cases known to all who have had much to do with epileptic and feeble-minded young, whose lives would be or would have been much more satisfactory to themselves and others had surgical interference came to their relief, to say nothing of the lessened anxiety and expense their care would thus have entailed. This is a movement which it is wise to make haste slowly, but the profession should not shirk its plain responsibility in assisting to shape legislation which while permitting desexualization, shall hedge the operation by suitable safeguards from abuse (A. C. Rogers, 1897, p. 50).

This passage is most interesting for its historically located perspective on sterilisation. The stress placed on protecting people from abuse was balanced against outside pressure from prominent authorities calling for widespread sterilisation. This outside pressure later culminated into compulsory sterilisation laws. A second passage published in 1898 also reflects this historical location:

> And lastly, one word as to the value of castration. This is a most delicate subject, but some considerable experiences gives me the conviction that often it is necessary to adopt this course, no matter if it be shown to be in a sense an evil. Assuredly the procreation of offspring from those of feeble minds is to be emphatically deplored. I might also say it is never to be desired. If, then, procreation may be laid aside, what is the value of the sexual instinct to those defectives? (Taylor, 1898, pp. 80-81).

Another German journal which started in 1909 was titled *Zeitschrift für die Erforschung und Behandlung des Jugendlichen Schwachsinns* and roughly translates[12] as *Magazine for the Discovery and Treatment of Childhood Mental Illness from a Scientific*

---

[12] Thanks and acknowledgement must go to my erstwhile colleague, Renate Froemel, for her support in translating the indexes to the first 5 issues of this journal from German to English during her meal breaks on night shift.

Basis. Among the many varied topics, such as the pathology of Down syndrome, tuberous sclerosis and epilepsy, this journal also published articles on sexual education for girls with an intellectual disability leaving school (Heidenhain, 1909), the condition of late-descending testicles in males with an intellectual disability (Berkhan, 1912), and sexual education for people with an intellectual disability (Boas, 1913). These topics remain contemporary and still engage researchers 100 years later.

Eugenics

Eugenics was defined by Sir Francis Galton as the “improvement of inborn qualities”, a phrase coined from his research on the epidemiology of human genius (Judge, 1987). Judge asserted while eugenics is often referred to as *social Darwinism*, Darwin’s work was primarily concerned with how species evolved. It was actually the scientific endeavours of Mendel that determined why one generation was different to the next. It is unfortunate that Darwin’s work resulted in the label social Darwinism, often cited as the pseudo-science which inspired the eugenic sterilisation of certain people in society (e.g., Cocks & Stehlik, 1996; Di Giulio, 2003; Diekema, 2003; Wolfensberger, 2008). Judge stated Darwin once expressed surprise that his ideas were being used by others to discover why some people were disabled and others were not.

Eugenics took its strongest hold in America; the first compulsory sterilisation law was passed in Indiana in 1907 for confirmed criminals, people with an intellectual disability, and rapists (Rhodes, 1993). Within ten years a total of 17 States had also passed similar laws (Diekema, 2003). A sterilisation law was also passed in Canada in 1928, then Denmark, Switzerland and Finland in 1929 (Kanner, 1964). France and Sweden also enacted similar laws. Kempton and Kahn (1991) suggested compulsory sterilisation laws reinforced the view that society was “under threat” from people with an intellectual disability who were inevitably “criminal” and “promiscuous”. Tauber (1940) reminded us that throughout history males, not just males with an intellectual disability, have been castrated for religious, biological, and social reasons. Rhodes asserted by 1946 in America, 45,127 sterilisations had been performed with approximately half of those performed on people with an intellectual disability, a number which constituted a small percentage of the total population of people with an intellectual disability. Following the revelations of eugenic practices in Hitler’s Germany, the eugenic movement fell out of favour and US laws for compulsory sterilisation began to be repealed. In 1942 the US Supreme Court ruled procreation was a basic constitutional right (Diekema, 2003; Roy, 2006).

The War Years

Kanner (1964) suggested very little scientific or social advancement for people with an intellectual disability occurred during the period between the First and Second World Wars. This period did however see the significant development of pharmaceuticals[13] and the discovery of disorders such as phenylketonuria (PKU). Between the wars, and especially in the great depression, institutions had to cope with decreasing funds; admission increased and discharges decreased (Rhodes, 1993). Management of these institutions mirrored conservative social norms, so the sexes were segregated. Kempton and Kahn (1991) claimed almost universal homosexuality resulted from segregation. While segregation may foster practices that in other contexts would be considered homosexual, just because two males might practice anal intercourse does not make then

---

[13] The significance of the licensing of drugs, such as Phenobarbitol (1912) and Phenytoin (1938), to treat epilepsy, commonly associated with intellectual disability (Cassidy, 2006), cannot be understated historically in terms of their contribution to improving the quality of life for people with intractable epilepsy.

homosexual, they may simply be motivated by a normative belief that reinforces anal intercourse as one method to achieve pleasure (Dunn, 2001).

Sexology[14]

The development of the discipline of *sexology*, which combined biological, social, cultural, and clinical observations, has contributed historically toward a contemporary understanding of human sexuality. Sexology as a term was coined by Iwan Bloch in 1907, a German dermatologist who is credited as being the father of sexology (Hawkes & Scott, 2005b). Bloch combined both medical and social ideas, but is perhaps most renowned for his assertion that women were more sexually based than men. Bloch's assertion was actually arrived at through observations of behaviours by asylum patients where conventional inhibitions were purportedly "withdrawn" (Hawkes, 1996). A second very important sexologist was Marcus Hirschfeld who founded the world's first gay rights organisation in 1897 and was instrumental in forming the world's first sexological associations and the first journal of sexology in 1908 (Hawkes & Scott, 2005a). McCarthy (1999) pointed out how Ellis, a major sexologist, focussed on what was normal sexual behaviour as opposed to Kraft-Ebing's focus on what was abnormal. Hawkes and Scott stated that Kinsey then took up the mantle from Ellis in describing normal sexual behaviour, a move which also signalled the shift in the centre of sexology from Germany to America during the war years. Masters and Johnson followed Kinsey as they attempted to map physiological sexual responses and later sexual dysfunction.

---

[14] There are too many important sexologists to mention them all within this thesis. However, Emma Goldman and Margaret Sanger and two prominent female sexologists who advocated for the freedom of women from sexual repression at the turn of the 19th century and whose endeavours don't always rate a mention. Sanger, a nurse, argued for the rights of women to have access to contraception and is considered a pivotal birth control pioneer, often breaking the law to provide access to contraceptives for thousands of poor American women who were otherwise subjected to revolving pregnancies (Hickman, 1999).

Kinsey was the founder of the Institute for Sex Research at Indiana University whose history can be traced back to 1938 when the Association for Women Students petitioned Indiana University for a course for students who were married or contemplating marriage (The Kinsey Institute, 2007). Kinsey's data, collected from the "normal" population, included quantitative data on when respondents developed secondary sexual characteristics (Hawkes & Scott, 2005a). Data such as Kinsey's have been pivotal in comparing delayed and/or abnormal sexual development in people with an intellectual disability (e.g., Mosier, Grossman, & Dingman, 1962). Being able to compare normal with abnormal, or delayed, development, has been instrumental, for example, in assisting endocrinologists and paediatricians to identify then treat conditions such as hypogonadism in males with an intellectual disability. Such differentiation between normal and abnormal, stated Morrow (2005), saw the birth of sex therapy. In contrast, some feminists argue that sexology sought to normalise which therefore contributed to the marginalisation of the abnormal, such as people with an intellectual disability (McCarthy, 1999). Other critiques of sexology are more general, for example Connell and Dowsett (1992) suggested sexology has been unable to define pleasure and desire within a meaningful context; pleasure has been described through nerve endings, blood flow and muscular spasm, desire as libido or sex-drive.

Notwithstanding the range of critiques, sexology as a discipline occupies a strong interdisciplinary relevance today. The first *World Congress for Sexual Health* was held in Sydney in 2007 where over 600 presentations spanned the epistemological, cultural, economic, and religious continuum. For example, my presentation (N. J. Wilson, 2007d) was in a session which also discussed tantric sex, the vulva, barebacking in the Australian gay community, surrogate therapy, breast cancer and intimacy, electroejaculation in men with spinal cord injury, women in the Canadian sex industry, enabling sensual touching, and more. Allen (1992) questioned whether the epistemological, philosophical and methodological divide between positivist and reflexive inquiry in research exploring sexual issues might ever be broached. It would appear the World Association for Sexology (WAS) might have bridged this divide:

> The World Association for Sexual Health promotes sexual health throughout the lifespan and throughout the world by developing, promoting and supporting sexology and sexual rights for all. WAS accomplishes this by advocacy actions, networking, facilitating the exchange of information, ideas and experiences, and advancing scientifically-based sexuality research, sexuality education and clinical sexology, with a trans-disciplinary approach (Rubio-Aurioles, 2005).

Summary of Scientific Era

This era can be most clearly described as the shift from a religious, toward a bio-psycho scientific explanation of human functioning. For example, instead of seeking religious reason for intellectual disability in moral terms, the scientific era started to identify the role of the brain and metabolic processes as causes of cognitive impairment. Significantly, the rise and fall of eugenics, both as a moral and scientific pursuit, occurred during this time. The discipline of sexology emerged from the combined efforts of several prominent fields of inquiry which gradually evolved from a focus on the individual, toward the influence of society.

SEXUAL SOCIOLOGY

The emerging social sciences in the later 20th century signified a gradual shift from purely bio-psycho scientific endeavours, toward recognition of social influences. Social perspectives are usually defined as *social constructionist*, or what Connell and Dowsett (1992) called *frame theories*. Social constructionist accounts of sexuality can be broken down into structuralist accounts, deconstructionist accounts, interactionist perspectives, feminist approaches, and discursive approaches[15] (Hawkes & Scott, 2005a). Hawkes and Scott suggested it was anthropology, and in particular the work of Malinowski, that can be credited with shifting the research focus toward the social as anthropologists started to question the notion that an individual transcends cultures. In contrast to the dominant ideology at the time, Malinowksi, although persisting with seeking a natural functionalist[16] order, inadvertently brought cultural issues, and hence the social, to the fore.

Structuralist Accounts

Structuralist accounts relate to the effects sociological structures have on people; structures such as the church, capitalism, medicine, law, and politics. That is, human behaviour is largely determined by social structures. An example of how social structures intersect with sexual health can be found in the way HIV/AIDS rapidly became a cultural and political issue in the 1980s when health promotion sought to change behaviour (Hawkes, 1996; Hawkes & Scott, 2005a). Structural systems have historically affected the lives of people with an intellectual disability in the form of add-on legislation not related to citizens without an intellectual disability. For example, Wheeler (2004) argued the UK 1913 Mental Deficiency Act was pivotal in enshrining laws to segregate because of intellectual disability. Segregation, as a structural reality, then imparted additional influence over the sexual lives of people with an intellectual disability who were further segregated into same-sex wards.

---

[15] Other categories which echo social constructionist accounts do exist but for the purposes of this thesis will not be addressed. That is, the aim of this sub-section of Chapter 2 is to succinctly summarise the shift toward social explanations of disability and sexuality, not to dissect the myriad of social perspectives. These other perspectives include, but are not limited to, materialist, functionalist, structural-functionalist, relational, post-structural, cultural Marxism, queer theory, and critical social theory. Recent decades have also witnessed the emergence of a western Christian fundamentalism and a conservative counter-reaction (Hill, 2008), which, while also worthy topics for analysis, for the purposes of this thesis are equally as tangential.

[16] Malinowski's functionalist theory of culture hovered between nature and culture; in this theory sexual customs fulfil the natural need (Connell & Dowsett, 1992).

Deconstructionist Accounts

Deconstruction seeks to identify the contradictions that may exist in any matter presented as a logical whole (Schehr, 1997). Connell and Dowsett (1992) described one aspect of deconstructionist sexual accounts as the counterpoint between socially ascribed “normal” and “abnormal” sexual practices. A deconstruction of normal and abnormal sexual practices identifies that, except as social practises, they are in fact illusory. A deconstructionist approach, which ultimately only uncovers common sense, becomes a challenge to reconcile when its basis is used to challenge difference. That is, you cannot simultaneously embrace and reject a social category. For example, to reject your social identity as homosexual and hence your solidarity to the gay movement, makes the challenge to assertions of “difference” impossible. Weeks (1991) described this dilemma for those who belong to minority groups as both a personal truth and a political snare. That is, your sexual identity only exists within a vacuum of social control where your individuality is lost. Therefore, to try to break out of such binary logic is not possible without further reinstating the basis of the dilemma (Corker & Shakespeare, 2002). A similar deconstructionist dilemma faces people with an intellectual disability who may seek to challenge a disabled social identity.

Interactionist Perspectives

Hawkes and Scott (2005a) argued that an interactionsist perspective sees social order as the basis for sexual expression in contrast to bio-psycho “essentialist” accounts which suggest sexual expression is the basis of social order. That is, humans learn to interact from the foundation of socially constructed roles and socially ordained scripts such as conversation, absorbing popular culture, understanding and practising social rules and social order, education from family and church, and by noticing how certain sexual behaviours are rewarded or punished (Moore, 2005). Based upon this perspective, sexual expression by people with an intellectual disability would reflect the social context, institutional or otherwise, by which sexual behaviours were constructed. One problem with this approach is the lack of a definition for sexual behaviour outside the act of scripting or controlling (Connell & Dowsett, 1992). Interestingly, despite the sexual repression allegedly prevalent within institutional settings and subsequent lack of sexual scripts, Edgerton and Dingman (1964) identified rich layers of sexual scripts and sexual behaviour operating in spite of the moral scripts being therapeutically taught.

Gagnon and Simon (1973), pioneers of interactionist perspectives on sexual conduct, suggested sexual scripts are the prerequisite for sexual behaviour; without knowledge of a certain script, the behaviour is not sexual. The following excerpt from their seminal work describes this approach:

> Take an ordinary middle class male, detach him from his regular social location, and place him for some business or professional reason in a large, relatively anonymous hotel. One might even endow him with an interest in sexual adventure. Upon returning to the hotel at night, he opens his hotel door and there in the shaft of light from the hallway, he observes a nearly nude, extremely attractive female. One may assume that his initial reaction will not be one of sexual arousal. A few men – the slightly more paranoid – might begin to cast about for signs of their wife's lawyer or a private detective. Most, however, would simply beat a hasty and profoundly embarrassed retreat. Even back in the hall and with a moments reflection to establish the correctness of the room number, the next impulse would still not be one of sexual arousal or activity but most probably a trip to the lobby to seek clarification – via the effectively neutral telephone. What is lacking in this situation is an effective sexual script that would allow him to define the female as a potentially erotic actor (the mere fact of her being attractive or nearly nude is not sufficient) and the situation as potentially sexual. If these two elements did exist, much of what might follow can be predicted with fair accuracy. But without such a script, little by way of sexual activity or even sexual arousal will transpire (p.20).

Two well-known studies concerning people with an intellectual disability drew heavily upon theories of social scripting to analyse their data (Löfgren-Mårtenson, 2004;

McCarthy, 1999). Löfgren-Mårtenson conducted observations during discos and was able to highlight how social scripts were important in determining the sexual behaviour, and more importantly the sexual success, of experiencing warmth and intimacy. Significantly, social scripts prescribed by the morals, beliefs, gender, and age of the supervisory staff had the most telling legacy. McCarthy, in her study exploring the sexuality of women with an intellectual disability referred to her for sexuality counselling, suggested the lack, or incompleteness, of social scripts were a significant contributory factor to the more "mechanical", as opposed to "sensual", sexual experiences of these women. What these data tell us about social scripting, in tandem with the results of Edgerton and Dingman (1964), is mixed largely due to the different contexts within each study. However, as a sole approach to sexual matters, neither study links together the diverse meanings of human sexual expression. For example, Edgerton and Dingman described unsupervised sexual behaviour, whereas Löfgren-Mårtenson described fully supervised sexual behaviour; both are uniquely different contexts and both naturally described different scripted outcomes. Without any data from observation, it is hard to draw too many inferences from McCarthy's study beyond what the women told her in the context of her interviews with them.

Feminist Approaches

Feminist approaches to sexual matters are based upon a reaction to centuries of social oppression under patriarchy (Hawkes & Scott, 2005a). There are two main feminist perspectives on sexual issues and in turn on men: *liberal* which supports equality, and *radical* which is focussed on oppression. Allen (1992) stated some distinctly feminist analysis of human sexuality include perspectives on incest, rape, prostitution, pornography, paedophilia, lesbianism, maternity, anorexia nervosa, and beauty and the body. While feminist perspectives have shaken the historically patriarchal grasp on sexual matters, contradictions remain which can lead to confusion regarding a coherent theory of feminist sexuality (Horrocks, 1997). For example, some feminists reject cosmetics and fashion as symbols of femininity while others embrace them; some reject heterosexuality while others accept it; some radical feminists argue there is no male or female which begs the question what is real?; is the female form in fine art exploitation or artistic expression?; some feminists reject porn while others claim a right to their own eroticism.

Discursive Perspective

Discursive perspectives sit somewhere in between interactionist accounts and structuralist accounts but include aspects of both. For example, Foucault claimed sexual scripts (interactionist) were in fact historical developments within power structures (structuralist) (Foucault, 1978; Weeks, 1991). Foucault argued against the belief that sexual expression was historically repressed; instead the more structural powers tried to sexually repress society, the more powerful and energised sexual matters became. Therefore, discursive approaches suggest sexual matters are primarily shaped by the historical discourse. Horrocks (1997) suggested one prime historical example relates to masturbation which was both morally repressed yet remained unconsciously desired.

Another discursive perspective relates to the three dominant male–female categories of sexual relations in western society and has been labelled by Holloway (as cited in Moore, 2005) as the male *sex drive* discourse, the *have/hold* discourse, and the *permissive* discourse. The male sex drive discourse suggests males have an irrepressible sex drive that needs to be exerted by power over women who need to be coerced into satisfying it. The have/hold discourse reflects sex within relationships of mutuality, monogamy, marriage, and family life. The permissive discourse permits high arousal, sexual expression, and expectation of sexual satisfaction outside of gendered roles, but within the limits of exploitation.

Summary of Sexual Sociology

Sexual sociology, or social constructionist perspectives, has been described via a number of significant perspectives: structuralist, deconstructionist, interactonist, feminist, and discursive. Historically, social constructionist perspectives emerged as a counterbalance to the bio-psycho ideas of the scientific era which tended to focus more on the individual. While the scientific era generally sought to locate scientific “truth”, sexual sociology sought a deeper “meaning”.

However, limitations are inherent in both scientific and sociological perspectives if they are taken in isolation to represent a “whole truth”. That is, positioning truth and meaning as polar opposites creates an unhelpful and objectionable dichotomy. The following excerpt from Vance illustrates the futility of creating such an objectionable dichotomy and that reality perhaps hovers somewhere between the polar ends:

> First is that we should not be seduced by the fact that social construction challenges essentialist explanations so effectively. This explanation, as with all others of human sociality has its limitations. Second, we are all, to a greater or lesser degree, essentialists in our thinking about sex and sexuality. This is inevitable, she argues, as we live in a culture in which essentialist views remain pervasive. The third warning remark relates to the use of social construction as a dogma or faith (Vance, as cited in Hawkes & Scott, 2005a, p. 35).

Neither social constructionism or bio-psycho perspectives adequately explain when behaviour becomes sexual and the differences between a sexual and a non-sexual act. I recall working many years ago with a man who was born with congenital rubella; he had no eyes, was completely deaf, had an extremely limited scope to communicate his needs and wants, and had lived in an institutional setting from a very young age. This young man engaged in self-stimulatory behaviour daily and also sought out sexual contact with a female client which was vigorously policed by staff. If we accept this young man learnt how to be sexual via social scripts, or roles, or that his sexuality was a result of structural experiences, one must question where he learnt his sexually cultural scripts. He had no roles to watch and learn from and his severe intellectual disability precluded him from advanced learning. However, if we reject social constructionism, this young man was operating on a primal level driven by a biological urge, pheromones, and an evolutionary drive to procreate. Despite his considerable disabilities, I am convinced this young man did learn social scripts, but perhaps by reinforcement and repetition at the same time as experiencing a male sexual urge; both needed to be acknowledged to support this young man to develop a healthy male sexuality.

THE CURRENT INTELLECTUAL DISABILITY DISCOURSE

Three significant gatherings were convened in the early 1970s where people with an intellectual disability and sexual matters were formally debated as a concept beyond segregation, sterilisation, and/or eugenics[17]. The first conference held in Hot Springs, Arkansas in 1971 was titled *Human Sexuality and the Mentally Retarded* (de la Cruz & LaVeck, 1973). The underpinning philosophy of the conference was Normalization; the

---

[17] These three gatherings were solely dedicated to discussing sexual matters. In Montpellier in 1967, the first congress of the International Association for the Scientific Study of Mental Deficiency, now known as the International Association for the Scientific Study of Intellectual Disabilities (IASSID), was held. Of 31 separate symposiums, one was dedicated to sexual matters and was titled *Sexuality and Procreation in the Severely Retarded* (Richards, 1967). Although written in French from what I have thus far translated topics were more specific such as hypogonadism, procreation, and types of sexual behaviours, whereas the gatherings in the 1970s represented more of a philosophical and celebratory shift based on rights.

right to express oneself sexually. Invited speakers represented a vast interdisciplinary group: biology, medicine, psychology, anthropology, sociology, genetics, education, theology, social work, and law. A second gathering was titled *Symposiums on Reproductive Rights of the Mentally Retarded* and was held in 1974 in Washington D.C. The symposium considered informed consent plus economic, moral, legal, genetic, ethical, political, and gynaecological perspectives (Cochrane, 1974). The third conference was held in West Germany in 1975 and was titled *Mental Handicap, Human Relationships, Sexuality* (Katz et al., 1975), its aim was to further stimulate the dialogue.

McCarthy (1999) provided a comprehensive summary of the development of the current sexuality discourse in western countries as it progressed through the 1970s, 80s, and 90s. The 1970s was a decade focussed mainly on the “right” to and need for sex education, together with a focus on the “right” to date and marry. The 1980s represented a continuance and enhancement of sex education programs with a growing recognition of reproductive “rights”. As the area grew in prominence, disability services started to reflect this via the adoption of formal policies and procedures. The 1990s, argued McCarthy, saw a major paradigm shift as the uncomfortable truth of sexual abuse was confronted. McCarthy also suggested the 1990s moved toward a positive focus on same-sex relationships, gendered power relations, ethnic and cultural awareness, and HIV prevention work.

Into the 21st century, Cambridge (2001) cited the development of special issues of research journals related to sexual matters and intellectual disability as part of a continuing discourse. Cambridge asserted that this discourse is shaped by the ongoing awareness of sexual abuse, the articulation of “rights”, and emerging themes such as HIV, consent, and the sexuality of men and women with an intellectual disability (Cambridge et al., 2003). However, this claimed discourse largely represents the published material of a small group of UK authors whose writings suggest a largely sociological view point. Sociological perspectives are important, but the bio-medical/social dichotomy they present is weighted heavily toward a purely sociological perspective. That is, a bio-medical discourse is reactively constructed to represent the failed past, a past replete with the symbols of repression, control, seclusion, and eugenics. While these symbols did not represent the reality for most people with an intellectual disability, the construction of such a discourse shapes what we come to *understand as real* and therefore determines what can be, and is, said (Woods, 2002a).

A purely sociological discourse operating as a retort to a bio-medical discourse inadvertently overlooks what bio-medical perspectives have to offer both historically and currently. Sexual health, sex research, and sexology are hence rendered as largely bio-medical and secondary issues to the all-encompassing focus on the sexuality of people with an intellectual disability, or sexuality studies. Despite the promise of those gatherings in Arkansas, Washington D.C., and Germany over thirty years ago, a recent review of research that explored sexual matters for people with an intellectual disability stated there is "…a dearth of empirical evidence for the ideas and practice in this field. Second, when research has been conducted, it often lacked the scientific rigour" (Griffiths et al., 2004pp. 328-329). Furthermore, Grieve, McLaren and Lindsay (2006) in their review of sex education resources highlighted not only methodological concerns but also a bias toward resources more suitable for people with a mild intellectual disability. A more recent review identified a total of 68 sex education resources (Sexual Health and Wellbeing Network, 2008), which also indicates a suggested bias toward resources for people with a mild intellectual disability. To enable future research to progress beyond these current problems, Griffiths et al. suggested an interdisciplinary coming together to enable the complex links between biology, psychology, and the social sciences to be explored; a biopsychosocial approach.

While an interdisciplinary coming together may have the desired effect, there still remains a hiatus as the current discourse, whether constructed sociologically and/or biopsychosocially, still lacks a convincing ethical and theoretical analysis beyond an assumption that “rights” represent the key. Other than the odd reference to the ideas of Foucault, or Gagnon and Simon (e.g. McCarthy, 1999), or cognitive behaviour therapy in the treatment of sex offenders (e.g. Lindsay, Olley, Jack, Morrison, & Smith, 1998), most of the literature within the current discourse appears founded on statements about rights. Yet, as sexual rights are inextricably intertwined with issues of consent and capacity to consent, for people with a moderate to profound intellectual disability their sexual rights are limited by laws relating to capacity. Capacity to consent, or participation in legal exchanges, has been limited for people with more severe intellectual disability since at least the compilation of all existing Roman laws into the Justinian Code in 529 AD. As a result, erring on the side of caution may be the default position of substitute decision makers. Therefore, a discourse that allows a shift beyond rights needs to emerge. In contrast, as the preceding historical discussion has shown, people with a mild intellectual disability have participated in procreative unions irrespective of the era. Even published material during the height of eugenics and institutionalisation clearly reported that this was the case (e.g. Johnson, 1900; Popenoe, 1928). So, perhaps for people with a mild intellectual disability, a focus on rights may be a more central factor.

Another weakness in the current discourse is highlighted by the lack of clarity of the terms *sexuality* and *sexuality work*. Sexuality, the state or quality of being sexual, is a complex, individualised and subjective reality. While a variety of definitions exist, the following by López-Sosa and Tévar (2005) encapsulates the intrinsic complexity of human sexuality:

> Sexuality refers to a fundamental dimension of the fact of being a human being, based on sex, including gender, the identities of sex and gender, sexual orientation, eroticism, affecting linking, and love and reproduction. It is experienced or expressed in the form of thought, desires, beliefs, attitudes, values, activities, practices, roles, and relationships. Sexuality is the result of the interaction of biological, psychological, socio-economic, cultural, ethical, and religious or spiritual factors. Although sexuality can include all these aspects, it is not necessary that all are experienced or expressed. Nevertheless, in summary, sexuality is expressed in all that we feel, think and do (p.146).

López-Sosa and Tévar are highlighting that sexuality is in fact a central feature of being human; sexuality is manifested as both a product, and producer, of the human body.

For people whose capacity to articulate their inner-most thoughts and feelings is limited, how much of the complex reality of their sexuality can disability services in reality support? We may never come to learn about their perspective of eroticism, love, and desire. If sexuality is all that we feel, think and do, for this group of people how do we support their sexuality, as a whole, for example, when we may never be able to contextualise a problematic issue to their thoughts and feelings? Therefore, does this mainly leave the capacity to support such a person with their observable and measurable behaviours and/or pathology? That is, **sexual expression** and/or **sexual health**?

For example, an adolescent male with a severe intellectual disability and associated physical impairment may have a burning desire to engage in erotic sexual relations with another person, yet without communication skills to express such a desire and/or sufficient mobility to perform the task, this may remain an unfulfilled desire. Without any insight into the thoughts and feelings underpinning his sexuality or observable sexual expression to go by, if staff recognised him as a sexual being, services are ethically limited to only provide support with preventative sexual health matters. Therefore, when the current discourse articulated in the literature refers to “supporting sexuality” and “conducting sexuality work”, without any advanced theoretical, moral, or ethical framework underpinning this claim, has the discourse overstated things? That is, has the discourse over-simplified what is actually a very complex and individualised issue?

Sexuality work is in fact a highly specialised paradigm subject to professional regulation which, in Australia, includes professional sexuality educators, researchers, and therapists (Australian Society of Sex Educators Researchers and Therapists (ASSERT), 2009). Furthermore, the UK vocational framework for staff working in the sector, the Learning Disability Awards Framework, (probably the most comprehensive vocational framework known for disability support staff) has two topics of sexual foci: units 39/134 on sexual health and units 17/122 on sexual expression[18]. These units do not reflect “sexuality work” or “supporting sexuality” as the discourse has constructed. There appears to be a divergence between the current discourse and the complexity of the issues which staff confront. Three pertinent topics: sterilisation, sexual abuse, and masturbation, will now be discussed to illustrate the ethically and theoretically complex nature of sexual matters for people with an intellectual disability.

---

[18] There is no parallel framework for support staff in Australia. Emerging PhD research from The University of South Australia shows disability support workers construct sexual health/sexuality work as a “specialised” area outside their defined role and level of expertise (Parker, 2008).

Involuntary Sterilisation and Reproductive Rights

Involuntary sterilisation of people with an intellectual disability still occurs but is no longer based on eugenics (e.g. Servais, Hoyois, & Roussaux, 2000). It remains however, contentious and ethically challenging mainly because debate concerning *best interests* shifts over time and across moral, philosophical, socio-cultural, and professional standpoints (e.g. Carson, 1989; Green & Paul, 1974). Diekema (2003) rightly pointed out a distinction must firstly be made in the use of terminology between *compulsory sterilisation*, which was primarily concerned with the protection of society, *voluntary sterilisation*, and *involuntary sterilisation* which is when a person cannot give their informed consent. Involuntary sterilisation is subject to differing legal processes internationally (N. Lennox, 2005; Roy, 2006; Stansfield, Holland, & Clare, 2007) so even a westernised debate becomes complicated.

Aunos and Feldman (2002) reported findings from several studies which show parents, service workers, and teachers still favoured involuntary sterilisation over other forms of birth control. A US national survey of sexual behaviour of people with an intellectual disability reported 65% of female clients used contraception for birth control as opposed to for other medical reasons such as easing of menstrual problems (Gust, Wang, Grot, Ransom, & Levine, 2003). Arguments over the use of contraceptives are often balanced between the right to procreate and raise children against the right of the unborn child to have parents who can adequately sustain their developmental needs (Griffiths, 2007). Indeed, Roy (2006) asserted most requests for involuntary sterilisations today come from parents of a disabled child who sometimes cite their potential grandchild’s rights as part of their legal argument. A further issue relates to the emergence in the USA of *growth attenuation therapy*[19] which, in a recent and highly publicised case, also involved a partial hysterectomy and the removal of breast buds ("Parents defend growth-stunt operation," 2007).

The use of anti-libidinal medication in males with an intellectual disability represents an ethical issue with regard to reproductive rights that receives far less attention than the use of hormonal medications in females. The use of anti-libidinal medications are not usually referred to as an issue of reproductive rights despite their intention to chemically control fertility. Instead their use sits firmly within the discourse on inappropriate male sexual behaviours. Sajith, Morgan and Clarke (2008) stated that the use of all androgen depleting drugs[20] will result in varying degrees of hypogonadism with other adverse effects such as reduced erections, libido, ejaculate volume, spermatogenesis, as well as a decrease in testicular volume and muscle mass, plus bone demineralisation. One of the main ethical issues regarding the use of anti-libidinal medication in males with an intellectual disability is the potential for their abuse as agents to control sexual expression when less aversive measures, which may be more effective, might be considered too costly.

Carlson, Wilson and Taylor (2000; 1997) sought information from legal, medical, and disability service providers about the surgical and chemical sterilisation of males with an intellectual disability in Australia. They concluded both surgical and chemical means are being used to sterilise males with an intellectual disability but the rationale seemed

---

[19] Growth attenuation therapy involves premature exposure to high-dose oestrogen which accelerates the fusion of growth plates in the skeletal structure which consequently attenuates growth (Gunther & Diekema, 2006).

[20] The two major androgens in humans are testosterone and dihydrotestosterone. These hormones are crucial to the development of male sexual characteristics, the regulation of sexuality, aggression, cognition, emotion, and personality (Sajith et al., 2008)

mixed and unclear. Particularly worrying were the reports from service providers, of GPs willing to prescribe anti-libidinal medication based upon sometimes anecdotal evidence and at other times in conjunction with counselling for sexually inappropriate behaviour. The following concluding remark highlights the limited ethical scrutiny that appears to be applied to this topic:

> The sterilisation (chemical or surgical) of young males who have intellectual disability is occurring around Australia, raises questions about the motivation of the decision-makers. Fertility control for prepubescent male children is pointless, given they have not reached sexual maturity. Chemical and surgical means of fertility control for post-pubescent young men is questionable given that it would be unthinkable for the non-disabled population of the same age.
>
> (G. Carlson et al., 1997, p. 78)

Sexual Abuse

Sexual abuse constitutes a large part of the recent focus on sexual matters, and hence the current discourse. Griffiths et al. (2004) pointed to four main methods used to evaluate the prevalence of sexual abuse, all of which have limitations mainly due to the subjective deduction required by the analyst to make sense of data. It is important to acknowledge these limitations, as the centrality of abuse to the current discourse has significant influence over policy, training, and regulation of the sector. For example, qualitative interviews with people with a mild intellectual disability cannot be generalised to those with more severe intellectual disability where communication is limited. Another issue occurs when people with an intellectual disability make allegations which later turn out to be false. Jones (2007) tackled this very challenging issue and questioned the fact service providers are “prescribed to listen and believe”. Other problems arise when displays of sexualised behaviour by a person with an intellectual disability lead to the assumption that abuse is likely to have occurred (e.g. Balogh et al., 2001), an outcome which not only assumes the worst, but may overlook the effects of pubertal changes and naturally occurring and developmentally appropriate sexual exploration.

Two key findings emerge within the literature concerning sexual abuse and people with an intellectual disability: both women and men are victims, and men who are known to the victims are usually the perpetrator (Brown, Stein, & Turk, 1995). Depending upon methodology and population group, prevalence of abuse varies between 8% and 58% (McCormack, Kavanagh, Caffrey, & Power, 2005). McCarthy (1996), and McCarthy and Thompson (1997) reported 61% of women and 25% of men referred to them for sexuality counselling had experienced some form of abuse. Brown, Stein, and Turk identified 85 proven or highly suspect cases from one regional authority in the UK. From these often-cited data, Brown, Stein, and Turk concluded about 1250 cases of abuse occur annually across the UK, but this assertion has not been empirically tested. In their 15-year longitudinal study, McCormack et al. identified from 250 allegations of sexual abuse, only 47% were actually confirmed. Furthermore, 94% of the perpetrators were male with approximately half being males with an intellectual disability. The sex offender with an intellectual disability, mostly male (Brown & Stein, 1997; Hays, Murphy, Langdon, Rose, & Reed, 2007; Lunsky, Frijters, Griffiths, Watson, & Williston, 2007), displays a range of characteristics. These include multiple pathology in the family home, school adjustment problems, behaviour problems, psychiatric problems, sexual naiveté, lack of relationship skills, poor impulse control, being easily influenced by others, have poor peer relations, negative early experiences, a lack of personal power (Lindsay, 2002), and are often the victims of physical or sexual abuse themselves (Hayes, 2009).

Ascertaining consent presents one of the challenges to a discussion of sexual abuse. Kaeser (1992) pointed out that few people with a moderate to profound intellectual disability would satisfy the mental capacity requirements to give informed consent to sexual relations with another person. Therefore, any receipt of sexual contact from another person with an intellectual disability could, and often is, constituted as abusive. Yet, argued Kaeser, to deny such a person the opportunity to engage in mutual sexual expression with another client because of limited capacity to consent, might deny them otherwise fulfilling and life-enhancing opportunities. Kaeser suggested a redefinition of consent might incorporate not only what was determined to be in the person's best interest, but also a determination of substituted judgement. Kaeser has urged for assent to perhaps be considered as one part of this complex issue. In their quest to assess the range of factors which need to be considered when assessing sexual consent capacity, Kennedy and Niederbuhl (2001) identified 5 criteria using factor analysis: 1) the consequences of sexual activity, 2) basic and essential sexual knowledge, 3) unessential sexual knowledge, 4) safety for self and others and, 5) basic safety skills. While these criteria need to be seen in the American legal context, they still represent an attempt to expand understanding in the area of sexual consent.

The UK Sexual Offences Act 2003 has received a number of criticisms despite the fact that part of its intention was to clarify a number of contentious issues, capacity to consent being one of them. Wheeler (2004) outlined the Act and described how some of the amended definitions fail to provide an objective test for capacity. A lack of capacity is defined by a lack of *sufficient understanding*[21] of the nature and/or consequences of the (sexual) act. Assessment of sufficient understanding would be a highly subjective task.

---

[21] It is interesting that the language used in this Act to define capacity, "sufficient understanding", has not altered too much since the 6th century AD where the Justinian Code used "deficient of understanding".

Furthermore, the Act summarises a new group of offences pertaining to support workers which, instead of providing clarity, may actually deter the provision of socio-sexual education and/or sex aids (such as condoms) as the Act prohibits a care worker to *cause* or *incite* sexual activity. An article by Hollomotz and The Speakup Committee (2009) concerning services who do not provide the private space for people with an intellectual disability to have sex, epitomised the dilemma for support staff and services. This dilemma is borne from the challenge of ascertaining consent coupled with the rights of the service and staff to protect themselves against accusations of causing or inciting sexual activity.

Masturbation

Given masturbation is reportedly such a common and developmentally normal practice (Fegan et al., 1993), it seems odd most of the commentary about this form of sexual expression is about masturbation as a problem (e.g. Cambridge et al., 2003; Hingsburger, 1994; Joseph, 1991; Robison et al., 1992; Shelton, 1992; A. Walsh, 2000). Perhaps the only recent in-depth discussion that views masturbation as an enjoyable and therapeutic form of sexual expression was written by Kaeser (1996a). Most importantly, Kaeser approached the topic from an ethical and philosophical angle with the client's right to receive a service that sees sexual expression as one part of an overall philosophy of quality of life. It appears no other author since has sought to develop, critique, or extend Kaeser's ideas. Instead, the literature offers a range of ideas on how to modify masturbation as an inappropriate behaviour but does not suggest how to promote it for health and well-being. In view of the legal issues raised, in particular in relation to the UK Sexual Offences Act 2003 and the protection of vulnerable adults, this is not surprising.

Summary of Current Intellectual Disability Discourse

This section pointed to several gatherings in the early 1970s as the symbolic starting point of a focus on sexual “rights” for people with an intellectual disability. Several widely published authors, particularly from the UK, have stated that a tangible sexuality discourse has evolved. In contrast, a seminal review of research into sexual matters and intellectual disability highlighted several important flaws. Questions have been posed as to whether the current sexuality discourse has sufficient connectedness between the philosophical slant of the discourse and the reality of day-to-day practise. Three pertinent examples have been discussed which illustrate just how complex sexual matters are for people who have an intellectual disability.

SEXUAL HEALTH AND WELL-BEING

Servais (2006) suggested sexual health for people with an intellectual disability has been overlooked in preference to a focus on sexuality and sexual rights. One of the reasons for this might be the assertion by Health Canada (2003) that a discourse built from a social constructionist perspective sees an automatic association between “health” and “medicine”, which in turn creates messages about what defines unhealthy, or abnormal, sexuality. Therefore, any definition of health is avoided. Servais stated the areas that have achieved some focus within the intellectual disability literature are: sexually transmitted diseases, unplanned pregnancies, sexual hygiene, gynaecological care, and sexual abuse. Servais’ summary is a fair representation of the literature.

Sexual health, however, is much more than this. Butler (2004) described the recent emergence of a re-conceptualisation of sexual health from its historical association with reproductive health. This new conceptualisation views sexual health as **the** underlying state across the lifespan, rather than a single component of the reproductive years. A simple definition of sexual health, from the WHO definition, is: “the experience of a permanent process of achievement of physical, psychological, and socio-cultural well-being related to sexuality” (López-Sosa & Tévar, 2005, p. 146). Health Canada suggested a positive view of sexual health is concerned with what promotes sexually healthy outcomes (e.g. self-esteem, respect, non-exploitation, sexual satisfaction, rewarding human relationships, the joy of desired parenthood) and how to avoid negative outcomes (e.g. unintended pregnancy, STD/HIV, sexual coercion). That is, humans seeking the pleasure associated with one’s chosen sexual activities without causing, or suffering, harm. A positive view also recognises there is such a thing as an unhealthy sexuality (Chilman, 1990).

Perhaps the most significant point is the total lack of acknowledgement within the intellectual disability literature of the theoretical development of sexual health and well-being, within a framework of primary health care. For example, sexual health work for young people with an intellectual disability currently underway in Scotland, represents an unparalleled and significant investment of Government funds into sexual health and intellectual disability, yet their comprehensive briefing report entirely neglects the mainstream literature (Fraser & Sim, 2007). The Pan-American Health Organisation and the World Health Organisation (2000), in conjunction with the World Association for Sexology, published a set of recommendations for the promotion of sexual health. Within these recommendations are a conceptual framework of definitions for sex, sexuality, and sexual health, plus a summary of what constitutes a sexually health adult, listed in Table 2.2, and a sexually healthy society.

The report also presents a summary of sexual health concerns, and problems (Pan American Health Organisation & World Health Organisation, 2000). Whereas the intellectual disability literature and research usually refers to inappropriate sexual behaviour, and isolates specific issues, this summary of concerns, and problems, would provide much needed clarity beyond stating a client has a problem with their sexuality. Tables 2.3 and 2.4 summarise these sexual health concerns and problems. While the content of these tables is not being presented as a panacea, they do represent something that is absent within the current intellectual disability sexual discourse; an agreed series of definitions enmeshed into a framework of what constitutes sexual health, further built into a categorical summary of concerns and problems.

Importantly, the described definitions and framework represent a biopsychosocial understanding of human sexuality; allowing for biological issues to surface within the social and emotional context. The intellectual disability sexual discourse is yet to acknowledge the comprehensive work that is being achieved in the mainstream. The World Association for Sexual Health urges all institutions, Government and non-Government, to embrace their sexual health for the millennium goals (World Association for Sexual Health, 2007), goals which assert that the attainment of sexual health fosters quality of life and the realisation of peace. These goals are to:

1) Recognise, promote ensure and protect sexual rights for all
2) Advance toward gender equity
3) Condemn, combat, and reduce all forms of sexually related violence
4) Provide universal access to comprehensive sexuality education and information
5) Ensure that reproductive health programs recognise the centrality of sexual health
6) Halt and reverse the spread of HIV/AIDS and other sexually transmitted infections
7) Identify, address, and treat sexual concerns, dysfunctions and disorders
8) Achieve recognition of sexual pleasure as a component of holistic health and well-being.

Table 2.2

List of life behaviours of a sexually health adult (Pan American Health Organisation & World Health Organisation, 2000, p. 12)

A SEXUALLY HEALTHY ADULT WOULD:

- **Appreciates one's own body**
- **Seek reproductive information as needed**
- **Affirm that human development includes sexual development that may not include reproductive or genital sexual experiences**
- **Interact with both genders in respectful and appropriate ways**
- **Affirm one's own sexual orientation and respect that of others**
- **Express love and intimacy in appropriate ways**
- **Develop and maintain meaningful relationships**
- **Avoid exploitative or manipulative relationships**
- **Make informed choices about family options and lifestyle**
- **Exhibit skills that enhance personal relationships**
- **Identify and live by one's own values**
- **Take responsibility for one's behaviour**
- **Practice effective decision making**
- **Communicate effectively with family, peers, and partners**
- **Enjoy and express one's sexuality throughout life**
- **Express one's sexuality in ways congruent with one's values**
- **Discriminate between life enhancing and harmful sexual behaviours**
- **Express one's sexuality while respecting the rights of others**
- **Seek new information to enhance one's sexuality**
- **Use contraception effectively to avoid unwanted pregnancy**
- **Prevent sexual abuse**
- **Seek early prenatal care**
- **Avoid contracting and transmitting STDs**
- **Practice health promoting behaviours**
- **Demonstrate tolerance for people with different sexual values and lifestyles**
- **Exercise democratic responsibility to influence legislation dealing with sexual matters**
- **Assess the impact of family, cultural, religious, media and societal messages on one's thoughts, values, feelings, and behaviours related to sexuality**
- **Promote the rights of all to people to have accurate sexual information**
- **Avoid prejudicial and bigoted behaviours**
- **Reject stereotypes about the sexuality of diverse populations**

Table 2.3

Summary of human sexual health concerns

SEXUAL HEALTH CONCERNS
1) Sexual health concerns related to body integrity and to sexual safety
2) Sexual health concerns related to eroticism
3) Sexual health concerns related to gender
4) Sexual health concerns related to sexual orientation
5) Sexual health concerns related to emotional attachment
6) Sexual health concerns related to reproduction

Table 2.4

Categories of human sexual health problems

SEXUAL HEALTH PROBLEMS
1) Clinical syndromes that impair sexual functioning
2) Clinical syndromes related to impairment of emotional attachment/love
3) Clinical syndromes related to compulsive sexual behaviour
4) Clinical syndromes involving gender identity conflict
5) Clinical syndromes related to violence and victimization
6) Clinical syndromes related to reproduction
7) Clinical syndromes related to sexually transmitted infection
8) Clinical syndromes related to other conditions

Summary of Sexual Health and Well-Being

Comprehensive frameworks to ensure sexual health and well-being as a concept has clarity and are easily understood have been developed by the mainstream. These frameworks offer a biopsychosocial basis to frame an understanding of healthy human sexuality. The current intellectual disability discourse has not engaged with this mainstream literature and hence places sexual health aside as a bio-reproductive matter.

SUMMARY

The primary purpose of this chapter was to historically situate the contemporary literature which seeks to explore sexual matters for people with an intellectual disability. Commencing with a short summary of the considerations required from an historical analysis of disability, this chapter presented pertinent historical and philosophical information from pre-Christian, Christian, scientific, and social eras. Once historically situated, the chapter then considered the main issues relating to the current sexual discourse for people with an intellectual disability. To close, this chapter described the seminal progress that has been made by mainstream sexual health research.

The main historical conclusions of this chapter are that laws, and hence restrictions, relating to competence go back as far as Greco-Roman times. Secondly, the responsibility of society to care for those who require it has remained fairly constant; its implementation of care has simply differed over time and reflected the dominant moral, scientific, and ethical tenor of the times. An examination of the current sexual discourse suggests a trend in the literature toward social perspectives of sexuality and disability. Recent theoretical advances in understanding sexual health as a biopsychosocial construct with a vision, based in primary health care, toward appreciating the factors which create sexually healthy humans, represents a promising framework. This framework is being largely overlooked by the intellectual disability sector.

Chapter 3 will now examine the specific sexual health issues for males with an intellectual disability. This will consist of a review of the available literature plus an examination of the influence that the intersection of masculinity and intellectual disability has on male health outcomes.

CHAPTER THREE

SEXUAL HEALTH FOR MEN AND BOYS WITH AN INTELLECTUAL DISABILITY

> *Research and practice in sexuality and learning [intellectual] disability has directly and indirectly highlighted the pathological sexual behaviour of men with learning [intellectual] disabilities, particularly their abuse and exploitation of women with learning [intellectual] disabilities, and relatively high HIV risk sexual behaviour with men without learning disabilities. It is consequently argued that there has been a relative neglect of their wider sexuality and sexual needs* (Cambridge & Mellan, 2000, p. 293).

Chapter 2 provided an historical review and concluded with an analysis of the current sexual discourse and a suggestion that a biopsychosocial framework of sexual health might offer a more useful model. This chapter will review the literature concerning male sexual health and intellectual disability. Drawing upon mainstream notions, theories, and perceptions of masculinity, this chapter will discuss the intersection of masculinity and intellectual disability. It will then explore the different ways male health is being tackled by the mainstream health sector including methods to engage males in supporting their own health and well-being. Lastly, this chapter will discuss the notion of a masculine health environment as a conduit for improving the sexual health of men and boys with an intellectual disability.

INTRODUCTION

Male health, or what is referred to as the health of men and boys, while not a new issue has received growing international interest over the last two to three decades (Connell, Hearn, & Kimmel, 2005; Courtenay & Keeling, 2000; Peate, 2003; J. A. Smith, 2007). Segal (2007) claimed males emerged in the 1990s as the new “social victims” experiencing social disadvantage together with poorer health and well-being. The advent of male-friendly initiatives in Australia such as Mensline, Gut Busters, Pit Stop, and Men’s

Sheds epitomise this interest. Borne from irrefutable statistics which show a marked disparity between the health of women and the health of men (Salzman & Wender, 2006), current male-friendly health initiatives are however operating outside any national health framework similar to that which exists for women's health. The health of men and boys, argued Macdonald (2005), remains a neglected area in organised health care.

Regarding the health of men and boys with an intellectual disability, there remains little research or other publications exploring the gendered context of their unique health needs (N. J. Wilson, 2005). As a consequence, men and boys with an intellectual disability are at risk of experiencing what Kerr (2002) described as a health "double jeopardy"; poorer health due to intellectual disability and gender. While the voice of unique and diverse groups of men and boys were widely represented at the 2007 National Men's Health Conference, from 60 presentations only one[22] directly concerned the health of men and boys with an intellectual disability (N. J. Wilson, 2007c). Identifying and communicating the unique health needs of men and boys with an intellectual disability remains a challenge that may, in part, be due to a lack of acknowledgment from the mainstream together with a lack of a voice from within their own communities. If indeed a health "double jeopardy" does exist, a seat at the table of male health needs to be attained. To achieve this end requires recognition and celebration of a unique intellectually disabled male identity; a position that comes with immense ideological baggage.

One of the outcomes of community integration for people with an intellectual disability over the last thirty years has been a swing toward the use of mainstream primary

---

[22] One other presentation explored issues for fathers of children with a disability and reported on a parenting education program for those fathers (King, 2007).

and secondary health services (Jansen, Krol, Groothoff, & Post, 2004; N. G. Lennox & Kerr, 1997). Following this policy shift, recent commentary points to the limited capacity of mainstream health services to adequately support people with an intellectual disability whom experience more health problems, or morbidity, than people without an intellectual disability (Beange, Lennox, & Parmenter, 1999; Durvasula, Beange, & Baker, 2002; Ouellette-Kuntz, 2005; Patja, Mölsä, & Iivanainen, 2001; Tyrer, Smith, & McGrother, 2007; Wallace & Beange, 2008). Moreover, mortality rates remain higher for all people with an intellectual disability (Bittles et al., 2002; Durvasula et al., 2002; Patja, Mölsä et al., 2001; Shavelle & Strauss, 1999; D. Strauss, Shavelle, Baumeister, & Anderson, 1998; Tyrer et al., 2007) and the levels of unmet health need remain unacceptably high internationally (Cooper et al., 2006; Health Scotland, 2004; Smeltzer, 2007; U.S. Department of Health and Human Services, 2005).

In recent years, males with an intellectual disability living in NSW have experienced greater mortality than females with an intellectual disability (New South Wales Ombudsman, 2007). While this appears to confirm the existence of the suggested male health “double jeopardy”, the disparity may partly be attributed to the fact more people with an intellectual disability, approximately 57-60%, are male (Australian Institute for Health and Welfare (AIHW), 2003; Emerson et al., 2000; D. Strauss et al., 1998; Tyrer et al., 2007). Male mortality reported by the NSW Ombudsman, approximately 68.5%, is however greater than the incidence of intellectual disability in males; males with an intellectual disability are currently at higher risk of death within NSW. Other intellectual disability specific data however suggested a less disproportionate picture. Tyrer et al. concluded approximately 55% of all deaths in Leicestershire (UK) were male, the same figure identified by Shavelle and Strauss (1999) in California during 1996 and by Durvasula et al. (2002) in northern Sydney. It would appear male mortality has unique trends in different contexts over time. While the selected data described above correlates mortality to cause of death, exploration of other factors such as environment and gender remains limited. Tyrer et al. (2007) found women in their study were at a greater risk of death than men, particularly women in younger age groups and women who lived in city, as opposed to rural, areas. Questions posed by this research suggest future contextual exploration of how gender places some people with an intellectual disability at greater risk of poor health.

Identification and recognition of gendered health risk factors occupies a central aspect of mainstream women's and men's health. A focus on male health risk factors has tended to suggest the cause of most male health disparity are stereotypical male behaviours that "need to change", such as the lack of help-seeking behaviour by men (Haines & Wender, 2006). However, while a focus on gender stereotypes can give some insight into understanding gendered behaviour (Wilcox, Finlay, & Edmonds, 2006), it tells only a small part of the story. Exploring constructs of masculinity, or masculinity theory, enables a greater insight into understanding gendered health disparity than does a focus based on stereotype (Lohan, 2007; Robertson, 2007). Therefore, a discussion of male health without consideration of theories of masculinity is incomplete.

Taking a mainstream approach further also suggests extending exploration to the context in which people experience their health, or their health environment. For people with a moderate to profound intellectual disability this is largely in a dependent care relationship and/or setting. Living in any care setting brings many challenges but with females often representing up to 95% of primary carers (McConkey, McAuley, Simpson, &

Collins, 2007), the potential exists for a reduced gendered sensitivity to male health needs. Folkestad (2004) is one of the few, if not the only researcher, to have asked men with an intellectual disability about their experiences being “surrounded by women”; a tacit asymmetrical gender balance. If men and boys with an intellectual disability experience a health “double jeopardy”, understanding the gendered context of their health environment can only enhance the understanding of any male health disparity.

MEN AND BOYS WITH AN INTELLECTUAL DISABILITY

Using groupings differentiating between intellectual and other disability types, men and boys with an intellectual disability are those with developmental delay, intellectual disability, autism, or a specific learning/attention deficit disorder (AIHW, 2003). Table 3.1, adapted from p. 24 of the AIHW report, provides a summary of total number and percentage of people with an intellectual disability in Australia as either a main, or part of other, disabling conditions. Of note are the shaded boxes highlighting the greater prevalence of men with an intellectual disability as a main disabling condition as a percentage of all men, compared with the same data for women. Furthermore, the AIHW report indicates the prevalence rate of boys with an intellectual disability, compared to girls, is steadily increasing largely in relation to an increasing diagnosis of attention deficit disorder and autism amongst boys.

Table3.1

Estimates of the prevalence of intellectual disability by sex and age, total number (in 1000s) and as a percentage of the Australian population of that sex and age, 1998.

	MALE		FEMALE		PERSONS	
	„000	%	„000	%	„000	%
All disabling conditions						
0-64	252.5	3.0	124.4	1.5	376.9	2.3
65+	46.8	4.7	79.3	6.2	126.1	5.6
Total	**299.3**	**3.2**	**203.7**	**2.2**	**503.0**	**2.7**
Main disabling condition						
0-64	154.4	1.9	54.5	0.7	209.0	1.3
65+	1.6	0.2	2.1	0.2	3.7	0.2
Total	**156.1**	**0.8**	**56.6**	**0.3**	**212.7**	**1.1**

Determining the reasons behind why males experience a higher incidence of intellectual disability is complex and requires analysis of genetic, biological, hormonal, behavioural, social, environmental, and psychological factors[23]. Sex discrepancy, stated Lockshin (cited in T. Thompson, Caruso, & Ellerbeck, 2003), can be attributed to, or during, differing biological processes; molecular, cellular, organ, intrauterine, and whole body. For example, the effects of androgen on the brain are thought to affect a 4:1 male to female ratio in autism and 10:1 for Asperger syndrome. Weaknesses are also associated with the single X chromosome which can cause a greater likelihood of miscarriage or stillbirth in males plus a greater prevalence of health issues such as colour blindness and haemophilia (Arevalo, 2003; Russell & Schofield, 1986, p. 72). Moreover,

---

[23] An expansive recent publication has summarised more than 100 years of scientific research into sex differences (Ellis et al., 2008). Chapter 5 of this publication summarises the research relating to intellectual, cognitive, self-concept and mental health/illness factors. In additional to clarifying more males have an intellectual disability than females, this chapter also highlights males develop language skills, literacy, spelling, reading, writing, at a slower rate than females. Further, more males are diagnosed with dyslexia and males generally perceive sexual interactions differently to females.

X-linked syndromes are responsible for between 20-30% of all intellectual disability (Feldman, 1996) which include fragile-X syndrome and Lesch-Nyhan Syndrome (Jenkinson & Wilson, 1996). In their study of 204 children with cerebral palsy, Murphy, Yeargin-Allsopp, Decoufle and Drews (1993) found a higher prevalence of cerebral palsy in males (61.5%). Females also benefit from female hormones which offer health protection until the onset of menopause. Therefore, while intellectual disability is not solely a male problem, there are specific issues of prevalence, aetiology, mortality, and morbidity that are unique to males.

As would be expected from a greater prevalence, males with an intellectual disability are also greater users of disability services than females with an intellectual disability. In their UK review of village communities, residential campuses, and dispersed housing schemes, Emerson et al. (2000) respectively found males represented 62%, 59% and 60% of total service users. In the six months to December 2007, 58% of all extended consultations with GPs under the new Australian Medicare item 718[24] were by males (Medicare Australia, 2008). Broken down into consultations per 100,000 population, female consultations were highest in the 35-44 (13 per 100,000) and 45-54 (15 per 100, 000) age bracket. In contrast, male consultations per 100,000 population, were higher for all age brackets and specifically for the 25-34 (12 per 100,000), 35-44 (20 per 100,000), 45-54 (18 per 100,000), and 55-64 (13 per 100,000) age brackets. In NSW, of 3,398 people with an intellectual disability who resided in community group homes during 2005-2006, 2017 (59%) were male. Table 3.2 shows the distribution of males and females with an intellectual disability receiving all types of funded support in NSW for the 2005–2006

---

[24] Under the enhanced primary care program, item 718 reflects the increased time taken for an annual health assessment by a medical practitioner (not a specialist or consultant) on a person with an intellectual disability in the practitioners consulting rooms.

year (Australian Institute for Health and Welfare (AIHW), 2008); these data support the proposition that most service types are used by more males than females.

Table 3.2

Distribution of males and females with an intellectual disability using government-funded services in NSW during 2005-2006.

	Group home	Large residential	Small residential	Own home respite	Centre – based respite	Host family	Flexible respite	Other respite
Males	2017	987	54	10	1676	148	1147	55
Females	1363	660	85	9	1058	111	794	32
Not stated	18	0	0	0	3	0	26	0
Total users	**3398**	**1647**	**139**	**19**	**2737**	**259**	**1967**	**88**

Sex Differences in Literature Relating to Intellectual Disability

Having established the fact there are unique sex differences in the prevalence and aetiology between males and females with an intellectual disability, the point is, does it really matter? According to Porter, Christian and Poling (2003), mention of sex, or gender, when describing data, reporting on service delivery, or presenting opinion or comment, does matter; potential problems with failing to report gender are real and potentially serious. However, with respect to a greater male prevalence and male mortality, raw statistics, while interesting, fail to provide deeper context and meaning. For example, weaknesses associated with the X chromosome are not going to be resolved in the immediate to medium future; natural biological variations are just that, natural. Discussion of sex differences in health start to matter when statistical data help to identify when a gendered health disparity becomes a gendered health inequity (Ouellette-Kuntz, 2005).

Exploration of gendered health inequity moves the debate beyond biological and genetic sex differences toward the contextual exploration of other factors such as social-environmental and behavioural (Sabo, 2005). Whereas mention of gender in intellectual disability research is often limited, discussion of gendered health inequity applied to people with an intellectual disability lags even further. For example, in their analysis of eight journals, Porter et al. (2003) found where participants with an intellectual disability were mentioned (65% of articles) gender was not mentioned in 26% of those. This is despite all journal articles in their analysis are prepared to the *American Psychological Association Manual* which states demographics such as sex be reported.

It is unclear whether the under-reporting of gender in academic journals is linked with what Francis (2000) labelled *gender feminism* which "…requires the elimination of not only of economic classes but of sex classes, i.e. the division of humans into male and female" (p.1). Certainly sex differences (male, female, hermaphrodites, masculine hermaphrodites, feminine hermaphrodites) can be measured whereas gender is malleable to interpretation or expression in any given social context. Irrespective, reporting of sex differences, or gender differences, is an important facet of the scientific process and should therefore be acknowledged. For example, the otherwise illuminating article by Fyson (2007) illustrates the importance of reporting sex-difference; although it is clear the school students in the study were both male (n=14) and female (n=1) the majority of the discussion referred to "pupils" and "young persons" instead of, for example, "boys" or "girls". Using gender-neutralising language such as this limits the capacity to draw wider contextual conclusions which may aid understanding of sex differences. In contrast, the recent publication by Emerson and Hatton (2008) stated in both title and content sex differences in subjective well-being between men and women; as a result a deeper contextualisation of data is enabled.

Tables 3.3 and 3.4 provide a summary of article titles from four prominent intellectual disability journals where the sex of the client was significant enough to include it in the title. Part of the rationale for conducting the summary was to also ascertain gendered topics of foci in the literature. The four journals selected are linked with associations whose main focus is in research and intellectual disability across the western world:

1) *Journal of Intellectual and Developmental Disability* (JIDD) 2000-2008; Journal for the Australasian Society for the Study of Intellectual Disability (ASSID)
2) *Journal of Intellectual Disability Research* (JIDR) 1996–2008; Journal for the International Association for the Scientific Study of Intellectual Disability (IASSID)
3) *American Journal on Mental Retardation* (AJMR) 2000–2008; scholarly journal for the American Association on Intellectual and Developmental Disabilities (AAIDD)
4) *Journal of Applied Research in Intellectual Disabilities* (JARID) 2000–2008; Research journal for the British Institute of Learning Disabilities (BILD).

Table3.3

Summary of article titles in JIDR (1996 +), JARID, AJMR and JIDD with the word male, man, boy or men in title since the year 2000

MENTAL HEALTH; n = 3
• Monosymptomatic hypochondriacal psychosis in a man with learning disabilities (Brooke, Collacott, & Bhaumik, 1996) • Autism and epilepsy (and tuberous sclerosis?) in two pre-adolescent boys: neuropsychotic aspects before and after epilepsy surgery (Gillberg, Uvebrant, Carlsson, Hedstrom, & Silfenius, 1996) • Diagnosis and treatment of a severe psychotic illness in a man with dual sensory impairments caused by the presence of Usher syndrome (Hess-Röver, Crichton, Byrne, & Holland, 1999)
SEXUAL MATTERS N = 9 (mostly problematise male sexuality)
• Men with learning disabilities who have sex with men in public places: mapping the needs of services and users in South East London (Cambridge, 1996) • Homo-erotomania for a delusional parent: erotomania with Capgras and Fregoli syndromes in a young male with learning disabilities (Mann & Foreman, 1996) • Erotomania in a brain damaged male (John & Ovsiew, 1996) • Can attribution theory explain carers' propensity to help men with intellectual disabilities who display inappropriate sexual behaviour? (Willner & Smith, 2008) • A psycho-educational group for men with intellectual disabilities who have sex with men (Withers et al., 2001) • The treatment of auto-erotic asphyxiation in a man with severe intellectual disabilities: the effectiveness of a behavioural and educational programme (A. R. Thompson & Beail, 2002) • Psychological factors in risk assessment and management of inappropriate sexual behaviour by men with intellectual disabilities (M. Smith & Willner, 2004) • Sterilisation, drugs which suppress sexual drive, and young men who have intellectual disability (G. Carlson et al., 2000) • Pharmacological management of inappropriate sexual behaviours: A review of its evidence, rationale, and scope in relation to men with intellectual disabilities (Sajith et al., 2008)

HEALTH AND WELL-BEING; n = 9

- Different presentations of late-detected phenylketonuria in two brothers with the same R408W/R111X genotype in the *PAH* gene (Giz·ewska et al., 2003)
- Sodium-Valporate-Induced pancreatitis in a man with profound intellectual disability: the significance of diagnostic difficulties (Hinder & Perry, 2000)
- Aspiration pneumonia and antibiotic resistant infections in a man with severe intellectual disabilities: how much care is enough? (Ghan-Shyam, Tan-Figuero, & Kuhler, 2000)
- High intensity cycling performances of boys with and without intellectual disability (Chia, Lee, & Teo-Kho, 2002)
- Hypogonadism in men with intellectual disabilities: a population study (McElduff et al., 2003)
- Men’s health and well-being: testosterone deficiency (McElduff & Beange, 2003)
- Pathological and neuropathological findings in two males with fragile-X syndrome (Sabaratnam, 2000)
- Blink rate in boys with fragile-X syndrome: preliminary evidence for altered dopamine function (Roberts, Symons, Johnson, Hatton, & Boccia, 2005)
- Self-reported well-being of women and men with intellectual disabilities in England (Emerson & Hatton, 2008)

CRIME/ANTISOCIAL BEHAVIOUR; n = 10 (word „abuse’ or ‘offend’ implied criminal behaviour)

- Prevalence of „criminal offending’ by men and women with intellectual disability and the characteristics of „offenders’: implications for research and service development (Holland, Clare, & Mukhopadhyay, 2002)
- Sexual abuse perpetrated by men with intellectual disabilities: a comparative study (Brown & Stein, 1997)
- Responses to treatment of sex offenders with intellectual disability: a comparison of men with 1 and 2 year probation sentences (Lindsay & Smith, 1998)
- Cognitive-behavioural treatment for men with intellectual disabilities and sexually abusive behaviour: a pilot study (G Murphy, Powell, Guzman, & Hays, 2007)
- Sexual knowledge and attitudes of men with intellectual disability who sexually offend (Lunsky et al., 2007)
- Group treatment for men with intellectual disability and sexually abusive behaviour: service user views (Hays et al., 2007)
- A group treatment for men with intellectual disabilities who sexually offend or abuse (J. Rose, Jenkins, O'Connor, Jones, & Felce, 2002)
- A follow-up of deinstitutionalised men with intellectual disabilities and histories of antisocial behaviour (Quinsey et al., 2004)
- Aggression-related hostility bias and social problem solving deficits in adult males with mental retardation (Basquill, Maguth-Nezu, Nezu, & Klein, 2004)
- Rate and characteristics of men with an intellectual disability in pre-trial detention (Crocker, Côté, Toupin, & St-Onge, 2007)

LANGUAGE/COMPREHENSION n = 8 (Note: Several articles exploring fragile-X syndrome all had at least one author in common)
• Difficulty in writing Japanese semantic characters in a 9-year old boy with Williams syndrome (Nakamura et al., 1999) • Language comprehension in boys with fragile-X syndrome and boys with Down syndrome (Price, Roberts, Vandergrift, & Martin, 2007) • Receptive vocabulary, expressive vocabulary, and speech production of boys with fragile-X syndrome in comparison to boys with Down syndrome (Roberts, Price et al., 2007) • Expressive language during conversational speech in boys with fragile-X syndrome (Roberts, Hennon et al., 2007) • Academic skills of boys with fragile-X syndrome: profiles and predictors (Roberts, Schaaf et al., 2005) • Receptive and expressive communication development of young males with fragile-X syndrome (Roberts, Mirrett, & Burchinal, 2001) • Memory skills of boys with fragile-X syndrome (Ornstein et al., 2008) • Autism profiles of males with fragile-X syndrome (Harris et al., 2008)
OTHER n=6
• Men in the lives of mothers with intellectual disabilities (Booth & Booth, 2002) • Face recognition and emotion perception in boys with fragile-X syndrome (Turk & Cornish, 1998) • Executive function and theory of mind performance of boys with fragile-X syndrome (Garner, Callias, & Turk, 1999) • Variable FMRP and early development in males with fragile-X syndrome (Bailey, Hatton, Tassone, Skinner, & Taylor, 2001) • Early temperament and negative reactivity in boys with fragile-X syndrome (Shanahan, Roberts, Hatton, Reznick, & Goldsmith, 2008) • Helping a man with multiple disabilities increase object-contact responses and reduce hand stereotypy via a microswitch cluster program (Lancioni et al., 2008)

Table 3.4

Summary of article titles in JIDR (1996 +), JARID, AJMR and JIDD with the word female, woman, girl or women in title since the year 2000

HEALTH AND WELL-BEING; n = 21
• Osteoporosis and women with Down syndrome (Millberger, LeRoy, Lachance, & Edelson, 2002)
• Going through the menopause: perceptions and experiences of women with intellectual disability (McCarthy, 2002)
• The nature and extent of help given to women with intellectual disabilities to manage menstruation (J. Rogers & Lipscombe, 2005)
• Menstrual profile and early menopause in women with Down syndrome aged 26-40 years (Ejskjaer, Uldbjerg, & Goldstein, 2006)
• Behavioural treatment of improper eating by an institutionalised woman with profound intellectual disability – description of a successful intervention (Saloviita, 2002)
• Early menopause in women with Down syndrome (Schupf et al., 1997)
• Age at onset of dementia and age of menopause in women with Down syndrome (Cosgrave, Tyrell, McCarron, Gill, & Lawlor, 1999)
• A prospective study of menopause in women with Down's syndrome (Seltzer, Schupf, & Wu, 2001)
• Breast cancer screening for older women with intellectual disability living in community group homes (Davies & Duff, 2001)
• Contraception and women with intellectual disability: prevalence and determinants (Servais et al., 2002)
• Health issues and quality of life in women with intellectual disability (Kyrkou, 2005)
• Prevalence of fractures in women with intellectual disabilities: a chart review (Schrager, Kloss, & Ju, 2007)
• Healthy ageing – Adults with intellectual disabilities: Women's health and related issues (Walsh, Heller, Schupf, & van Schrojenstein Lantman-de Valk, 2001)
• Women be healthy: evaluation of a Women's health curriculum for women with intellectual disabilities (Lunsky, Straiko, & Armstrong, 2003)
• Menstrual problems experienced by women with learning disabilities (J. Rogers, Lipscombe, & Santer, 2006)
• Menstrual discomfort as a biological setting event for severe problem behaviour: assessment and intervention (Carr, Smith, Giacin, Whelan, & Pancari, 2003)
• An exploration of issues around menstruation for women with Down syndrome and their carers (L. Mason & Cunningham, 2008)
• Meanings and experiences of menstruation: Perceptions of institutionalised women with an intellectual disability (Chou, Lu, Wang, Lan, & Lin, 2008)
• Self-reported well-being of women and men with intellectual disabilities in England (Emerson & Hatton, 2008)

• Women with intellectual disability at risk of adverse pregnancy and birth outcomes (McConnell, Mayes, & Llewellyn, 2008b) • Pre-partum distress in women with intellectual disabilities (McConnell, Mayes, & Llewellyn, 2008a)
SEXUALITY; n = 1 (Females as victims of sexual abuse)
• Evaluating a survivors group pilot for women with significant intellectual disabilities who have been sexually abused (Peckham, Howlett, & Corbett, 2007)
CRIME/ANTI-SOCIAL BEHAVIOUR; n = 3
• Prevalence of „criminal offending’ by men and women with intellectual disability and the characteristics of „offenders’: implications for research and service development (Holland et al., 2002) • Women with intellectual disability who have offended: characteristics and outcome (Lindsay et al., 2004) • Treatment of women with intellectual disabilities who have been involved with the criminal justice system for reasons of aggression (R. Allen, Lindsay, MacLeod, & Smith, 2001)
OTHER; n = 12
• Ring chromosome 15 syndrome in an adult female (Matsuishi, Yamada, Endo, Sakai, & Fukushima, 1996) • The effect of the presentation of visual and auditory stimuli on the breathing patterns of two girls with Rett syndrome (Woodyatt & Murdoch, 1996) • „A woman’s heaven is at her husband’s feet’? The dilemmas for a community learning disability team posed by the arranged marriage of a Bangladeshi client with intellectual disability (Hepper, 1999) • Family environment and cognitive abilities in girls with fragile-X syndrome (Kuo, Reiss, Freund, & Huffman, 2002) • Behaviour problems in adult women with Rett syndrome (Mount, Hastings, Reilly, Cass, & Charman, 2002) • An analogue assessment of repetitive hand behaviours in girls and young women with Rett syndrome (Wales, Charman, & Mount, 2004) • Cognitive performance in Rett syndrome girls: a pilot study using eye-tracking technology (Baptista, Mercadante, Nacedo, & Schwartzman, 2006) • Retreat and resilience: life experiences of older women with intellectual disabilities (LeRoy, Noonan-Walsh, Kulik, & Rooney, 2004) • Increasing independent decision making skills of women with mental retardation in simulated interpersonal situations of abuse (Khemka, 2000) • Men in the lives of mothers with intellectual disabilities (Booth & Booth, 2002) • Profiles of women who have mental retardation with and without a documented history of abuse (Hickson, Khemka, Golden, & Chatzistyli, 2008) • Ring chromosone 7 in an Indian woman (Kaur, Dhillon, Garg, & Singh, 2008)

A topical analysis of the titles suggests sex-specific health occupies more of a concern for women and girls while mental health and problematised sexual expression more so for men and boys. That several of the health-related articles for women and girls covered menstruation and breast screening mirrors, excluding cervical screening, a mainstream focus. The absence of prostate screening, testicular examination, or other male health promotion activities suggests a health inequity based upon gender: a difference which appears to be avoidable and unjust (Leeder & Dominello, 2005; Ouellette-Kuntz, 2005). Although cervical screening is covered by articles published elsewhere (e.g. J. Brewster, 2005; Lehman, 2005; Wood, 2007) articles exploring male-specific health screening are largely absent. Likewise, Hogg and Tuffrey-Wijne (2008) asserted considerably less attention has been placed on male-specific cancers than they have for females. In some way this inequity is to be expected as the limited male focus simply reflects targeted health frameworks for people with an intellectual disability which exclude men's health, such as IASSID's *Health Guidelines for Adults with Intellectual Disabilities* (n.d.). The differently gendered focus is further exemplified in Table 3.5, a summary of known books or book sections discussing intellectual disability from a sex-difference perspective.

Table3.5

Summary of known book titles or book sections from a sex-specific perspective

BOOKS
• Women with Intellectual Disabilities: finding their place in the world (Traustadottir & Johnson, 2000) • Sexuality and women with learning disabilities (McCarthy, 1999) • Health of women with intellectual disabilities (Walsh & Heller, 2002) • Women with disabilities ageing well (Walsh & LeRoy, 2004) • Secret loves, hidden lives? Exploring issues for men and women with learning disabilities who are gay, lesbian, or bisexual (Abbott & Howarth, 2005) • Taking more control of my health. A health guide for women (The Donald Beasley Institute, 2001) • Women with disabilities: Speaking out for ourselves (A Group of Women with Disabilities, 1996)
BOOK SECTION
• Men's health: the female of the species is more healthy than the male (Last chapter in book: Health of women with intellectual disabilities) (Kerr, 2002) • Women's Health (In: Health promotion for people with intellectual and developmental disabilities: the state of scientific evidence. No corresponding chapter for male health) (Nehring, 2005) • Women with learning disabilities and cancer (breast cancer and cervical cancer) (Hogg, Northfield, & Turnbull, 2001) • Rights of passage: life course transitions for women with intellectual disabilities (P. N. Walsh, 2000) • A gendered approach to intellectual and developmental disabilities (Despite title suggesting a chapter focussed on gender, it is in fact entirely about women with intellectual disabilities and women as support providers) (Walsh, 2007)

Sex differences in parenting and intellectual disability demonstrate another focus in the research literature. Using the same sources of data cited in Tables 3.3 and 3.4, Table 3.6 numbers the journal articles where family issues were the central topic; a predominant research focus on mothers was found. This greater focus on mothers reflected Blacher and Tan Mink's (2004) findings that fathers are rarely the focus of research. The sole article focussed on fathers of children with an intellectual disability (Ricci & Hodapp, 2003), while comparing perceptions between Down syndrome and other causes of intellectual disability, demonstrated differences between fathers responses, and hence perceptions, depending on whether their child with an intellectual disability was a boy or a girl. These are important research findings. In another article, Grant and Whittell (2000) found women experienced greater self-belief, self-confidence, and ability as carers than men. Some of the men in this study also found distance from the caring role afforded simultaneous emotional distance from their child as a coping strategy. Sex differences in parenting impact significantly on the child with an intellectual disability so their interrogation will provide further contextual meaning to the lives of men and boys with an intellectual disability.

Table3.6

Number of journal articles in JIDR (1996+), JARID, AJMR and JIDD related to family issues whose title mentioned gender since the year 2000

Mother	Father	Both parent(s)	Mother with intellectual disability	Father with intellectual disability	Sibling
36	1	19	5	0	1

The influence of sex differences on mental health, pathophysiology, behavioural presentation, cognitive, and cultural factors play a huge role in how interventions for people with an intellectual disability are structured and implemented (T. Thompson et al., 2003). For example, Baron-Cohen, (cited in T. Thompson et al.), suggested males “systematize” better then females, who are often better empathisers; autism being the “extreme form of the male brain” (p.352). Females with autism were found to have better superficial social and language skills than males with autism who tended to display more hyperactivity and aggression. T. Thompson et al. also stated sex differences can be seen in the presentation of mental health issues; females with an intellectual disability are more likely to present with mental health and anxiety disorders whereas males are more likely to display aggression and other forms of acting out. Lunsky (2003) also found sex differences in symptoms and risk factors for depression arguing for such differences to be explored as one of the key factors in assessment and treatment. Despite the importance of understanding sex differences when designing services and interventions, beyond these articles, it too has attracted little research focus. Box 3.1 highlights the small number of articles using the same data cited in Tables 3.3 and 3.4 which seek to understand sex differences.

Box 3.1

Articles in JIDR (1996 +), JARID, AJMR and JIDD from 2000 whose focus was sex, or gender, differences

- Depressive symptoms in intellectual disability: does gender play a role? (Lunsky, 2003)
- Sex differences in performance over 7 years on the Wechsler intelligence scale for children – revised among adults with intellectual disability (Kittler, Krinsky-McHale, & Devenny, 2004)
- Psychiatric co-morbidity and gender differences in intellectual disability (Tsakanikos, Bouras, Sturney, & Holt, 2006)
- Gender differences in repetitive language in fragile X syndrome (M. M. Murphy & Abbeduto, 2007)
- Diagnosing intellectual disability in a forensic sample: Gender and age effects of the relationship between cognitive and adaptive functioning (Hayes, 2005)
- Living conditions of adults with intellectual disabilities from a gender perspective (Umb-Carlsson & Sonnander, 2006)

PATHOLOGISING MEN AND BOYS WITH AN INTELLECTUAL DISABILITY

Having established that unique sex differences exist and that an imbalanced topical focus within the research literature predominates, does this amount to suggesting that men and boys with an intellectual disability are being unnecessarily *pathologised*? Cambridge and Mellan (2000) suggested the wider sexual needs of males with an intellectual disability are often overlooked due to the focus on males as abusers and the inappropriate sexual behaviour of some males with an intellectual disability. While a small body of research has sought to positively explore the sexual identity of males with an intellectual disability (e.g. D. Thompson, 1998; Wheeler, 2007; Yacoub & Hall, 2009), there has been no direct challenge to what appears to be an imbalanced focus in the literature based upon gender.

Within mainstream literature and opinion, there is a view that a pathological narrative of maleness is reinforced by popular culture and constitutes a form of *misandry* (Nathanson & Young, 2001). Misandry, stated Macnamara (2006), is not as widely known as misogyny (the hatred and vilification of women) but is an emerging trend where males are often blamed for the ills of society. Nathanson and Young (cited in Macnamara), put this alleged misandry into context thus: “the traditional universe on which men relied for self-esteem and self-confidence is crumbling. A suitable replacement has not yet emerged, and almost any attempt to create one is quickly demonised” (p.61). Misandry is generated through portrayals of men in the media fastened to negative or pathological male flaws, flaws such as men as abusers, as violent, or incapable of emotion.

Reflecting upon the topical difference between Tables 3.3 and 3.4 provides some initial evidence of a parallel between the problematised focus in the media and the intellectual disability literature; males with an intellectual disability as offenders, abusers, and as sexual deviants. While Tables 3.3 and 3.4 provide a limited analysis from four key journals, it is probable a range of diverse factors are behind the unbalanced narrative. What that difference is, and where it stems from, is unknown. However, one explanation might be found by the influence of what Gardiner (2005) refers to as *superiority feminists* who see their version of masculinity as defining for all men; that gender is dependent on sex, and sex dependent upon male force. While McCarthy (1999) does not call herself a superiority feminist, she appears to suggest a feminist perspective is exclusive to understanding gender relations: "… it was only a feminist perspective which allowed a proper understanding of the gendered nature of power relations between men and women with learning disabilities" (p. 240); and "…the only hope for women to be able to get and keep what they want in a relationship and not constantly be giving men what men want is if they can become sufficiently assertive" (p. 241). These statements, in isolation, are relatively unimportant. However, McCarthy has become a high profile and often-cited author regarding sexual matters and intellectual disability which suggests a feminist perspective may hold a widespread credence.

Likewise, Hollomotz (2006) draws upon feminist ideology to suggest how people with an intellectual disability have become victims to the label "vulnerable". For example: "People with learning difficulties are socialised into being vulnerable, like adolescent girls are socialised into sexual subordination" (p.32); "… to be female is to be sexually available on male terms, in other words to be vulnerable to male sexual approaches" (p 33). Hollomotz is not the first to claim a correlation between vulnerability and male social pathology. McCarthy and Thompson (1997) asserted "… the sexual abuse of people with intellectual disabilities is overwhelmingly a problem caused by men, as it is with all other victim groups" (p112). Sweeping statements such as these in isolation do not represent widespread misandry, they seem to represent an unchallenged and perpetuating myth despite the fact only some, not all, males display such pathological behaviour. While incorrect discussion of gendered violence are being challenged in the mainstream (e.g. Woods, 2007), the same is not occurring in the intellectual disability sector. Male social pathologies, what Macdonald (2005) referred to as “men behaving badly”, are often portrayed as the problem, vulnerable females the victim.

Therefore, a thematic and tonal difference is evident in the way males and females with an intellectual disability are being discussed. There appears to be little analysis of the thematic differences between the genders and applying this analysis to deepen gendered understanding. Other than pointing to gendered stereotype, such a position is partly borne out of taking statistics at face value without a wider interpretation of, for example, the environmental context. For example, G. Murphy and Fernando (1999) highlighted how males with an intellectual disability are approximately four times more likely to display challenging behaviour than females with an intellectual disability. On the one hand, statistics such as these confirm the gendered nature of some violence and hence validates the stereotype. On the other hand, acknowledging the unique physicality of male interaction and communication enables male violence to be seen more contextually as perhaps interaction or communication gone wrong. The problem might lie not with expressing maleness, but with the degree, capacity, and/or limitations of that expression.

Figure 3.1 illustrates a continuum representing the tonal difference between the gendered themes that perpetuate a more “reactive” approach to male health. That is to say, the strong advocacy of female health needs by, not only high profile feminist authors such as Michelle McCarthy, but also by the disability sector at large, has reinforced male health needs as a reactive afterthought. Male health needs responded to on a *behavioural risk hierarchy* simply reduce males to their behaviours at the expense of the person and the context in which they live (Williams & Robertson, 2006). As a result, one end of the continuum reduces male health needs to the "social dysfunctional", the other end promotes female health needs to the "social functional". What transpires within such a construction is a perpetrator/victim dependant variable. Therefore, instead of asking how service systems and structures can be modified to better support maleness, there are, for example, calls to implement same-gender safeguards to protect females from male behaviours (Howlett & Danby, 2007; McCarthy & Thompson, 1996). Whereas violence, physical or otherwise, is unacceptable, unique male physicality, sexuality, and communication should be celebrated with appropriate supports built into services, not services changing to manage a pathological stereotype.

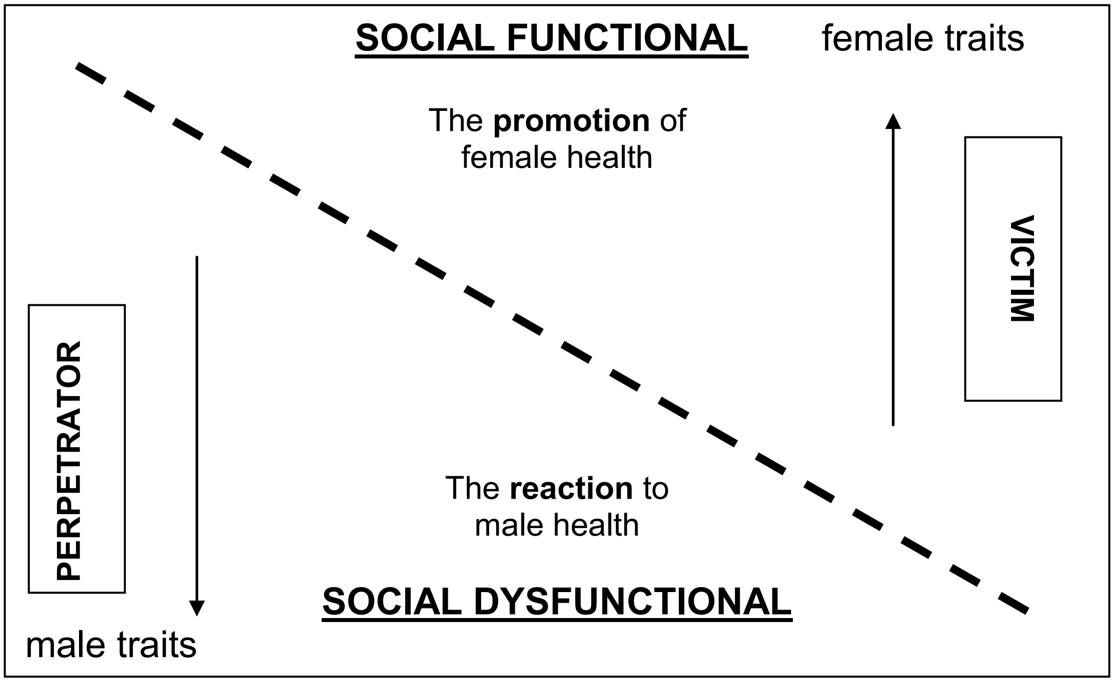


Figure 3.1

The health promotion/reaction continuum

To challenge a focus on male pathology, Williams and Robertson (2006) argued the narrow and stereotypical assumptions of maleness need to be surmounted. Some of the proponents of male health in the mainstream utilise the emerging theories of men and masculinities to overcome this obstacle. The basis of the emerging theoretical framework is underpinned by the recognition of different male groups with different needs, men and boys with an intellectual disability are one such group. Each group faces unique challenges within the context of their lives: Sabo (2005) argued that “The fact is not all men are alike, and various male groups face different conditions in the gender order. At any given historical moment, there are competing masculinities–some dominant, some marginalised, and some stigmatised” (p. 336). The one striking contextual difference that sets men and boys with an intellectual disability apart from other male groups lies in their cognitive impairment.

THEORIES OF MASCULINITY

Theories of masculinity, or *Critical Studies on Men and Masculinities*, have emerged from the critical analysis of gender undertaken by feminists and feminism over many decades (Connell et al., 2005; Connell & Messerschmidt, 2005). The analysis of gender by feminists placed the focus on men by putting masculinity in the spotlight. Largely framed within a sociological construct by theorists within the social sciences, men and masculinities are understood as both gendered in their intersection with other social features, and shaped by internal factors such as, but not limited to, age, class, culture, function, and status. The sociological intersection implies men and masculinities are more than simply about being male. Perhaps one of the most influential authors of the initial development of theories on men and masculinity, R. W. Connell’s work was important in identifying the existence of not a solitary masculinity, but a multitude of masculinities (Connell, 1998; Segal, 2007 pp. 80-83). With regard to male health, the importance in understanding the notion of different masculinities lies in appreciating that differences will generate unique health practises and effects (Robertson, 2007; Schofield, Connell, Walker, Wood, & Butland, 2000)

Emerging at roughly the same time as critical studies on men and masculinities, the men's movement was framed more by a bio-psychological paradigm in what was seen as a reaction to radical feminist challenges to patriarchy. The men's movement, or what Connell (2000) has referred to as the "mythopoetic" men's movement spawned by "pop-psychologists", saw an essential masculinity, or manhood, in crisis. Connell referred to Robert Bly as the main proponent of the ideology behind this movement with Steve Biddulph Bly's Australian follower. Biddulph (2000) described the movements opinion of patriarchal charges thus:

> This image of a man – the honourable husband and father– was utterly denigrated in the 1970s ideology of postmodernism, and was recast as a patriarchal brute who dominated the family for his own gratification. But the simplification, the idea that most men lived by power and domination, or even wanted to, is an offence against the truth, and against the millions of men who strove throughout history to be honourable, protective, nurturing and fair. It is chilling to discover it in serious academic writings, or enshrined in government policy on domestic violence. (p.4)

It would seem the mutual denigration of each perspective is based in a stark ideological divergence separating the sociologically framed critical studies on men and masculinities, and the bio-psychologically framed men's movement. The divergence reflects the similar bio-medical/social differences in ideology identified in Chapter 2 with regard to human sexuality and disability.

Irrespective of the divergence, the notion of *hegemonic masculinity*, first coined by Connell, appears to be the accepted analysis to appreciating men and masculinities. Williams and Robertson (2006, p. 26) provided a tabular summary to describe the concept of hegemonic masculinity and its connected categories of understanding: complicit, marginalised, and subordinate. Connell's hegemonic baseline emphasises hegemony, and hence gendered power, as the determining factor within and between each category; complicit, subordinate, and marginalised exist because of their lack of gendered power relative to hegemonic masculinity. Table 3.8 illustrates Williams and Robertson's summary which incorporates an explanation of the different categories.

Table 3.8

Connell's framework for understanding masculinities

Hegemonic masculinity	Hegemony refers to the process by which a minority of men strive for dominance in social life to ensure that unequal gender relations, or patriarchy, is maintained. Cultural ideas and organisational power are interdependent in the process of achieving dominance in society, which includes the subordination of women and the subordination or marginalisation of some groups of men.
Complicit masculinity	Few men have dominant positions within society, but this does not stop most benefiting complicitly from the effects of hegemony. Hence the majority of men share in the benefits, the patriarchal dividend, of an unequal society where women and subordinated and marginalised men are less powerful.
Subordinate masculinity	Some forms of masculinity are subordinated to the leading form of hegemonic masculinity. Gay men may be subordinated, which means they may be stigmatised, excluded, abused or experience socio-economic discrimination.
Marginalised masculinity	Some men may not be subordinated like sexual minorities, or encounter direct or overt threats or discrimination, but are marginalised from full participation in society by material and structural constraints. Marginalised masculinity may be associated with the experiences of men with a disability, ethnic minority men, unemployed men, or men who have low income.

Based upon Connell's framework, gendered power is realized through implicit association with patriarchy and the socio-cultural desire of the hetero-normative ideal. In the western cultural context, achieving hegemonic masculinity has been defined by three markers of success; independent living, establishment of an heterosexual relationship, and becoming a father (J. A. Smith, 2007). Hegemonic masculinity can also evidently be reinforced institutionally such as through the militarised power relations implicit within the armed forces (Connell, 1998), so too within differing cultural contexts (Schofield et al., 2000).

However, there are inherent problems with using gendered power, or hegemonic masculinity, as a starting point. While the experience of power and powerlessness for people with an intellectual disability has often been articulated through arguments for equality, notwithstanding feminist arguments, this has not extended to notions of gendered power. The powerlessness most people with an intellectual disability experience centres from their cognitive impairment and opportunity for independent decision making. Within critical studies on men and masculinities, critiques of the widely accepted analysis, hegemonic masculinity, have started to emerge. Connell and Messerschmidt (2005) suggested the most coherent critique has come from the theoretical work of the Scandinavian social theorist Øystein Gullvåg Holter.

Holter (2005) asserted gender in modern society is experienced more as an independent social system of socio-structural relations, distinct from patriarchy which has become partly dismantled. Therefore, either gender is seen within the context of power and patriarchy, or gender is seen as a system of contextual meaning. While neither Connell nor Holter described their contextual notions as divergent entities, their deviation based upon gendered power renders each perspective divergent from the other. Figure 3.2 illustrates the divergence in perspective between Holter's and Connell's perspective. This illustration suggests a dichotomy based upon gendered power. While such sociological dichotomies often present a contentious positioning, Figure 3.2 suggests gender is either seen within the context of patriarchy, or as a system of meaning.

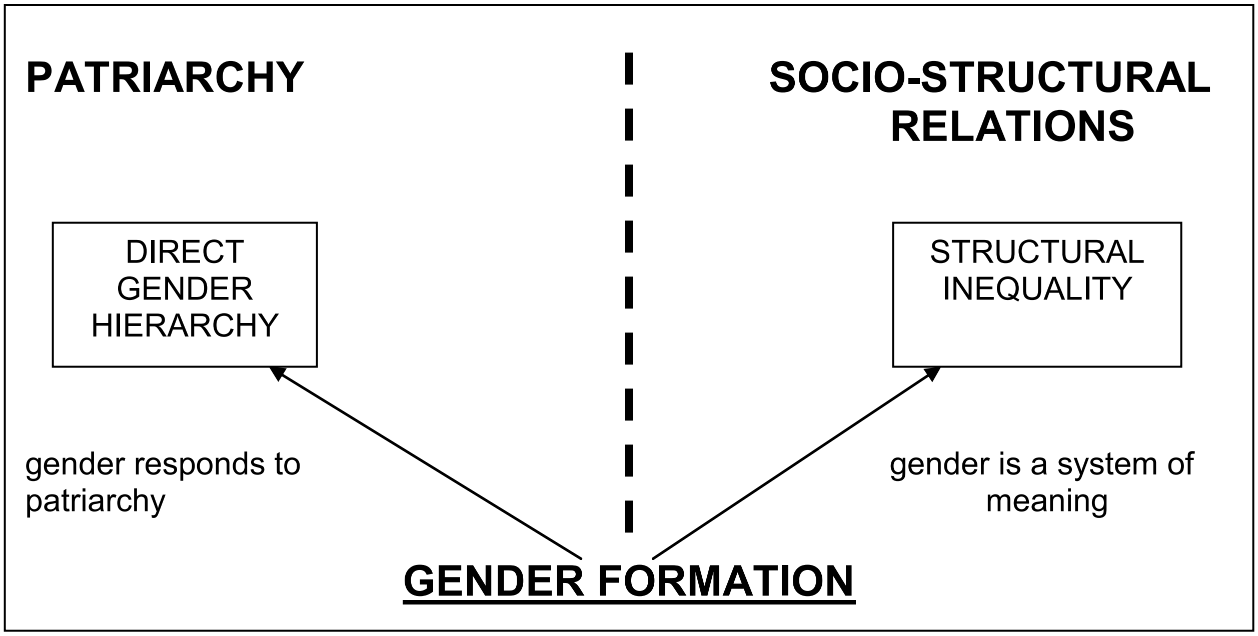


Figure3.2

Two perspectives of gender formation

While the divergence between gendered hierarchy and structural inequality has more theoretical origins, a critique of hegemonic masculinity has also emerged within mainstream men's health. This critique argues hegemonic masculinity has evolved into an explanation for culturally stereotypical male behaviour irrespective of one's position within Connell's hierarchy. The *alpha-male*, which Stibbe (2004) suggested is one dominant western cultural stereotype, can be found on any cover of *Men's Health* magazine. The presence of a chiselled-jawed male with full head of hair is surrounded by themes of sexual prowess, body-building, beer-drinking, and meat-eating male power. Masculine cultural representations such as the alpha-male, only reifies hegemonic maleness through stereotypical behaviours associated with the stereotype. This serves as the explanation for male problems and has been used to describe why males do not use health services, do not seek help for emotional problems, take unnecessary risks, aspire to heterosexual virility, choose violence, and are less likely to take preventative steps for their health and well-being (Lee & Glynn-Owens, 2002). Reducing hegemonic masculinity to such stereotypical individual male behaviour has inadvertently pathologised maleness. Concern for one's health is evidently a feminine concern; males the dominant (hegemonic) muscular sex able to cope with pain and see physical suffering as a weakness. Masculinity is the problem.

Direct Gender Hierarchy: The Gender–Power Quandary

Viewing masculinity through the gender/power lens has two main problems argued Holter (2005): 1) that gender as a response to patriarchy is not as relevant in modern western society as it historically was and, 2) not all men experience gendered power nor enjoy the dividend of other's gendered power. For men and boys with more severe intellectual disability, the construction of power via social, individual, and structural hegemony appears to be one major contradiction. Their masculinity is not constructed with or by any male-dominated hegemonic framework; they lack power and therefore lack rights. If a hierarchy such as Connell's does exist and naming categories helps, their position might be a sub-category of subordinate masculinity; a **reliant–supported masculinity**, or **subjective masculinity**, or perhaps even a **sheltered masculinity**. Whether attaching a masculinity label, arguably a diminished one, to men and boys with an intellectual disability would facilitate better health outcomes is unclear. It is also unknown how tolerable such an exercise might be given the misuse and pejorative tone of other demeaning labels in the past. The fact is they face restrictions as recipients of welfare, are reliant upon families and/or support staff, are relatively powerless to the system and its legislation, and exist within the controls of the dominant ideology of the day. Fealy (2006) asserted that despite the legislative focus on rights, whose aim is to reverse powerlessness, it has not been possible to legislate for acceptance, engagement or inclusion by non-disabled society. Is masculinity another of these elusive aims?

Although direct gender hierarchy approaches do not appear to mirror reality for men and boys with an intellectual disability, the notion of *different masculinities* remains very relevant and understanding these differences is central to understanding male health (Wilkins & Baker, 2004). It is when trying to understand masculinity simply as *behaviour* or *power*, that barriers surface in understanding the contextual differences between male and female health. As J. A. Smith (2007) asserted, linking hegemonic maleness to disparate male mortality and morbidity has been unhelpful. This view seeks to point the finger of blame at male behaviour; that the poorer health status of men is a direct result of masculinity (Macdonald, 2005). It medicalises masculinity by asserting masculinity is a problem that requires remedying (Rosenfeld & Faircloth, 2006). This discourse suggests if only males could *feminise* themselves, therein lies the answer to conducive health outcomes (Macdonald, McDermott, & Di Campli, 2001). Whereas it is not empirically evident within the literature (see Tables 3.3 and 3.4) that men and boys with an intellectual disability are being called to feminise, masculinity and intellectual disability appears to be behaviourally viewed through the lens of male-power.

Tables 3.3 and 3.4 illustrate a trend in the literature towards a pathological view of men and boys with an intellectual disability. Taken at face value and without challenging stereotypical assumptions, the Tables confirm that male pathology and power exist in the form of challenging behaviour, sexual offending, inappropriate sexual expression, and crime. Holter (2005) argued that seeing male pathology and power through a direct gender hierarchy lens can only confirm the existence of gendered power. It does little towards explaining the context, causes, dynamics, and possibilities for behaviour change. Holter importantly showed the direct gender hierarchy perspective to be more of a static notion held up by cultural and social perceptions and not a systematic theory. Whereas viewing masculinity as a wider system of meaning through a lens of structural inequality opens up these other possibilities. It also allows other masculinities to emerge, masculinities not dependent upon power. It makes room for men and boys with an intellectual disability to have **access to masculinity** uninhibited by power, or indeed a lack of power. Power is but one part of a wider framework; its helps provide meaning but it is not **the** meaning.

Structural Inequality: Gender as a System of Meaning

Holter (2005) differentiated structural inequality from direct gender hierarchy mainly as it sees the historical discrimination against women occurred as a result of male roles in society, not as a result of men and masculinity. This means all of society is involved in the historical discrimination of women, not just men. I am drawn to an illustrative example told by my late father-in-law how his father suffered a debilitating accident deep in a Yorkshire coal mine; my father-in-law subsequently became a 14-year-old coal miner as his male role was dictated by society and circumstance. A patriarchal view sees the reinforcement of male dominance while women stay at home rearing children; a structural inequality perspective sees the social and financial reality which also allows a discourse questioning the inequality and injustice for both males and females. Structural inequality existed for both men and women and was reinforced by social roles, expectation, and need. In the modern context, Holter described how the sphere of production (work) renders the family (reproductive historical core of patriarchy) to a less pivotal part of structural patriarchy; production (work) weighing more in the total picture of gender discrimination. That is not to say that reproduction remains outside of any discriminatory framework, it is but one relational part of overall structural inequality.

Males working in traditional female-dominated spheres provide one salient example of how appreciating structural inequality allows for a deeper meaning than would otherwise surface if focussed solely on stereotypical gendered hierarchies (Jacobs, 1993). Holter (2005) explained how care-giving, traditionally a secondary-status feminine social role, does not automatically equate to the experience of secondary status within that role. Indeed, females within that sphere may actually encourage gender segregation and a *hegemonic femininity*, rendering male care-givers to the tokenistic “others”. Jacobs described such segregation as a social “prestige penalty”. Within these roles males have been shown to inadvertently adopt expected stereotypical behaviour. Holyoake (2001) asserted that the male nurse “…is subjectivised as an ideologically obedient male subject who, as a performer, masquerades male performances that he recognises as being true to himself” (p. 107). Males are in a weak position not because they now share a relatively equally weak social status, but because of the structural inequality associated with care-giving. The inequality is gendered but it is not solely due to gender. Holter asserted that: “The societal and cultural context is vitally important. Gender is not an isolated subject. Gender discrimination does not exist in the world alone, does not act as a social force in isolation, but mainly exists and is socially effective through its connection to other main forms of discrimination, including social status and race” (p.30).

Woods (2002b) also believed a structural focus has far more traction in dealing with men’s health than a purely gendered emphasis on masculinities. With regard to the theoretical development and dominance of gender relations Woods asserted "…the application of such theorising to men's health is a largely futile enterprise, only serving to divert attention (and resources) from areas where a difference can be made" (p.5). Furthermore, Woods argued if it is men who control society, and in turn the health system, there is no logic to explain why males experience greater mortality and morbidity. That is, a structural approach better identifies inequality in health irrespective of gender. The argument for more of a focus on structural factors allows for the social gradient to be better explored as one structural facet of society compared with the hegemonic aspect of gender relations.

Masculinity and Intellectual Disability

However notions of masculinity are viewed, particularly as new understandings emerge through the ongoing debate between gender, structural, and bio-psychological theorists, it remains a very relevant concept despite the shortcomings identified. It remains most important for men and boys with an intellectual disability as perceptions of maleness have played a part in formulating service responses within the disability sector. For example, McElduff and Beange (2003) highlight how the default position of pubertal failure, not reaching sexual maturity, in men and boys with an intellectual disability is to not treat with testosterone therapy, the opposite of the approach for males without an intellectual disability. The likely explanation for this position rests in a fear of stereotypical masculine expression; increased aggression supposedly related to testosterone therapy, despite the adverse health consequences of hypogonadism, which men and boys with an intellectual disability experience at a greater rate than their non-disabled peers (McElduff et al., 2003). Conversely, a treatment option for some males with an intellectual disability who display sexually inappropriate behaviour can be anti-libidinal medication, or even orchidectomy (removal of the testes) (G. Carlson et al., 2000; G. Carlson et al., 1997; Sajith et al., 2008). In both cases, masculinity is shaped to reinforce a *diminished masculinity*[25]; the asexual, manageable, and safe image synonymous with low testosterone. Negative stereotypes have diverted attention away from a positive health outcome. If there happened to be a masculine side-effect from testosterone therapy, there is no reason why it could not be managed in the same positive way that hormonal issues, including side-effects of medication, are dealt with for females with an intellectual disability.

Why negative stereotypes, depicted in the two hormonal examples described above, have been permitted to perpetuate is starting to emerge. Whether there has been a tendency by the disability sector to adopt a fatalistic view of maleness, steeped in hegemonic stereotypes that assumes "boys will be boys", is unclear. Another possibility could be that a form of gender-feminism has been subconsciously adopted as the philosophical pose coupled with a sociological leaning within the sector that has no need to question matters masquerading as the truth. Apathy and/or under-resourcing within the sector may also be limiting the type of advocacy required to stimulate masculinity as an emerging and potentially useful construct, certainly the disability sector should not rely upon the mainstream men's health movement to paternalistically seek it out. Irrespective of the rationale, of which there are probably a few, the example of testosterone replacement illustrates how constructs of masculinity may offer some insight into how the unique health needs of men and boys with an intellectual disability can be better met. Moreover, it reinforces why masculinity should be considered as one component of a wider contextual meaning alongside the many other factors.

---

[25] The notion of diminished masculinity and its origins are explored by the book chapter in Appendix 7.

MALE SEXUAL HEALTH AND INTELLECTUAL DISABILITY

The proposition that males with an intellectual disability are pathologised, and are viewed within an unhelpful power-based construct of masculinity, has led to the problematising of male sexual health within the intellectual disability specific literature. Box 3.2 provides a summary of the key points reported in the literature concerning the sexual health of men and boys with an intellectual disability. The summary of the key points in the literature in Box 3.2 highlights just how pervasive and all-encompassing the problematised focus is. Figure 3.3 illustrates the all-consuming nature of this pathological fortress in addition to contextualising the issues which lead to a reactive approach to male health as depicted in Figure 3.1.

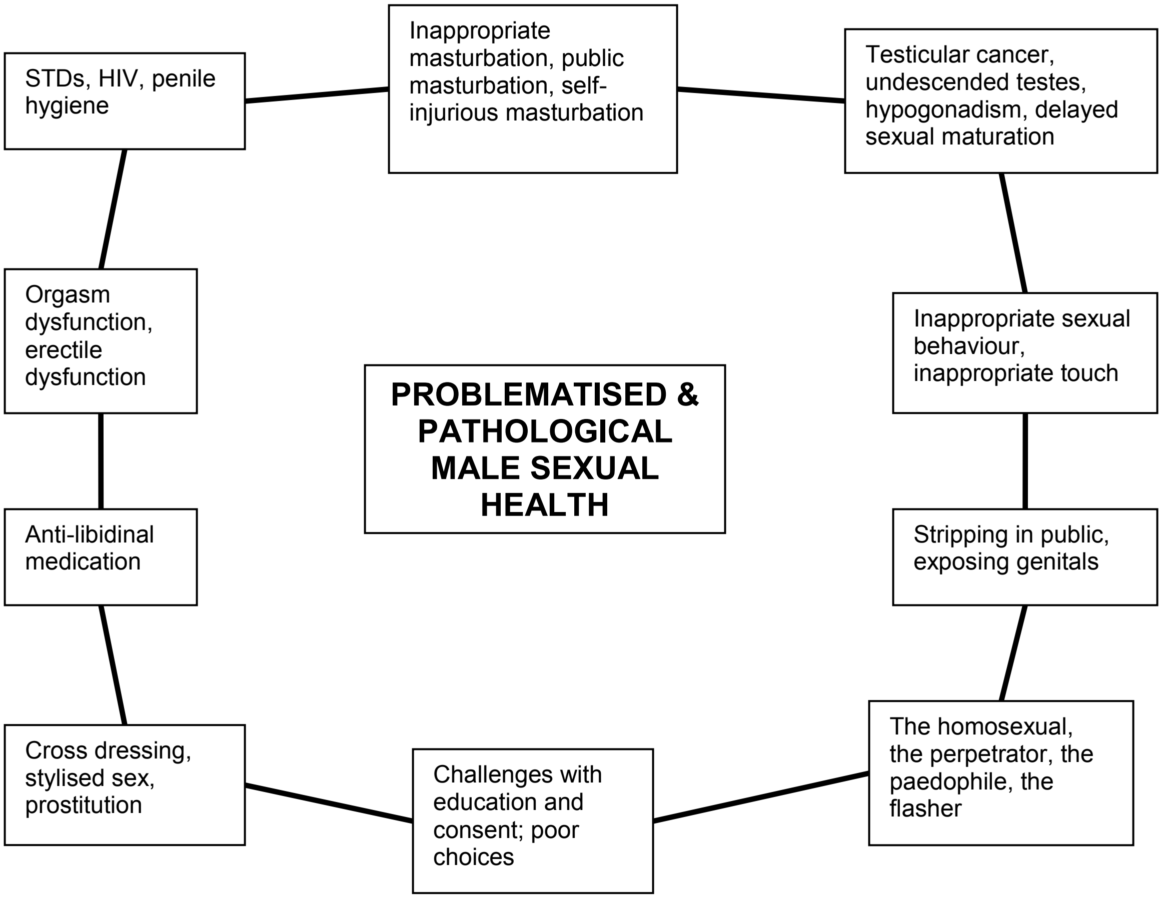


Figure3.3
The pathological fortress of male sexual health

Box 3.2

Summary of the literature concerning male sexual health and intellectual disability

- Rates of sexually transmitted diseases recorded at eight times higher than in men without an intellectual disability (van Schrojenstein Lantman-de Valk, 2005)
- Rates of testicular cancer for males with a profound intellectual disability exceeds expected incidence (Patja, Eero, & Iivanainen, 2001)
- Undescended testes at twice the rate of males without an intellectual disability (van Schrojenstein Lantman-de Valk, 2005)
- An incidence of hypogonadism of approximately 20% (McElduff, Center, & Beange, 2003)
- In males a link between a greater degree of intellectual disability and later sexual maturation (Saunders, 1981)
- Males with an intellectual disability display inappropriate sexual behaviour at a disproportionate rate (Quinsey, Book, & Skilling, 2004; Wheeler & Jenkins, 2004)
- Some men with an intellectual disability are at high risk of HIV infection (Cambridge, 1996, 1998; Di Giulio, 2003)
- Sex education training resources more suitable for people with a mild intellectual disability (Grieve, McLaren, & Lindsay, 2006)
- Capacity to consent to sexual interaction with another person remains fraught with difficulty (Conahan, Robinson, & Miller, 1993; Wheeler, 2004)
- Use of anti-libidinal medication in some males with an intellectual disability (G. Carlson, Taylor, & Wilson, 2000; G. Carlson, Wilson, & Taylor, 1997; Sajith, Morgan, & Clarke, 2008)
- Penile hygiene in men and boys who are uncircumcised (Servais, 2006; N. J. Wilson, 2005; N. J. Wilson, Cumella, Parmenter, Stancliffe, & Shuttleworth, 2009)
- Males reported to have made poor progress in safer sex choices following a self help programme (Withers et al., 2001)
- Orgasm dysfunction in males who try to masturbate (Kaeser, 1996a, 1996b)
- Erectile dysfunction (Parkes & Keoghan, 2007)
- Inappropriate masturbation (Cambridge, Carnaby, & McCarthy, 2003; Hingsburger, 1994; A. Walsh, 2000)
- 33% of support staff had experienced males with an intellectual disability masturbating in public (McConkey & Ryan, 2001)
- Stripping in public (Beebee, 2003)
- Exposing genitalia in public (Wright, Herzog, & Seymour, 1992)
- Self-injurious masturbation (Robison, Conahan, & Brady, 1992; Shelton, 1992)
- Men with severe mental retardation engaging in mutual anal intercourse (Kaeser, 1992)
- Lack of understanding in how to pleasure a woman sexually (D. Thompson, 2001)
- Use of pornography, cross dressing, prostitution, stylised sex, sex with children (Cambridge & Mellan, 2000)
- Males with an intellectual disability lacking in confidence regarding sexual activity (Löfgren-Mårtenson, 2004)
- Men with intellectual disabilities perceiving their identity and sexual identity as “not quite normal, but normal enough” (Wheeler, 2007)
- Inappropriate sexual-touch towards female care staff (D. Thompson, Clare, & Brown, 1997)
- Young boys (11-17) with an intellectual disability displaying inappropriate sexual behaviour (Fyson, 2007)
- Men with an intellectual disability referred for sex education at twice the rate of women with an intellectual disability, mainly due to being a sexual perpetrator (McCarthy, 1996)

An Emerging Male Sexual Health Agenda

The main conclusion drawn from the summary of key points, as illustrated in Figure 3.3, is a lack of convergence between the male health issues reported. That is, discussion of hypogonadism is not linked with discussion of orgasm dysfunction and its possible association with inappropriate sexual behaviour or self-injurious masturbation. Penile hygiene, hypogonadism, and testicular examination are not exclusive topics. Sexual perpetration, a lack of appropriate training resources, and poor progress in making safer sex choices has a direct correlation with HIV transmission and other sexually transmitted diseases. The obvious omissions within the literature include testicular examination, screening for prostate cancer, nutrition, and exercise as complimentary to overall health and well-being, including sexual health and well-being. Nor are there narratives of males developing and engaging in meaningful relationships, or of sexual expression for fun and enjoyment.

This chapter has, thus far, established that men and boys with an intellectual disability are a unique group of males who experience unique health needs. A male health agenda has emerged; the issue however remains what is to be done with this knowledge? There is no simple answer; the complexities of male biology and behaviour need to be explored alongside constructs of gender, structural power, and masculinity. The emerging sexual health agenda can be summarised by four main points:

1) issues are discussed as isolated problems, there is no biopsychosocial congruence
2) a pathological perspective of doing-maleness through gendered power dominates
3) a reactive and controlling, as opposed to health-promoting, approach prevails
4) no understanding of developmentally appropriate, and positive, sexual health.

The recent article by Lohan (2007) described how a blend of ideas on masculinities and male health inequalities provides a clear path toward better male health outcomes. Both masculinities and male health inequality remain either vastly under-researched or ignored by the literature concerning men and boys with an intellectual disability. As a result, masculinity and male health as they are emerging in the mainstream occupy a separate concern.

MALE HEALTH AS DEFINED BY THE MAINSTREAM

A recent national needs assessment exploring the scope of male health education and resources across Australia (Hardy, 2007) identified a paucity of uniform guidance, a generalised lack of funding, and what services are funded generally operate in isolation. This review also uncovered a similar pattern described through Chapters 2 and 3 of a divergence between bio-medical, psychological, and sociological perspectives. Furthermore, this needs assessment highlights that while the disability sector may not be engaging with mainstream men's health, there is no overly coherent mainstream framework to actually engage with. Key findings in particular are listed in Box 3.3:

Box 3.3

Key findings from men's health education needs assessment

- inequity of access to health education exists for males
- No national policy and no current state or territory policy document
- Peak bodies are increasingly frustrated by the limited national recognition of men's health
- Approaches to health education are fragmented
- Education and resource development focuses on relationships, parenting, prostate cancer, isolation, love, sexuality and personal development compared to biomedical aspects of health
- biomedical aspects focus on sexual and reproductive health and cancer screening
- Delivery of education most effective when delivered in male-oriented environments
- education programmes need to be available outside normal working hours
- males need to be more involved in the delivery of education
- Attendance at a GP service increases after the receipt of relevant health education
- A „Men's health in society' post-graduate package is currently being written
- Only one men's health course is available at undergraduate level – an elective short course based at The University of South Australia
- Most health education programmes have no evaluation strategy
- Very little health promotion literature is specifically directed at males; it is not man-friendly.

In 1999, NSW Health released the document *Moving Forward in Men's Health* which NSW Health at the time called "a policy" (Kakakios, 2001). The national needs assessment however suggested the document was outdated and as it contains no policy framework there was actually no mandate for action in male health (Hardy, 2007). The Doctors Reform Society has developed a "position statement" which Macdonald (2006) suggested is not overly helpful as it is steeped in a focus on negative and stereotypical male behaviours. Gregory, Lowy and Zwar (2006) in a special male health issue of the *Medical Journal of Australia* pointed to areas of growing momentum in male health and asserted having taken up the baton of men's health, the momentum needs to be maintained. It would appear the momentum is growing; at the 2007 National Men's Health Conference, a resolution was passed to create a national body to represent male health in Australia. This body is the Australasian Men's Health Forum. Moreover, the current Australian government has promised to develop a national policy and while progress has been arguably slow, groups such as The Fatherhood Foundation have recently held a forum aimed at keeping the issue prominent (Marsh & Andresen, 2008).

Despite the growing prominence of men's health as an issue of concern in Australia and the engagement of a range of male sub-groups, men and boys with an intellectual disability are the exception. For example, the Australian Medical Association suggested a policy framework should include a life-cycle approach that encompasses the unique health issues for young boys, adolescents and young men, adult men, and elderly men. It also suggested a focus on specific issues for populations at greater risk such as Aboriginal males, males in rural regions, gay and bisexual men, and Vietnam veterans. Other male sub-groups and/or male issues receive a mention elsewhere; soldiers, artists, sportsmen, and fathers (Webb, 1998). Concepts such as friendship, school, manhood, and the wild male spirit are suggested as other areas of focus (Biddulph, 1995). Even issues facing the male nurse are receiving growing prominence (e.g. Holyoake, 2001; O'Lynn & Tranbarger, 2007). This begs the question: are men and boys with an intellectual disability actually experiencing a "treble jeopardy"? Treble because of their gender, their disability, and as a forgotten and silent group of males. While not wanting to draw a focus onto one group at the expense of another, the gravity of the disparate focus numerically dawns when the 50,000 surviving male Australian Vietnam veterans (Department of Veterans Affairs, 1999) are compared against the 150,000 males with intellectual disability as a main disabling condition (see Table 3.1).

A Definition of Male Health

Peate (2003) highlighted the lack of an internationally recognised and accepted definition of male health as recently as 2003. In 2004, a definition proposed by the UK Men's Health Forum (Wilkins & Baker, 2004) used the term "male health issue" as it encompass both boys and men and is perhaps the most comprehensive and meaningful available:

> A male health issue is one arsing from physiological, psychological, social, cultural or environmental factors that have a specific impact on boys or men and/or where particular interventions are required for boys or men in order to achieve improvements in health and well-being at either the individual or population level (p.5).

A definition such as this allows for the uniqueness of different male groups to emerge. For example, social, cultural and environmental factors which impact upon health for males who are gay/bisexual and live in the inner city differ significantly to those for young heterosexual fathers trying to enter the housing market in residential areas. For this reason, the unique social, cultural and environmental determinants affecting males with an intellectual disability can surface. These might include, but are not limited to, the structure of supports systems and networks, the capacity of supports to manage unique male health needs, the underlying attitudes of people within the system, environmental and architectural factors, communication limitations, the nature of the workforce, Government funding, and regular restructuring of key departments.

Factors such as deinstitutionalisation are also potentially important for males with an intellectual disability. For example, some expressions of male behaviour within a secure and isolated large residential setting automatically takes on a different meaning when placed within a suburban context. Masturbating outdoors in a large enclosed ward yard is a far different issue than doing the same thing in a residential garden surrounded by neighbours. Inexperienced staff taking over a shift from well-trained and experienced staff changes the context of managing male behaviour; boundaries alter, different rules emerge, changed expectations surface. It is conceivable the gender of staff also has an impact on the factors which contribute to male health, a precedent well established for women's health. What is unknown however are the effects of what Folkestad (2004) asserted as men in care, surrounded by women.

A Feminised Health Environment?

There is a great diversity between the nature of home-based supports, respite care, domiciliary care, and supported accommodation. One constant however is the greater proportions of female carers and paid staff in each type of support. For those men and boys with an intellectual disability who reside in home-based care, their primary carer is invariably female: mother 68.6%, father 6.3%, other female relative 4.6%, and other male relative 1.4% (Australian Institute for Health and Welfare (AIHW), 2005 , p.242). Staff working in residential settings are also predominantly female; between 80-95% female across all sectors in the UK with similar proportions in the USA (McConkey et al., 2007). Percentages of female staff as low as 69.5% were found in an Australian study of NSW Government employed support staff (Dempsey & Arthur, 2002). The Australian Community Services and Health Industry Skills Council highlighted several important facts from their review of industry skills; a high proportion of female part-time staff, only 17% of the workforce are in professional positions, a high turnover of staff, an ageing workforce with replacement demand issues, and large sectors of the workforce unregulated (Community Services and Health Industry Skills Council, 2005).

While these statistics do not infer that male health needs are inadvertently overlooked or missed, the question still arises whether the potential exists. Are the health needs of men and boys with more severe intellectual disability, who rely upon their health needs being communicated via proxy, adequately addressed by a largely female workforce in a sector that is beset with structural problems such as high turnover? Importantly, this question is not suggesting that male staff should be the sole gate-keepers of male health. However, there are parallels between what was historically perceived by females as an androcentric perspective toward female health and the notion of a feminised health environment. An additional key point rests on whether male carers and paid staff, who are just as likely as female staff to lack comprehensive training and skills, can move beyond the often unjust gendered stereotypical assertions of paedophilic and abusive tendencies identified by McConkey et al. (2007), and have the confidence to effectively advocate for the health needs of male clients. It is known concerns about inappropriate touch affect the way male staff interact with their clients (Dobson, Upadhyaya, Conyers, & Raghavan, 2002), whether these concerns also extend to avoiding a focus on sexual health matters as an inappropriate interest is unknown.

A Masculine Health Environment?

If a feminised health environment as suggested does have some effect on male health outcomes, the question logically arises as to what a masculine health environment might be? J. A. Smith (2007) suggested males do feel threatened by feminised environments. Macdonald (2005) utilised a *Man in the Waiting Room* cartoon to depict how primary health services, geared towards women and reproduction, provide one example of a feminised health environment. In this cartoon a man is sat beside the female receptionist’s desk surrounded by health promotion posters encouraging breast examination, baby checks and vaccination schedules. While a community group home does not resemble a GP's waiting room, the pertinent question is whether the environment is as accessible to males with an intellectual disability and their unique health needs as it could be?

Examples of environments created to be supportive to women with an intellectual disability offer some key insights. Brewster (2005) described a women's health curriculum day for women with an intellectual disability where breast screening, pap smears, genital hygiene, and informed consent were discussed. Over 100 women attended the day and the article portrays the strength gained through mutually gendered understanding of intimate issues that could only be discussed in such an open and supportive feminised environment. An action research project carried out in Victoria, Australia, sought to identify and develop strategies to improve sexual health for women with an intellectual disability (Women's Health Goulburn North East, 2002). Topics included womanhood, social life, health, education, and barriers to accessing health services. The research project facilitated the emergence of a health group for young women with an intellectual disability titled *Groovy Chicks*. Lunsky, Straiko and Armstrong (2003) described a women's health promotion project for 30 women with an intellectual disability covering health education, coping skills, exposure to medical settings, and assertiveness training. Run by two female facilitators the group explored how to cope with procedures such as pelvic examinations through a graded exposure to the types of instruments and settings a pelvic examination might be carried out in. All three papers described how females and femaleness was positively promoted, honoured, and celebrated through collegiality to achieve better health outcomes; a feminised health environment.

Examples of a masculine health environment supportive to males with an intellectual disability are harder to locate within the literature. A Men’s Shed project presently trying to gain some funding, also in Victoria Australia, aims to create an environment where males with an intellectual disability can be mentored by older males who in turn provide a bridge between the local community and those who are isolated (SkillsConnection Colac, 2008). Men’s Sheds offer a unique project in a setting which Bradley (2004) described as an excellent medium to foster a symbiotic relationship between older males who support younger “at risk” males. Smith (2007) reported Men’s Sheds represent one area of best-practice in male health. Whereas a Men’s Shed may offer some males with an intellectual disability a supportive masculine place to go, for others, particularly those who require intensive behavioural supports, an environment with powerful machinery and tools might be considered too dangerous. Tyler and Parker (2001), two female community disability nurses, set up a men’s health group for six men with a mild intellectual disability in the UK. Recognising they needed a male presence, the authors invited a male staff member from the day programme as “…the men did not know the facilitators at the beginning of the group, the facilitators were female, and an independent evaluator was required in order to promote candid feedback” (p.25). While the aims of the group were to achieve best practice, which Tyrer and Parker should be saluted for, the lack of male facilitators in such a group limits the capacity for best practice to be achieved just as it would be considered anathema for male facilitators to run a women’s health group.

A Salutogenic Approach to Male Health

Thus far, this chapter has demonstrated some of the ways the lives of men and boys with an intellectual disability might differ from the lives of women and girls with an intellectual disability. Perhaps the starkest difference can be found in gendered health focus and the problematising, and subsequent reactive approach, to supporting male health needs. Any potential for a masculine health environment would appear constrained by the focus on the determinants of male social pathology. That is, a problematised paradigm of maleness, whose origins are located in genetic and biological differences, has emerged to react to male pathologies. This problematised paradigm of male health is depicted by Figure 3.4 as a combination of bio-genetic factors, stereotypical constructs of masculinity, and a focus on male pathology.

Figure 3.4

A problematised paradigm of male health

An approach advocated by the Men's Health Information and Resource Centre in NSW to counter a problematised paradigm of male health is by adopting a *salutogenic* view of health. A salutogenic theory for health promotion was developed by Aaron Antonovsky whose aim was to understand the question “what creates health”? (Kickbusch, 1996). Salutogenic being the antonym of pathogenic; that which creates disease (Macdonald, McDermott, Woods, Brown, & Sliwka, 2000). Salutogenic differs significantly to the pursuit of many whose aim was, and remains, to determine that which creates disease. Significantly, Antonovsky critiqued the axiom that health systems exist either to prevent or cure disease; Antonovsky described this approach as creating a dichotomous belief that people are either those who have temporarily, permanently or fatally succumbed to disease, or those who have yet to succumb (Antonovsky, 1996). Antonovsky argued a dichotomous perspective between the diseased and disease-free, forces a focus onto “risk” and minimising “risk factors”. Risk factors, or what are also phrased as lifestyle factors, include for example smoking, excess alcohol consumption, high-fat food, and excessive sunbathing. Humans are duly encouraged to engage in low-risk behaviours in order to minimise disease. Instead of this healthy/unhealthy dichotomy, Antonovsky suggested a health–illness continuum whose basis is the fact we are all inherently flawed. If health can be depicted as a river, the health/illness dichotomy suggests we are either onshore or offshore; Antonovsky’s continuum suggests we are always in the river, our challenge is determining how dangerous that river is and understanding how well we can swim. The dichotomy is focussed on disease prevention, the continuum on health promotion.

A salutogenic approach to health promotion also includes the goal of sustainable futures with emphasis not only on the common factors which underpin health, but also on happiness and the spiritual meaning in our lives (Gregg & O'Hara, 2007). Antonovsky (1996) developed the *Sense of Coherence* (SOC) construct to capture those meaningful factors which underpin our capacity to determine the danger posed by the river and our motivation to swim with or against it. The stronger a persons SOC, the more able they are to cope with stressors to their health and well-being. A person with a strong SOC will:

- wish to, be motivated to, cope (meaningfulness)
- believe that the challenge is understood (comprehensibility)
- believe that resources to cope are available (manageability) (p.15).

Antonovsky argued one's SOC becomes a dependent variable that is not constrained by cultural variations as it combines cognitive, behavioural and motivational parts. It can be applied across any environmental context. Therefore, if we can picture a person swimming in a river (health environment); health status is determined by the constant interchange between the person and the river. The river is filled with health determinants (bio-psycho-social) as is the person. Macdonald (2005) used the term *life-force* to portray the continuum, a persons SOC the constant interchange. Figure 3.5 presents an illustration which embodies Antonovsky's SOC construct and Macdonald's notion that one's life force is the effect of one's location on the continuum:

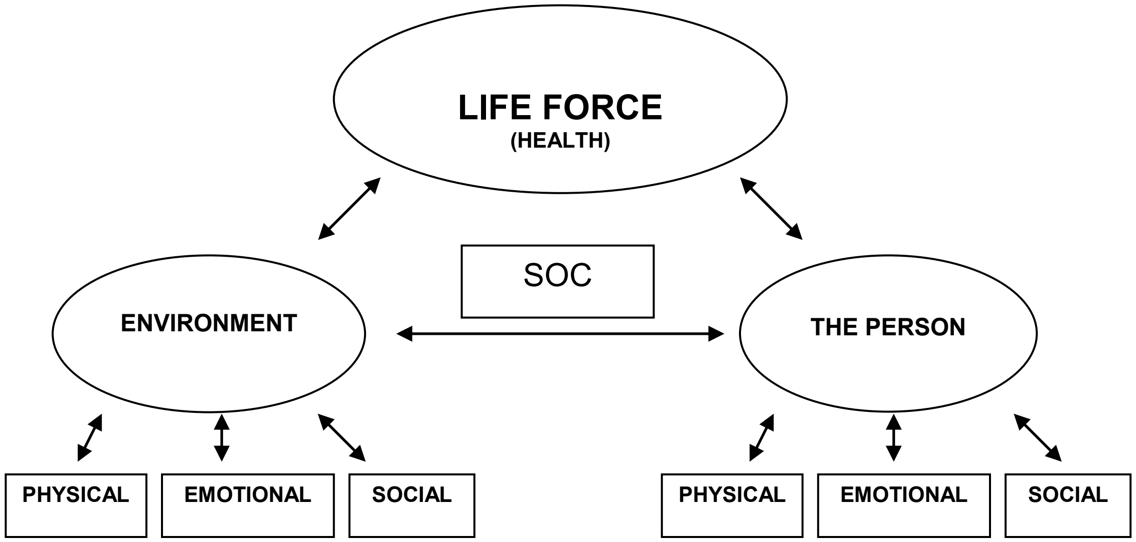


Figure 3.5

Salutogenesis

Therefore, a salutogenic view of health forces the reorientation of focus from that which causes ill health, to that which promotes health. Applied to a focus on male health, salutogenesis, argued Macdonald (1998), enables a view of "…what is positive and life-enhancing in male characteristics and behaviour and to applaud and foster the positive elements" (p.261). Authors such as Steve Biddulph, referred to as a proponent of the mythopeotic men's movement, have written extensively about the need for society to re-learn how to appreciate and celebrate maleness (Biddulph, 1995, 1997). Slogans such as "dads do matter", "five fathering essentials", "confident maleness", and the "wild spirit of man" epitomise the suggested propinquity boys require from older males to nurture successful and well-balanced young men. Biddulph suggested the presence of positive male role models during the vital stages of boyhood is needed to create environments where maleness can flourish. Macdonald et al. (2001) called such environments salutogenic.

The Potential of the Male Carer

A suggestion for a focus on male role models logically places scrutiny on the role of male staff and their work, actual and potential, supporting men and boys with an intellectual disability. An historical review of nursing by O'Lynn (2007a) confirmed the first formal nurses, in ancient Greece, Rome and India, were actually male. Often referred to as a nursing pioneer, O'Lynn described how the many reforms Florence Nightingale was able to bring to nursing were underpinned by her view that women, by virtue of their nature, were better suited to nursing than men. Since then argued O'Lynn, it was only by the efforts of the 20th century male visionary Luther Christman that the challenge to the domination of nursing by women began. Christman believed the problems men faced in nursing were similar to the problems women had in medicine; a problem of gendered power relations. Holyoake (2001) asserted that within nursing, the dominant signs of performing *maleness-equals-risk* such as pervert, pretence, weak, impotent, inactive, unprotected, under scrutiny and scared, needed to be rejected. Instead, a statement of how males do care in their own male way, not a fatalistic and gendered resignation where male carers are subjectivized into adopting historically and stereotypical "…encoded symbols and myths, and the connotations they harbour" (p.76). That is, a rejection of the stereotype that "real" men don't do nursing (Braun, 2003; Sullivan, 2007). In addition to a rejection of gendered stereotypes, Young (1996) also asserted "…there is room for feminism within nursing, but nursing must not become a feminist profession" (p.29).

The most salient, and perhaps helpful, standpoint should therefore move beyond a perspective of gendered power and instead view maleness and femaleness as both capable of caring, but in unique gendered ways. For example, Löfgren-Mårtenson (2004) found the way female staff "cared" in monitoring interactions between males and females with an intellectual disability during discos, was more restrictive than male staff who were more allowing of sexual expression. Löfgren-Mårtenson suggested one of the consequences from a feminised monitoring of interactions, were a group of young men with an intellectual disability who were "passive" and "insecure" compared with their female peers. The young men would insecurely wait for sexual cues from the young women before permitting themselves to respond. Löfgren-Mårtenson asserted the gendered setting reflected "…a female world with a restricted set of rules" (p. 205). This might logically be referred to as an example of a feminised environment where males with an intellectual disability lacked sufficient male role models and male staff, while willing to allow greater expression between clients, were also operating in a female-dominated world. Seeking to understand the context of gendered supports is no different from the desire to better appreciate the role of male teachers in the professed “crisis in boys’ education” (Donnelly, 2005; West, 2004). That is, there are constructive and unconstructive gendered aspects to caring, as there is to teaching; the challenge is to better contextually understand these gendered differences.

A review of studies seeking to explore masculine styles of care by O’Lynn (2007b) highlighted the lack of any constructive outcome which advanced knowledge in the area other than the fact males and females do employ different styles. O’Lynn further pointed out no theoretical frameworks have been developed seeking to explain and interpret male care-giving. The studies found males tended to employ a “friendship” as opposed to “maternal” way of developing interpersonal relationships, that masculine caring occurs in a context where its existence is almost denied, and that caring is viewed through a lens of competently anticipating client need through task, teamwork, communication and advocacy. O’Lynn concluded his review by arguing strongly for formal guidelines to educate male nurses on how to approach the under-explored and fear-driven issue of touch. O’Lynn recommended a seven point framework which, although he acknowledges has not been empirically tested, provide some preliminary guidance to support male carers:

1) Innocent until proven guilty
2) No requirement for automatic chaperones except in exceptional cases
3) Confidence with touch; confidently gentle, not weak
4) Touch accompanied by communication
5) Directionality; *progressive* touch from safe toward less safe zones
6) Privacy
7) Cultural awareness (pp. 136-138).

Therefore, some key issues are quite clear: reconstructing professional and procedural touch will reorientate the focus from a pessimistic view of masculine caring towards an optimistic one. Caring, or the care-sector, is seen as a female world and this needs to be challenged. In the interim, males are at risk of becoming the tokenistic “other” taking on compensatory and stereotypically subjectivized roles (Holter, 2005; Holyoake, 2001). Similar to the issues in the education of boys where the uniqueness of male teachers has had to be argued, a clearer understanding of what it is that makes the masculine carer unique and the role of the masculine carer in supporting male health needs to emerge.

SUMMARY

This chapter has reviewed the literature relating to the sexual health of men and boys with an intellectual disability. Data have been presented which shows intellectual disability has unique issues for men and boys covering biological, genetic, environmental, psychological, and sociological factors, within a framework of supports that cannot yet be defined as male-sensitive.

The sexual health needs of men and boys with an intellectual disability have been discussed within the context of mainstream ideas relating to male health and theories of masculinity. It has been argued male health should be seen outside of stereotypical and unhelpful constructs of maleness. This chapter has presented several ideas still emerging in the mainstream literature whose aim is to adopt a strengths-based construct of both masculinity and male health. It has further been argued a pathological paradigm exists which may be acting as a barrier to men and boys with an intellectual disability fulfilling their potential as boys and men. This chapter has also discussed the idea of a masculine health environment and the need to explore the potential of the masculine carer. The next chapter will present the research question then seek to describe the most effective research methodology that will provide the most satisfactory manner to answer it.

CHAPTER FOUR

ETHNOGRAPHY AS A RESEARCH METHODOLOGY

> *Because ethnographers traverse both territorial and semantic boundaries, fashioning cultures and cultural understandings through an intertwining of voices, they appear heroic to some and ludicrous to others. They are cross-dressers, outsiders wearing insiders' clothes, while gradually acquiring the language and behaviours that go along with them* (Tedlock, 2000, p.455).

Once the research topic was decided and some background reading had been completed, a research methodology needed to be identified which would allow the sensitive topic of male sexual health to be best explored. Chapters 2 and 3 pointed to the presence of a theoretical dichotomy within the three main topics of foci the present study sought to investigate: disability, sexual health, and masculinity. Therefore, a research methodology which would allow data to emerge naturally and without adhering to one theoretical doctrine or another was vital. Moreover, the methodology would need to enable me, the researcher, to put aside the reality of my own experiences which have shaped a view not entirely congruent with the current discourse of disability, sexual health, and masculinity. In addition, as the topic sought to explore sexual health for men and teenage boys with a moderate to profound intellectual disability, as opposed to men and teenage boys with a borderline to mild intellectual disability, meant data collection was not going to be straightforward. A research methodology was required which could access meaningful information regarding a group of males whose capacity to communicate was limited.

This chapter will outline how an ethnographic approach was chosen as the appropriate methodology to explore such a sensitive topic. An overview of how ethnography developed as an anthropological method will provide some historical background into how methods pivotal to observing and understanding different cultures are replicated today in understanding the rich variations within modern societies. A summary of ethnographic methods used by other researchers seeking to understand the lives of people with an intellectual disability will give some insight into how an ethnographic design allows for understanding despite the presence of communication barriers. This chapter will also explore some of the ethical and moral sensitivities a researcher needs to consider when researching vulnerable social groups. Furthermore, there will be a discussion of the implications, strengths, and weaknesses associated with a male researcher seeking to understand male issues.

THE RESEARCH QUESTION

The aim of this study is to construct an understanding of the sexual health needs of men and teenage boys with a moderate to profound intellectual disability. Chapter 2 identified that sexual health is not solely about disease prevention and procreation; it encompasses a wide range of psychological, biological, and sociological factors in a constant developmental interaction with each other. Chapter 2 also identified that little is known about the sexual health needs of people with an intellectual disability and the context in which such needs materialise. Chapter 3 discussed the development of a problematised discourse for the sexual health needs of males with an intellectual disability. Importantly, chapter 3 also summarised the meaning of masculinity to male health outcomes, in particular an appreciation of structural inequality as one of the many social determinants of health. Therefore, the research question seeks to construct male sexual health by seeking to **understand,** as opposed to **measure,** sexual health.

The research problem can be summarised into three distinct questions:

1) Primary question: What are the sexual health needs of men and teenage boys with a moderate to profound intellectual disability?

2) Secondary question: In what contexts do men and teenage boys with a moderate to profound intellectual disability experience their sexual health needs?

3) Secondary question: What role do concepts of masculinity play in the sexual health needs of men and teenage boys with a moderate to profound intellectual disability?

THE CHOICE OF METHOD

Research, stated Emerson, Hatton, Thompson, and Parmenter (2004), has both the prospect of enhancing the lives of people with an intellectual disability, and the capacity to waste valuable resources if targeted at tangential and meaningless issues. It is vital therefore that any research question has, as its foundation, the potential to generate knowledge and understanding to remedy the disadvantage so many people with an intellectual disability encounter. The way the question is asked will automatically shape the nature of data. Leedy (1997) illustrated this relationship between question and data with the following example:

> A man from a remote village decides to travel to the big city. While he is there, he takes his first ride on a commercial jetliner. No one in his village has ever flown before, so naturally when he returns home, they are curious about his trip. One afternoon, two friends ask him about his experience yet each approaches it very differently. The first asks such questions as, „How fast did you move?' „How far did you go?' and „How high did you fly?' The second wants to know more about the man's personal experience and asks questions such as, „How did you feel moving so fast?' „What was it like being above the clouds?' „What did the city look like from so high above it?' and „How was being in a jetliner different from other experiences you've had?' (p.103).

The above quote illustrates how questions about the same topic posed in different ways will elicit different data; either "what happened", or "what it felt like". Regarding the topic of sexual health, had the research question been framed thus: “What do men and teenage boys with an intellectual disability do to sexually express themselves?”, the research would encompass data in a range of expressed, measurable behaviours. This research question would provide knowledge of what men and boys **do**, but give no insight into the **why**; the why being the context their sexual expression occurs in. Alternatively, had the research question been framed thus: “What is the range of sexual health needs reported to general practitioners?”, this research question would have generated entirely different data, which would have been obtained with different research methods. For this reason, stated Leedy (1997), the research question shapes the kind of data the researcher desires which then dictates methodology; they are inextricably interdependent.

Ethnography was chosen as the best method to answer the research question simply because I wanted to describe and understand the perspective of the men and teenage boys within the variation and patterns of their natural setting. What distinguishes ethnography from other methods of enquiry is its focus on:

> a) discovering cultural patterns in human behaviour,
> b) describing the perspective of members of the culture, and
> c) studying the natural settings in which the culture is manifested”
> (Gall et al., cited in Leedy, 1997, p. 159).

Figure 4.1 illustrates the ethnographic process that I determined would produce the data to answer the research question. It represents my desire to answer the research question via a perspective of the men and boys with an intellectual disability and to do this within the context of the natural setting.

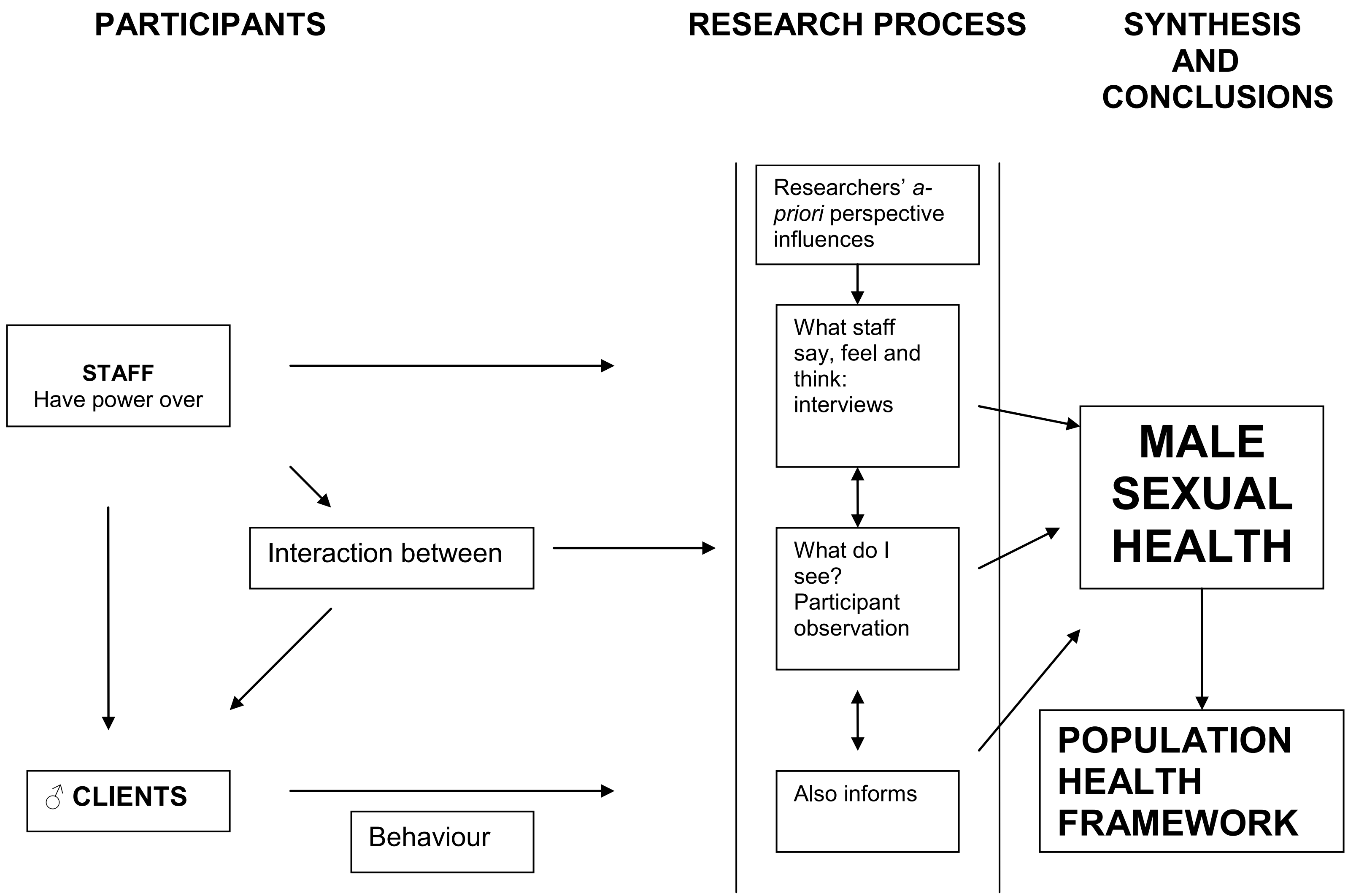


Figure 4.1

The research process

A DEFINITION OF ETHNOGRAPHY

The term *ethnography* originated from the Greek word *ethnos* used to represent a people or race, or cultural group (Vidich & Lyman, 2000). When united with the word *graphic* and forms *ethnographic*, it refers to descriptive anthropology: the science of describing humankind. In simpler terms, Silverman (2005) described ethnography as the combination of folk (ethno) and writing (graph) which translates to "…the social scientific writing about particular folks" (p.378). Vidich and Lyman stated ethnography grew partly as a consequence of the findings of Columbus and other explorers; westerners sought to understand and connect foreign findings to the previously held article of faith that man had descended from Noah. A conundrum, stemming from having to account for a non-Christian world, which beset early explorers seeking to understand "the other" in many ways remains a challenge to the modern ethnographer. Is reality to be understood via the values of the ethnographer, or via the values of the observed? Furthermore, Vidich and Lyman posed the question: "how is it possible to understand the other when the others values are not one's own?" (p.41). Ethnography, then, is not simply about describing humankind, ethnography also challenges those seeking to understand, to first understand themselves.

ETHNOGRAPHY AS METHODOLOGY

While the early colonial explorers and naturalists were intrigued by and concerned with both westernised and non-westernised populations, it was not until the late 19th century that anthropology as a discipline urged these explorers to document their findings within the scholarly framework of what was to be labelled *fieldwork* (Tedlock, 2000). Fieldwork requires immersion by the researcher into a culture to learn the language and participate in social events with the people, while at the same time maintaining an objective distance from the culture (Silverman, 2005). Tedlock stated it was the Polish anthropologist Bronislaw Malinowski (1884–1942) who enshrined fieldwork, as a research paradigm, within the discipline of ethnography. Malinowski's work set new ethnographic standards and influenced an entire generation of Anthropologists. Tedlock observed that recently ethnography has been adopted as a research method in cultural studies, literary theory, folklore, women's studies, sociology, cultural geography, and social psychology. In applied research areas, ethnography has also been used to great effect for example, in educational, counselling, nursing, psychology, psychiatry, and criminology. What motivates such an array of disciplines to use ethnography is the fact immersion in the lives of people gives access to an understanding that is not possible by using other methods: intimate understanding of their day to day activities and experience. The main ethnographic data collection technique is *participant observation*. It is accepted that ethnography always includes some form of immersion within the culture by "hanging around" and "picking things up" (Walford, 2001). Leedy (1997) stated observation is the *sine qua non* of ethnography.

Walford (2001) argued that for a study to be called ethnography, it needs to include certain criteria which Walford has broken down into the following seven elements:

1) A study of culture: taking account of individual lives within the wider context of their social structures; culture being made up of values, practices, relationships and identifications
2) Multiple methods, diverse forms of data: as cultures are complex and multifaceted, this must be mirrored by looking at the culture in different ways. A study which uses only one field technique, irrespective of how comprehensive, does not constitute ethnography
3) Engagement: Observation of the culture in its natural setting via the elements of connection with participants and time. The more familiar a researcher's presence becomes, the more participants can relax and act naturally
4) Researcher as instrument: The ethnographer is their own primary source of data; subjective strength or weakness is seen as an inevitable feature as long as an "open mind" is present

5) Participant accounts have high status: While the researcher is the "information broker", they remain the highest authority as they select from what is seen and heard. The researcher is offering an account of the participant's world
6) Cycle of hypothesis and theory building: Hypothesis and theory are constantly modified with each piece of additional data; theory development is therefore a process going beyond data generation
7) Intention and outcome: The nature of sample selection means any attempt to generalise findings should be met with caution; the aim of the research is to achieve some kind of understanding of a particular culture, people or setting (pp. 7-11).

Walford suggested while the above seven elements are not an exhaustive list, they are sufficient to differentiate ethnography from other types of qualitative enquiry.

Ann Gray's (2003) discussion on "grasping living cultures" provides an example which illustrated the complexity of ethnography and in particular what Walford has called the role of the *researcher as instrument*. Gray argued while ethnography can appear deceptively simple, the researcher needs to be aware of the dangers in assuming empirical truth; there is fact no such thing as the "whole truth", just a version of truth as transcribed by the researcher:

> Imagine that you are an ethnographic researcher into music festivals. You live and work in the UK so have visited Glastonbury and spoken to, listened to, observed, photographed people involved in that event. Think then of „scraps' of different kinds of data: a black and white photograph, a hand-bill, a voice telling you a story, an observers account of an event, an analysis of a musical text or performance, a list of sponsors for the event, a description of the space, the noise, the smells, the atmosphere. As a researcher you would find yourself dealing with a great amount of such material, and there are no clear or hard and fast rules as to what you might do with the data. These fragments of data can be combined and juxtaposed in a variety of ways, they may be multiple reflections of one event and as such are changeable and fluid (p.22).

Gray suggested a music festival, like any other living culture, can be described in many ways depending upon what data the researcher prioritises to tell the story. While ethnography can be structurally defined, as Walford has displayed, perhaps the most significant factor affecting the rich diversity of outcomes is dependent upon the researcher as instrument. Ethnography has the power to tell the same story in many different ways; the early colonial explorers sought to understand “the native other” while post-modern ethnographers seek to understand the smaller parts within individual cultures. As a methodology, ethnography offers ways of describing the multiple realities of contemporary societies; a reality fuelled by a new-age of global uncertainty where new language, theories and forms of practice are required (Corker & Shakespeare, 2002).

BIAS IN METHOD SELECTION

Whereas Leedy (1997) has provided a very logical and straightforward précis of how research methodology is selected, by the objective sum of research question and data, McVilly, Stancliffe, Parmenter, and Burton-Smith (2008) suggested the professional and personal stance of a researcher also needs to be declared lest this stance has adversely shaped the choice of method. That is, scientific rigour can be too easily undermined where this stance predicates method choice without any attempt to objectively evaluate what the research question is actually asking. This counsel has similarity to the disciplinary myopia Courtenay and Keeling (2000) claimed often affects men’s health as a field when one discipline subjectively “assumes” epistemological superiority over others. While on the surface this seems a fairly straightforward proposition, one cannot totally avoid the inherent bias of one’s personal and professional sphere. Therefore, it appears to be a balancing act between declaring both the inherent limitations and strengths of one’s bias.

An apt example of a researcher describing their professional perspective is presented by Atkins (1998) in her unpublished doctoral thesis exploring nurses’ perspectives on the quality of life of people with severe multiple impairments. Atkins stated as a specialist developmental disability nurse she had, and shared, a unique view on quality of life for people with severe multiple impairments with her peers. This view, wrote Atkins, was based on her belief that developmental disability nurses have a more accurate view of what quality of life means for this client group, a view shaped by the nurse spending considerable 1:1 time interacting and coming to know the “little things” each day. Atkins has adequately declared her *a-priori* stance and then explains how this phenomenon will be best explored using symbolic interaction as a qualitative methodology, and analysed using grounded theory as an approach.

An example of a researcher presenting their personal and political perspective is in McCarthy’s (1999) work titled *Sexuality and Women With Learning Disabilities*. McCarthy stated that having had both negative and positive heterosexual experiences, her own sexuality, shaped by these experiences, has influenced her dual work as a paid professional and as a researcher with her subjects. McCarthy sought to explore the sexuality of women with an intellectual disability visiting her in her role as a paid sexuality educator/counsellor. Indeed, McCarthy expected to hear negative and sad stories of sexual experiences, based upon prior work and feminist knowledge, and this is indeed what the data presented. Moreover, McCarthy acknowledged as a paid sexual educator/counsellor she “…was actively trying to influence them” (p.118) to be assertive and make positive sexual decisions.

MY THEORETICAL PERSPECTIVE

Although research in nursing has been integral to the nursing process since the time of Florence Nightingale (Daly, Elliott, & Chang, 2000), nursing research does not share the same epistemological pedigree and importance as it has historically elsewhere, such as in the discipline of psychology. Appreciation of any particular research paradigm was not pivotal to undergraduate nursing studies or professional registration as a nurse. My first direct experience with research was as a support for a young man with chronic schizophrenia who agreed to participate in a randomised controlled trial of high-dose Ethyl-EPA fish oil. My role was to support with collection of baseline demographic data plus a mental health and functional analysis at start, mid point, and completion of the trial. What astounded me most during the course of the trial were the subtle changes in this young man's mood and persona; not only could his increased sense of humour be measured quantitatively by smiles and jokes that were not previously present, but also by the meaning this had on his quality of life. His interpersonal skills improved, his restlessness decreased, his drowsiness was less obvious, a previously foreign interest in physical activity surfaced, the quality and quantity of his engagement was measurably better. Suffice to say I became "hooked" on research, not so much on correlating the quantitative efficacy of the fish oil on quality of life, but on the observed enhanced meaning to this young man's quality of life through increased engagement outside of his psychosis. Although his life remained relatively monotonous and restricted compared to most, this research project embodied the potential for significance in meaning where cure and treatment were elusive. Such a perspective is congruent with the discipline of nursing where the nurse-patient relationship, interwoven with so many layers of contextual meaning, has been described by Benner (cited in White & Chiarella, 2000) as "…a kaleidoscope of intimacy and distance in some of the most dramatic, poignant, and mundane moments of life" (p.2). Hence, as a specialist disability nurse I feel I naturally lean more toward the qualitative paradigm and what gives meaning to people's lives.

McVilly et al. (2008) stated one's theoretical perspective is influenced by their ontological perspective; that is how they view reality as being conceptualised. Daly et al. (2000) called ones ontological perspective their "world-view". My ontological perspective views sexual health more as a sphere of subjective meaning than that of an objective reality. For example, while an STD is on the one hand an objective reality (bacteria, virus, or fungi), it is the contextual relationship between the person and their environment which offers greater insight into supporting a person with an STD. This ontological perspective is not only supported by the paradigm of nursing but also by the principles of primary health care; health targeted at unique populations. McVilly et al. further stated a researchers' theoretical perspective is also influenced by their epistemological perspective, what Daly et al. have called ones "way of knowing". That is, is reality understood objectively (a discernable truth exists), subjectively (reality imposed by the researcher), or constructively (truth and meaning emerge through engagement between researcher and subject)?

As a male disability nurse I do not entirely view myself as an "outsider" to the lives of men and boys with an intellectual disability, however, I acknowledge ethnography demands a certain physical, social, and emotional separation. My ethnographic role is therefore not that of a colonial explorer in full safari-suit regalia about to board an expedition into the complex web of an, hitherto, unknown culture; an alien or outsider - looking in. Yet I am also not an "insider"; I don't have an intellectual disability nor do I live in a community group home. The key point however is the recognition I may have a uniquely male view that differs from others. For example, I have participated in team meetings as the only male nurse where female staff have discussed, at length, what to do about the "problem" of a male client's erection presenting as an obstacle to adequately securing an incontinence pad. My view differs: I do not see the erection as a problem but more as a temporary and healthy physiological response. Whether my male view is correct or incorrect is irrelevant, as an ethnographer I need to see things through a clear and unbiased lens; I need to be able to ask “what is going on here, how does this work, and how do people do this?” (Walford, 2001, p. 8) instead of “what do I expect this to be”?

ETHNOGRPAHIC TECHNIQUES TO UNDERSTAND THE LIVES OF PEOPLE WITH AN INTELLECTUAL DISABILITY

Apart from the research question pointing to an ethnographic approach and ethnography as a qualitative methodology fitting within my world-view and way of knowing, a significant body of similar research supports the use of ethnographic approaches. Perhaps the first formal attempt to use ethnographic techniques to understand the lives of people with an intellectual disability was undertaken by Robert B. Edgerton (Klotz, 2004). Edgerton’s aim, wrote Klotz, was to move beyond the preponderant view of “professionally knowing” people with an intellectual disability solely in terms of their diagnosis, or disability. Edgerton sought to give insight to what it meant to have an intellectual disability. In particular, his pioneering work titled *The Cloak of Competence* described how the experience of deinstitutionalisation for some was not always as positive as was believed (Edgerton, 1993). The work of Edgerton and others based at a large institutional setting in California led to an understanding of how isolation for some contrasted with deep friendship for others; how entrepreneurial activities were possible for some; that dating was not only a possibility but was enjoyed with “decorum” and “self-control” (Edgerton, 1984). Importantly, Edgerton stated the research problem concerning people with an intellectual disability is one of environment-organism interaction; such a claim not only mirrors the theoretical premise of Antonovsky's work as described in Chapter 3, but also a biopsychosocial view as described in Chapters 2 and 3.

Ethnographic approaches to understanding the concept of *quality of life*, particularly for people with a limited repertoire of communication skills, have been used to great effect in expanding what Atkins (1998) describes as a previous tendency toward mechanical pre-formed meanings. For example, an ethnographic study from Belgium was able to display quality of life operating within an "oppressive care culture" (De Waele & Van Hove, 2005). Lyons (2005) created a *Life Satisfaction Matrix* intended to subjectively inform those who support the lives of people with profound and multiple disabilities of the types of preferred activities which give rise to enhanced quality of life. Klotz (2004) argued in order to fully appreciate the inherent meaning and significance of symbolic systems, particularly for people with profound and multiple intellectual disabilities, engagement over a period of time using ethnographic techniques is required.

A recent study by Umb-Carlsson & Sonnander (2006) used an ethnographic approach to explore, from a gender perspective, the living conditions of adults with an intellectual disability in a Swedish county. While the researchers' data highlighted the way people with an intellectual disability tend to be treated as gender-neutral by the generic and special support systems, they were also able to describe many differences based upon gender by using participant observation and semi-structured interviews. For example, women with an intellectual disability were more likely than men with an intellectual disability to participate in visits to the cinema, library, reading books, and practicing hobbies. Specifically, this research was able to identify that where gender differences exist in the general population, those differences are far less likely to transpire for people with an intellectual disability. That is, the socio-cultural experiences of people with an intellectual disability were less dependent upon gender, a finding which provides insight into understanding how community participation and integration might be experienced.

An ethnographic approach was also used by Edwards (1998) to explore the concepts of "touch" and "space" within the nurse–client relationship. Significantly, their study was able to report on the specific challenges that gender differences place on the use of touch and space between nurses and their clients. Essentially, male and female nurses employ differently gendered ways of negotiating touch and space. Such data were vital to use as an additional interpretive angle when exploring the issue of sexual expression and people with an intellectual disability, in particular the role of support staff and the gendered construct of therapeutic touch.

Perhaps most importantly in terms of relevance to this study, an ethnographic methodology was used by Löfgren-Mårtenson (2004) in her examination of sexual interaction between males and females with an intellectual disability. Drawing upon symbolic interaction as a framework to elicit interactional understanding within a socially constructed view of sexuality, in addition to the data already discussed in Chapter 3, Löfgren-Mårtenson found young women with an intellectual disability were much more forward in their approach to sexual expression than were young males with an intellectual disability. Rich data were generated by the use of both observations during discos plus interviews with key persons; the reader is given an insight into the cultural milieu and how it influences behaviour. In contrast, McCarthy's (1999) data only comes from interviews with the women. Although McCarthy called her study ethnographic, the lack of data from observation renders her results, while still important, unable to describe the rich relationship between culture and behaviour; the reader has no insight into the cultural context the behaviour occurs. In comparing the two studies the most salient point is the significance of observation, and hence ethnography, to the overall outcome.

SENSITIVE RESEARCH OF THE VULNERABLE

Perhaps the most common theme emerging from this short examination of other ethnographic studies is the vulnerable nature of the populations under study to exploitation from others. Claiming to be the sole text purely focussed on researching vulnerable populations, Liamputtong's (2007) volume suggested *the sensitive researcher* is both a title and a characteristic required to conduct research with vulnerable populations. However, before understanding what constitutes a sensitive researcher, it is first apt to appreciate who the vulnerable are and what distinguishes the vulnerable from others in society. Liamputtong described the vulnerable as people who are: hard to reach, silent, hidden, deviant, tabooed, marginalised, and invisible. Taking these descriptions further, Liamputtong suggested they specifically include homeless people, children and adolescents, older people, people with disabilities, the chronically and terminally ill, female victims of rape and violence, sex workers, gay men, lesbians, indigenous populations, people from ethnic minorities, the mentally ill, illicit drug users and dealers, and those with stigmatised diseases such as HIV/AIDS. Whereas policies promoting community participation have made people with an intellectual disability more visible, some still remain hidden from the bulk of society and as a result often remain marginalised, invisible, hard to reach, and silent citizens. Men and boys with a moderate to profound intellectual disability not only fit Liamputtong's description of a population vulnerable to exploitation, but also experience further disadvantage by constituting a forgotten part of the mainstream men's health discourse (N. J. Wilson, 2007c).

In part, the aim of this research is to bring some balance back to the problematised discourse which in turn makes focussing on descriptive male pathologies inevitable. While the sexuality of people with an intellectual disability has evolved into a more "accepting" discourse (Griffiths et al., 2004), sexual matters remain very sensitive issues. This fact is where Liamputtong (2007) located the notion of sensitive research; combined with a vulnerable population, sensitive topics require closer scrutiny with the choice of methodology and the conduct of the research. While on the surface these concepts appear to be nothing more than the usual rigorous ethical processes concerning the researching the vulnerable (Griffin & Balandin, 2004), Liamputtong argued it is more than this. Certain groups are more vulnerable than others and focusing on topics such as people with an intellectual disability and sexual matters can be ethically challenging. Researching the sexual health needs of men and teenage boys with a moderate to profound intellectual disability perhaps involves the most vulnerable of all males with an intellectual disability as their capacity to communicate and make autonomous decisions is more limited.

A focus on the word "vulnerable" and the suggestion that people with an intellectual disability are labelled vulnerable is however a contentious point for some. Hollomotz's (2006) thesis argued that vulnerability as a social construction is created by the way society reacts to women with an intellectual disability and as such, automatically places "the vulnerable" into vulnerable situations which lead to, among other things, being the victim of sexual violence. Mays (2006) shared this perspective where she asserted domestic violence is often a consequence of the vulnerability created by dimensions of gender and disability. A focus on disability as a defining difference also limits the opportunities for expressing womanhood and one's sexuality (Women's Health Goulburn North East, 2002). Furthermore, feminist disability theory also views the lives of women with an intellectual disability through a perspective that the social creation of powerlessness is at the hands of a male-dominated system (L. Carlson, 2001; Jeffreys, 2008). Whereas Liamputtong (2007) provided a sharp definition of vulnerability, as a means to generate better research of the utmost beneficence, others argue accepting such a premise as anathema to fostering a rights-based perspective.

Interestingly, while Liamputtong (2007) defined the vulnerable and argued sensitive research and the vulnerable are inextricably intertwined, her arguments are based within a feminist and post-modern paradigm. That is, sensitive research is best explored via flexible and fluid qualitative methodology using a feminist epistemology and ontology as a starting perspective. However, one of the basic tenets of feminist methodology is its worldview that women are the focus of investigation and any feminist research must be of benefit to women; process and outcome are equally as important. Therefore, while it is clear the present study is very much focussed on a vulnerable population, and focuses on a sensitive issue, Liamputtong's definition of a feminist approach to this topic is clearly invalid. Moreover, the fact the literature, specifically summarised in Chapter 3, highlights some problems a feminist approach to male health issues creates, suggests a worldview different to feminism is required.

MASCULINE ETHNOGRAPHY AS RESEARCH METHOD

Masculine ethnography is being proposed here, not solely as a reaction to, but as a natural response to understand gendered approaches to research. As Ashkenazi and Markowitz (1999) suggested, a genderless stance in ethnography is not possible to uphold. The proposition of a masculine methodology has been previously mentioned, but usually with the reservation questioning "...what can men say or write about men that has not already been said by women, or could not be said by them in the future?" (Morgan, as cited in Pringle, 1995, p. 14). But, there are subjects which men do not want to share with women just as there are subjects women do not want to share with men. Other than suggesting the concept of masculine methodology may build upon the expanding epistemological discourse of post-modern methodology, it is an important point for the same reasons feminist methodology is important; it recognises sex/gender differences.

It is also not surprising that masculine methodological approaches to research have yet to surface; it was not until the late 1970s, well into feminism's morphosis, before a women's standpoint of social scientific research was argued for (Haney, 2002). As critical studies on men and masculinities undergoes adaptations, it will perhaps be some time before a masculine methodology might become as well-defined as feminist methodology is some 30 years after its inception. Alternatively, that a masculine methodology within a post-modern world is yet to emerge is surprising when so many other ethnographic spheres are declared: autoethnography, performance ethnography, and photoethnogrpahy (Liamputtong, 2007), institutional ethnography (D. E. Smith, 2002), critical realist ethnography (S. Porter, 2002), and cultural studies (Gray, 2003).

Perhaps the most salient example to this study of masculine ethnography in practice is the work of Shuttleworth (2000), whose exploration of sexuality with a group of men with cerebral palsy living in the San Francisco bay area epitomises for males what feminist methodology purports to do for females. Shuttleworth produced ideas that were not only about men but were also for men; it provided a sense of how disabled men perceived their own *sexual access*. To paraphrase Olesen's (2000) feminist summary, Shuttleworth "…centres and makes problematic women's [**men's**] diverse situations as well as the institutions that that frame those situations" (p.216). Shuttleworth introduced the idea of *sexual access* to disability theory, not simply environmental access, but inclusive access framed within the sociocultural context and in his particular study from a male viewpoint (Shuttleworth, 2003, 2006). Men with cerebral palsy were encouraged to tell their stories within the context of their disability and environment, their hopes, dreams, and desires. These stories challenged stereotypes and created pathways to redress male inequality. Feminist methodology provides both the language and the rationale for masculine methodology to co-exist.

Liamputtong (2007) summarised the essential notions of feminist methodology which apply equally to the lives of men and boys (emphasised words in brackets are my addition):

- Feminist [**masculine**] research focuses on gender and gender inequality; it implies a strong commitment to decreasing inequality
- It aims to give voice to the personal and everyday experiences of women [**men and boys**] and other marginalised people
- It commits to social activism aiming to bring about social transformation to improve the living conditions of women [**men and boys**] and the marginalised
- It promotes reflexivity to scrutinise gender, class, ethnicity, and sexual orientation
- It rejects traditional power imbalances between the researcher and the researched giving participants more power (p.14).

SUMMARY

Ethnography was the most appropriate methodology to choose given the research question, and it provided access to insights that other methodologies could not. In addition, ethnographic methodology reflects my epistemological and ontological perspective. Furthermore, ethnography also mirrored my background as a male specialist disability nurse where ascertaining the views of people with communication impairments often requires advanced observation skills.

This chapter has taken the themes presented in Chapters 2 and 3 and provided a methodological concept to answer the research question. This concept is the notion of a masculine ethnographer capable of tackling a sensitive topic concerning a vulnerable population through recognition of the capacity of unique maleness. Chapter 5 will describe in detail the procedures involved in conducting research using a masculine ethnography.

CHAPTER FIVE

PROCEDURE: UNDERSTANDING SEXUAL HEALTH

As sensitive researchers, we are obliged to consider the safety and well-being of our research participants. Ethically sensitive research approaches are, however, complicated (Liamputtong, 2007, pp. 24-25).

The aim of this chapter is to describe the **how** of the research; how to locate some participants, how to gain ethics approval, how to collect the data which will answer the research question, how to analyse the data so it makes sense, and how to conceptualise the data into a framework which will contribute to evidence-based practice. This chapter will also describe how the research process was conducted with ethical and scientific rigour despite the fact that ethics in qualitative research is not always a black and white issue. This chapter will also pay particular attention to accessing the field, design of research tools, the process of collecting interview and observation data, a summary of the constant comparative method to analyse qualitative data, and exiting the field. Figure 5.1 represents the process of enquiry, the shaded areas illustrate this chapters focus.

While this chapter will summarise the research process in chronological order, the lived reality was in fact far from orderly. Comforted by the promise of a natural “emergent methodology”, it felt far more chaotic and reactive than the emergent image conjured. Reassuringly, James Watson (1968, as cited in Walford, 2001), who helped unravel the DNA double-helix, revealed how much his research outcome relied upon luck, guesswork, compromise, personal involvement, and inter-researcher rivalry. Walford, in using the example of Watson, argued that the step-by-step model of research as it is often taught comprises a best-case scenario; research is frequently achieved by compromise, short-cuts, hunches, and serendipitous occurrences.

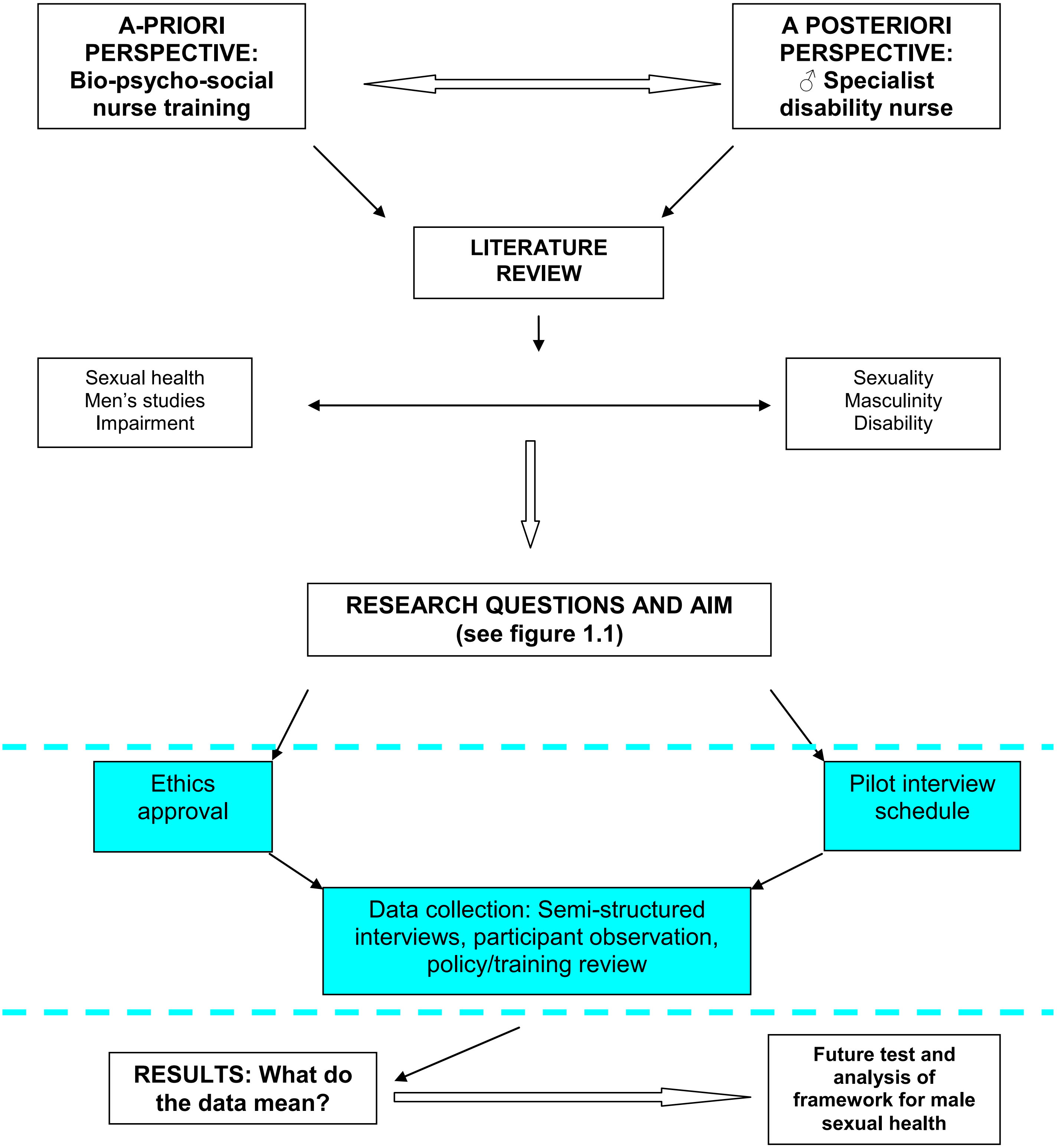


Figure 5.1.

Process of enquiry

ETHICAL RESEARCH

Cumella (2001) asserted that curiosity and desire to improve the lives of others are the general motivators for researchers exploring the lives of people with an intellectual disability. While such motivation may be well intentioned, any research involving humans must have a sound ethical basis to its design and application. Cumella stated the three main ethical challenges facing the researcher seeking to study people with an intellectual disability are: 1) an historical lack of interdisciplinary consensus on ethics, 2) the problem of consent, and, 3) the need for reliable information. Both Cumella, and Liamputtong (2007) asserted that a lack of consensus prevails between disciplines as to the nature and need for certain types of consent. Medical research tends to be dominated by the need for consent to ethical treatments, research in the social sciences is more preoccupied by maintaining individual confidentiality. Regarding consent, research as a concept can be difficult to explain and, for those with more severe levels of intellectual disability, there exists the need to not only question what their views may be, but also a parallel questioning of "…whether they can be said to have views about complex conceptual issues at all" (Ware, 2004, p. 176). The need for reliable information in disability services has it roots in the need to evaluate treatment/services; to this end Cumella suggested that researchers observe the principles of *non-maleficence, beneficence*, and *informed consent*. Beneficence refers to the good that outweighs the potential harm to both the individual and society (Holloway & Wheeler, 2002).

Edgerton (1993), in his revised edition of *The Cloak of Competence*, wrote how his original work did not incorporate consent, informed or otherwise, from participants as would be demanded by today's rigorous ethics processes. Yet, the nature of the study and its reported outcomes were clearly conducted with utmost confidentiality and propriety; its contribution to understanding the lives of people with an intellectual disability and the context of their lives stands up to the test of non-maleficence and beneficence. Although conducted much later, Atkins' (1998) study included observation of interactions between staff and adults with a severe to profound intellectual disability. While individual consents were obtained from staff participants, no proxy consents were obtained from the substitute decision-makers of the clients under observation; consent to carry out the study was obtained from the institution providing the care. Again, it is clear Atkins work, too, was conducted with utmost propriety.

McCarthy (1999) quite strongly and coherently argued that the mandatory acquisition of a signed consent form, for example from people with a mild intellectual disability, is at risk of being turned into a token gesture. That is, consent for a complex and deeply contextual phenomenon does not automatically imply comprehension. In fact, McCarthy eventually decided against following ethics committee recommendations as she felt ethical considerations, including consent, "…are not easily or adequately addressed at one moment in time–that is at the outset or when approaching ethics committees" (p.107). Asking someone who you know will quite happily acquiesce and sign a document they do not comprehend, is akin to what Brewster (2004) referred to as "putting words into their mouths". McCarthy's research was characterised by honesty and integrity with the intention to improve the lives of women with an intellectual disability; it could be argued her research has generated a focus on women's health that may not have otherwise transpired. McCarthy's honest, confidential and respectful transcription of deeply personal and intimate stories represents a sound indicator of achieving non-maleficence and beneficence.

The absence of consent informed or otherwise, does not automatically result in unethical research. However, while McCarthy's (1999) bold stance was ethical, it can also be argued a denial of human rights ensues when one assumes, without clarification, that someone lacks the capacity to consent. Clearly, ethics in research is a complex matter; the challenge for researchers must be to navigate the divide between ethical and unethical practice knowing that even strict adherence to consent procedures does not always equate to an informed agreement to participate. For example, Lindsay, Olley, Jack et al. (1998) described the court-ordered treatment of two male stalkers with an intellectual disability which contains some potentially identifying and personally detrimental information. In this case, Lindsay et al. would have been required to determine whether the knowledge gained in publishing this paper outweighed the potential distress a breach of confidentiality may have caused the two men. This is an onerous responsibility for the reason outlined by Stake (1998): if a case study is of public interest, this should not extend to a "…licence to invade the privacy of others" (p.102).

In their summary of the historical *1978 Belmont Report* into the protection of human subjects in research, Griffin and Balandin (2004) summarised its three ethical principles: 1) distributive justice, 2) beneficence and, 3) respect for persons. It is therefore appropriate to review these principles as they apply to this research project. The sensitive nature of the topic sexual health coupled with the vulnerability of the men and teenage boys involved in the research project adds extra weight to these principles. Without ethical deliberation there is a potential risk of harm, distress, and if not conducted ethically, a challenge to the human dignity of these men and teenage boys. Silverman (2005) asserted that all qualitative research is contaminated by the researchers' own moral and political values; therefore does beneficence actually exist or do the researchers’ own values ensure that beneficence can be persuasively argued?

In terms of distributive justice, Chapter 3 specifically presented an argument that an imbalanced discourse exists; that there is a trend toward focussing on male pathology as opposed to male health promotion. While a culture of maleficence may not directly underpin this discourse, the result is not beneficence. This research project aims to redress this situation by focusing on the specific needs of men and teenage boys with a moderate to profound intellectual disability. The aim of this research is not only to engage with the ideas of the disability sector, but also with the mainstream male health sector, and with mainstream sexuality studies. Lastly, this research project is heavily contaminated with the researcher’s own political and moral values; that men and boys with an intellectual disability, the way they do maleness, communicate maleness, and express maleness, deserves more respect.

Ethics Application

At the outset, the research proposal was structured with the above principles in mind; interviewing the men and teenage boys with a moderate to profound intellectual disability was never going to be ethically sound or practically achievable due to major communication problems. The proposal was therefore structured in three stages: 1) to conduct semi-structured interviews with support staff and parents/family members, 2) to conduct participant observation of staff and client interactions in public areas of the residential setting and, 3) to review policies, training, and any other pertinent artefacts. While this structure was intended to minimise the ethical challenge, challenges remained as I intended to ask questions about a sensitive topic. The proposal needed to answer potential participant’s questions about the research, how I would use the data, how the data would be stored, the time commitment involved, the benefits and risks of participating, the need to ensure confidentiality of their views, and the right to withdraw from the project at any time.

Submitted in time for The University of Sydney Human Research Ethics Committee (HREC) June 2005 meeting, several concerns were raised by the committee. First, the committee objected to the first word of the proposed title: *Constructing the Sexual Health Needs of Men with an Intellectual Disability*. The committee felt “constructing” may be confusing and added little to the application and was hence replaced in the ethics application with “defining”. Second, the committee requested a more detailed explanation of how any distress caused to participants would be handled; the offer of psychological counselling through the Centre for Developmental Disability Studies was added. Third, the committee requested more information about the observation phase of the study; the summary was condensed to make it easier to understand. Fourth, a summary was requested of how information would be destroyed. Finally, a summary was requested as to how recruitment would proceed. The revised proposal was re-submitted to the University of Sydney HREC and was approved in writing via a letter dated the 16th September, 2005 (reference number 09-2005/3/8330). Appendices 1–5 contain the said letter along with authorised consent forms, participant information sheet, recruitment letter, and semi-structured interview schedule.

Ethical Concessions

As any qualitative research study unfolds, the researcher is faced with the dilemma of an altered course in the direction of the research as new data emerge. Mason, as cited in Silverman (2005), stated “the changing directions of interest and access during a qualitative study mean that new and unexpected ethical dilemmas are likely to arise during the course of your research” (p. 257). Swain, Heyman, and Gillman, as cited in McCarthy (1999), suggested ethics is more a “continuing process of decision making which runs through every stage of the process up to and including publication” (p.107). Liamputtong (2007) argued that the ethical process extends even beyond the completion of a research project as there may be lasting effects on participants. For this reason, McVilly, et al. (2008) suggested consent, as one component of conducting ethical qualitative research, should be considered an emergent phenomenon; ethical challenges, and consent, being re-appraised as the research challenges emerge. In addition, Holloway and Wheeler (2002) stated that there is realistically no way the qualitative researcher can accurately inform participants at the outset the potential or actual path of the research, so true informed consent may therefore be an elusive ideal.

McCarthy’s (1999) ethical concession to a written consent evolved into taped verbal consent at the outset of any interview. McCarthy then made an additional concession which centred on her inability to switch on and off of the voice recorder between the consent phase and interview phase as was requested by the ethics committee. McCarthy felt it was too much for her participants to take on board the difference between recording verbal consent (which had to be kept and stored) and recording the interview (which was to be recorded during the same session, transcribed then destroyed). Although McCarthy does not state this within her work, her stance does mirror the post-modern and feminist idea of moving beyond the limits imposed by formal and rigid structures of institutional ethics committees. Instead the post-modern and feminist researcher “…takes demonstrable responsibility for the issues of power, negotiation and transformation within their research designs and interpretations of findings" (Grbich, 1999, p. 77). However, there is a risk in discarding total formality as the researcher inevitably faces a crisis in being able to claim a representative and legitimate narrative.

Two ethical challenges emerged while conducting this research project. Their resolution is described below:

1) The first issue centred on a "wall of photos" displayed in residential house number two. The "wall of photos" became an important tool to communicate various themes and interactions during interviews and observation sessions. One photograph proved particularly important to staff, so a decision was made to seek consent to include a copy of it and a narrative within the data analysis. A written letter was forwarded, via the community group home manager, to the substitute decision maker of the young man in the photo together with appropriate documents approved by the HREC. A copy of this letter with signed consent is located in Appendix 6.

2) The second issue related to the data about the men and teenage boys who lived in the houses; data about them firstly emerged during interviews then was amplified during the observation stage. While the original ethics application clearly stated observation was of interactions between paid staff and clients, the intention was to observe staff and not necessarily the responses of the men and teenage boys. In hindsight it was clearly a naïve assumption to observe staff interaction and not record or document the variables which triggered or initiated that interaction. Moreover, I unavoidably also became involved in the interactions as it became obvious the role of an unobtrusive observer was not possible; the role morphed into one of a participant-observer. The ethical issue related to the absence of consent from the substitute decision

makers of not only the men and teenage boys being supported, but also the other female clients and staff who were present in the house; did it matter, was it unethical not to have these consents? The major ethical challenge was one of anonymity; would any of the data, or more importantly the way it was reported, expose the identity of any clients? The test of beneficence and non-maleficence therefore rested squarely on my shoulders with my conduct, the presentation of data in the thesis, and any subsequent publication.

ACCESS TO THE FIELD

Access to the field of study requires negotiation with *gatekeepers* (Holloway & Wheeler, 2002; Walford, 2001). The gatekeepers of disability-specific accommodation settings in NSW are divided into either Government or non-Government providers. Due to the less bureaucratic nature of the non-Government sector, Chief Executive Officers (CEOs) on behalf of three non-Government service providers in a geographically convenient location were invited to participate in the study. Two of the three accepted the invitation to participate, the third never responded to the initial written request or subsequent follow-up phone calls. However, while the CEOs agreed to participation, middle managers became second-tier gatekeepers. This required face-to-face meetings plus attendance at a team meeting in one of the houses to establish my role as a non-threatening intrusion to their lives. The other important facet of negotiation with second tier gatekeepers was to generate interest in the study; Walford argued this is best done face-to-face as in essence the researcher is trying to “sell” themselves as a researcher. As a researcher very familiar with disability services and accommodation settings, I was able to negotiate these stages somewhat as an insider who understood the daily challenges disability services face.

Setting: the Australian Context

To ensure replicability of any study, Stancilffe, Emerson and Lakin (2004) stated a precise description of the residential setting is required. These include the size and location of the residential setting, the type of staff support, and the composition of co-habitants. The setting for the study consisted of community-based group homes for people with an intellectual disability requiring 24-hour support and care where at least one person was a male with a moderate to profound intellectual disability. Stancliffe and Keane (2000) defined this model of accommodation support in Australia as a *group home*:

> Involves a household of 3 to 7 people with **full time** support (at least during waking hours) by paid staff from an accommodation support agency for people with a disability. There may be times on weekdays when all residents are away from the house attending their day programmes and no staff are on duty. Night support may be provided by awake shift staff or sleepover staffing, or there may be no staff present when residents are asleep. Staff are present at all other times (p.284).

Three homes were identified by the CEOs that met these criteria and will be referred to hereon as *community group homes* which were located in residential areas broadly representative of Australian city-fringe suburbia. That is, homes that were free-standing (detached), single-storey, with four to five bedrooms, in quiet suburban streets, with two of the houses on the outer fringes surrounded by areas of bushland.

1) Community group home 1: Older client group (40 +) accommodating one male and four females. All clients have a mild to moderate intellectual disability, the male client was the least able. Staffed 24 hours a day with a nightly sleepover shift.
2) Community group home 2: Younger client group (13-23) accommodating two males and three females. All clients have a severe to profound

intellectual disability plus significant physical disabilities. Staffed 24 hours a day with an awake night shift.

3) Community group home 3: Young adult client group (18–30) accommodating two males and one female. One male has a moderate intellectual disability, the other severe, the female a mild to moderate disability. Staffed 24 hours a day with a nightly sleepover shift.

The three community group homes described are representative of the group home model in Australia. The structure of disability accommodation services in Australia differs for example, from those in the UK; in NSW, the State Government funds a disability service whereas in the UK a person receives individual funding. This degree of centralisation in Australia has embedded the *group home* model as the standard whereas in the UK decentralisation has enabled a variety of models to emerge such as intentional village communities, assessment and treatment centres, dispersed housing schemes, community housing associations, and supported living schemes. A degree of generalisability can be inferred from the selection of the three community group homes if applied to others with similar 24-hour in-house staff support. Sánchez-Jankowski (2002) stated the first line of generalisation starts with the selection of a group that represents a population the researcher wants to portray. Two non-identifying vignettes illustrate the broad support needs of the group I wanted to portray:

1) Client A: Older man (50+) with Down syndrome and moderate intellectual disability who has effective receptive communication skills but poor expressive communication skills. Requires full support with the preparation of meals including cutting food into small pieces. Requires partial support with holding utensils to place food and drink into mouth. Is occasionally

incontinent of urine and faeces but will use the toilet correctly if and when taken by staff at timed intervals. Requires full support with personal hygiene and partial support with dressing and grooming. Offers very little communication and interaction with the people he lives with. Attends a day placement for people with an intellectual disability and is dependent on staff for community participation. Support needs are increasing rapidly as client ages and dementia advances[26].

2) Client C: Younger male (18–23) with a severe intellectual disability and physical disability. Requires full support with all personal care tasks and grooming and is incontinent. Requires full support with meal preparation and consumption. Has minimal communication skills but can communicate feelings such as happiness by non-verbal cues. Requires full support for community participation and attends a day programme for adults with an intellectual disability.

Interview Participants

Interview participants were paid staff working in the community group homes previously described. Participant information sheets (see Appendix 3) were left with each community group home manager to distribute to their team and staff were asked to contact me to participate. Of the 24 permanent staff who worked in the 3 community group homes, 18 staff, 3 male and 15 female, agreed to participate in the study. All staff participants were interviewed within the community group home at their request while they were on shift; a verbal offer was made but rejected by each participant to meet at a neutral venue such as a café where I could buy them a coffee. The participants consisted

---

[26] This man died shortly before the submission of the thesis for examination.

of a mix of full-time and part-time staff and represented 75% of the potential sample of 24 staff. A total of 6 staff participants were from community group home 1, 7 from community group home 2 and 5 from community group home 3. One female participant pulled out of the study after reviewing her interview transcript citing concerns over the confidentiality and nature of some of her responses (see “transcription of interviews” below for further discussion); the final sample was therefore reduced to 17 participants.

DATA COLLECTION

Data collection involved three phases: 1) semi-structured interviews, 2) observation, and 3) review of organisational policy and training related to sexual matters. Grbich (1999) described four modes of analytical procedures in qualitative research. The *iterative mode*, where data collection and analysis occur in an evolving and cyclical approach, reflected the nature of this study. While data collection and analysis occurred simultaneously, it will be presented below separately.

Design of Interview Schedule and Pilot Interviews

A draft semi-structured interview schedule was designed based upon the dominant themes identified within Chapters 2 and 3. Table 5.1 describes these themes. Table 5.2 describes the semi-structured interview schedule as presented to participants during a small pilot with seven staff in the disability service provider where I am employed. The pilots aimed to tease out the type of data that might emerge and to identify any problems with the schedule. Furthermore, the pilot enabled me to develop a confident and relaxed interviewing style; a strategy Holloway and Wheeler (2002) suggested will benefit the novice researcher. Janesick (1998) and Gray (2003) stated a pilot also allows the researcher to focus on previously unclear areas, to test certain questions, to build rapport with potential participants, and to develop effective communication patterns. Janesick also pointed out a pilot may uncover some insight not previously expected. This was certainly the case in that the scope and breadth of responses were far wider than anticipated. This triggered a change in strategy; the plan to collect additional data from family members would overwhelm my resources when added to what was emerging as a significant amount of staff data. That is, although the additional data promised much, it was decided interviewing family members would be better suited to a separate study. Lastly, the pilot also gave the researcher some insight into the sorts of prompts that may be required to get participants to open up. The first two themes occasionally required a prompt from myself such as "*sexual health means whatever you believe it means"*, or "*by masculinity I mean the essence of being male*".

Table 5.1

Thematic summary of semi-structured interview schedule

Theme	Thematic intention
Sexual Health	What participants believe constitutes the sexual health needs of men and teenage boys; to include anything participants feel is relevant
Masculinity	How participants feel their ideas of masculinity and intellectual disability come together
Gender	What gender means to participants in relation to men and teenage boys with an intellectual disability
Male staff	Thoughts on male staff and sexual health needs of men and teenage boys; interactions, attributes, perceptions, feelings, beliefs
Female staff	Thoughts on female staff and sexual health needs of men and teenage boys; interactions, attributes, perceptions, feelings, beliefs
Policy	Awareness of or content discussion relating to gender-specific policies
Training	Verbal recollection of any gender-specific training

Table 5.2

Semi-structured interview schedule

SEMI-STRUCTURED INTERVIEW SCHEDULE FOR SUPPORT STAFF
1) Do men and teenage boys with an Intellectual Disability have **sexual health** needs? Tell me what you think they might be.
2) What does the word **Masculinity** mean to you within your daily interactions and perception of men and teenage boys with an Intellectual Disability?
3) Do you think that **gender** and **identity** are important concepts when working with men and teenage boys with an Intellectual Disability?
4) What impact, if any, do female care staff have on men and teenage boys with an Intellectual Disability? Do female care staff have a role to play in men's sexual health?
5) What impact, if any, do male care staff have on men and teenage boys with an Intellectual Disability? Do male care staff have a role to play in men's sexual health?
6) Are you aware of any policies or initiatives within your work that are gender specific?
7) Have you ever received any training that focuses on gender-specific themes?

Interviewing

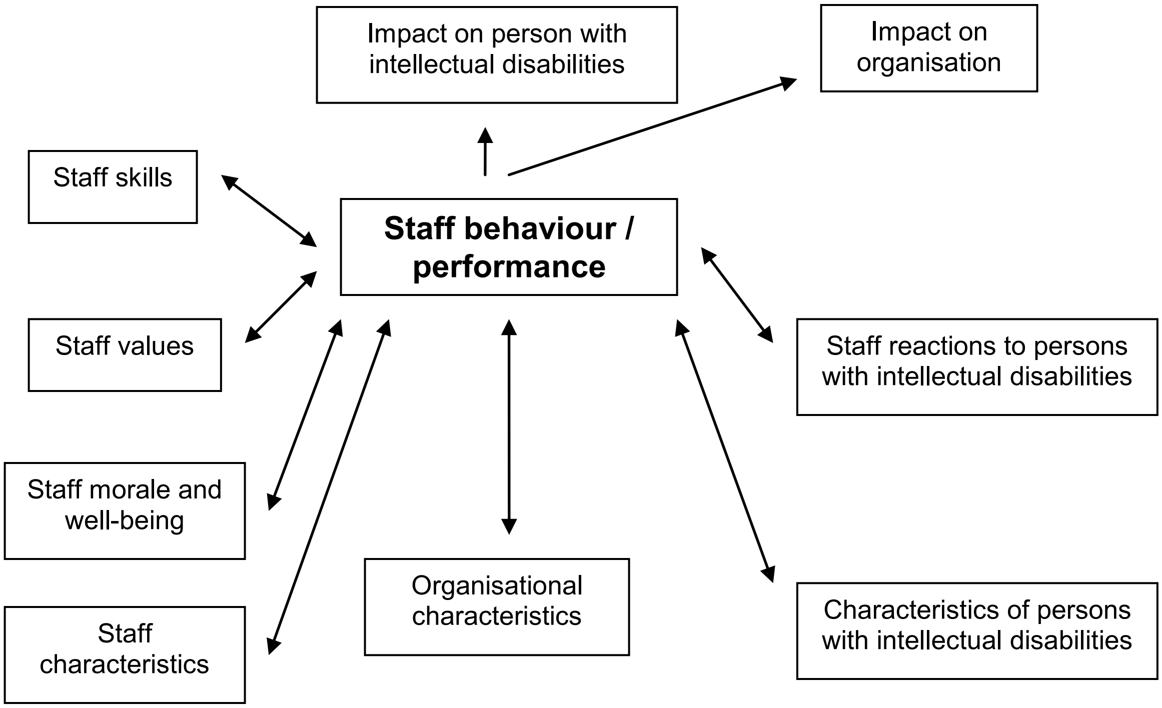
The core assumption of this research is based on the premise that support staff have a direct and significant impact on the lives of all people with an intellectual disability; an impact which is greater the more severe the intellectual disability. Hatton, Rose and Rose (2004) concluded research exploring the support staff of people with an intellectual disability generally has three conceptually linked themes:

1) Staff behaviour has a direct causal influence via interactions
2) Staff behaviour has an indirect causal influence via their impact on organisational capacity to deliver support
3) Staff behaviour is multiply determined by a plethora of factors associated with clients, staff, and the organisation.

These themes have been crafted into a hypothesised framework as depicted in Figure 5.2

Figure 5.2.

Core constructs and hypothesised links between them (Hatton et al., 2004, p. 582)



The aim of the interviews was not to **measure** but begin to **understand** how constructs such as masculinity and sexual health potentially intersected with staff skills, values, morale, well-being, characteristics, and reactions. The interview was also the route to discovering staff feelings, perceptions, and thoughts (Holloway & Wheeler, 2002, p. 80).

One of the first occasions recorded speech was included as evidence in a qualitative study was in a book titled *Knowledge and Control* published in 1971 (Walford, 2001, p. 82). Walford stated that historically, recorded speech gave the qualitative researcher an irrefutable and reliable record that would stand up to the scrutiny of the positivist paradigm; tape recordings of interviews became the qualitative orthodoxy. The qualitative researcher today has an array of digital recording devices which are much smaller, less cumbersome and, perhaps, less obtrusive than the devices of the 1970s; such a device was used for the interviews in this study. However, while a fully transcribed interview provides the “hard” data desired by a positivist critique, Walford argued it is important to remember ethnography is much more than a recorded interview; people don’t necessarily always do as they say.

While Walford’s (2001) warning reminds the researcher that people do not always tell the truth; “…I think that once we all used to communicate by telepathy and we only invented language in order to lie” (p.87); interviewing remains the staple of much qualitative work. It is ironic that an interview is a most unnatural situation, yet ethnography aims to record data in the natural setting. Therefore, the researcher should take on board these issues and seek to minimise the artificial nature of the exchange. For example, in the present study interview participants were given the choice of location and all elected to be interviewed while on shift in the community group home. This choice gave the interviews an element of naturalistic enquiry in an unthreatening location. While this can diminish the “threat” of an interview, Walford also pointed out the interviewer takes away a recording, to later dissect, of something perhaps more than the interviewee might have wanted to relinquish. Certainly this appeared to be the case for the one interview participant who was removed from the study at her request; despite the interview participant insisting certain things were not said the recording proved they were indeed said which clearly “threatened” this participant. Obviously, as Holloway and Wheeler (2002) reminded us, research participants wishes are always paramount and any decision to refuse to continue participation must be respected.

Challenges exist in designing, conducting, and validating interviews, but the fact remains people still have views and essential knowledge about their world which can be elicited via an interview (Liamputtong, 2007). The key to unlocking the views and essential knowledge is in the conduct, or technique, of the interview. Gray (2003) suggested a more reflexive interview technique, where the interviewer remains an active listener while thinking on their feet for opportunities to delve deeper into the participant's meaning. Gray also suggested revealing something of yourself may provide an opportunity to "open up" the discussion by allowing the participant to get to know you a little. This certainly proved a useful "ice-breaking" ploy when it was clear a participant was nervous or perhaps suspicious of my motives; by telling them a little about my research, my experience in the sector and why I was doing a PhD enabled the participants to see me as less of an inquisitive "outsider" and more of a respectful and questioning "insider".

The interviews were conducted between November 2006 and July 2007 in separate stages: interviews in the first community group home were followed by a period of transcription and initial analysis, followed by the second community group home, analysis, then the third community group home. Although the semi-structured interview schedule (see Table 5.2) has ordered questions, the interviews were not conducted in this way; they were open-ended and flowed as naturally as the discussion allowed. During the interviews I occasionally made some brief notes when I wanted to return to a theme, to seek further clarification, or to delve deeper. Most interviews lasted approximately one hour with a couple ending slightly sooner and others ending later. Most interviews were conducted later in the evening when the mood in the house had settled down but one was conducted around midnight and a few others on a weekend; these times were dictated by the community group home routines and reflected the natural environment.

One of the most surprising elements of the interview stage of data collection, although in hindsight it was not so surprising, was the level of engagement and involvement I encountered with all of the clients and other staff. No interview was a simple matter of knocking on the door and beginning the interview; quite a considerable amount of time was spent being introduced, having cups of tea, waiting while other more important things were attended to, interruptions from the telephone, interruptions from other visitors to the community group home, as well as time spent reading organisational policies and procedures. In short, my role as observer started before I realised; this enabled some conceptual understanding of the interview as it was occurring in a natural environment. For example, where an interview lasted for one hour, I may have been at the house for a total of two hours taking in the context of the environment.

Observation

In highlighting the limitations of the interview as a source of collecting accurate data, Mason (2002) suggested the researcher should explore ways of collecting more meaningful data via non-verbal communication. The most common method is via observation in a natural setting. Angrosino (2004) stated when observation occurs in a natural, as opposed to a clinical/laboratory setting, the researcher participates in that setting hence the term participant-observer. However, Angrosino also suggested participant observation is actually not in itself a data-collection technique; more the context in which data can be collected. Indeed, McCall and Simmons (1969) more than three decades ago recognised attempts to bring participant observation as a technique into line with methodological principles only muddied the waters of what it actually entails. Therefore, other than conducting oneself ethically, with no formal manual of how to “do” participant observation, the main tenet states Angrosino was the demand for “time” spent in the natural setting.

In the absence of any technical manual, there remains a need to find an approach determined by subjective and/or objective data; in a natural setting, the main risk is to err too much on the side of subjectivity, or to “go native” (Angrosino, 2004). The ethnographer who enshrines complete subjectivity and goes totally native adopts friendship, sympathy, belief, and love within the culture by becoming complete members who spend the rest of their lives immersed in the culture (Tedlock, 2000). While the researcher exploring intellectual disability in an accommodation setting may never go totally native, the issue of subjective versus objective data remains. Gold (1969) described these different approaches as either the complete participant, the participant-as-observer, the observer-as-participant, or the complete observer. The complete participant assumes an insider role-pretence where their identity is not known to research participants; the participant-as-observer differs from the complete participant as there is no role-pretence, the participant is aware of the researchers stated task; the observer-as-participant observes participants for brief periods of time usually in the context of an interview; the complete observer is completely removed from social interactions with the participants. The approach used in this study was the participant-as-observer, or participant observation.

Grbich (1999) suggested the participant observer collects data within three domains which provided a solid framework to record data:

1) the building/setting/environment (space, colour, smell, and observer’s responses);
2) the people (age, sex, ethnicity, dress, status, relationships, grouping and observer’s comments); and

3) activities, events, behaviour and the dialogue of those under observation (p. 134).

Grbich also recommended while collecting these data the participant observer try to blend into the setting with the aim to establish close relationships. As someone familiar with disability accommodation settings I was able to blend quite naturally into each setting.

Participant observation, as a data collection technique separate to interviews, took place between November 2007 and March 2008. Each period of observation usually lasted between 2 and 4 hours and was conducted either during the evenings or on weekends at the discretion of the staff team. In total, 97 hours were spent in the three houses collecting data; 29 hours in community group home 1, 56 hours in community group home 2, and 12 hours in community group home 3. Observation in community group home 2 was stopped in February 2008 due to a lengthy hospitalisation of the sole male client who was eventually transitioned to an elderly care facility. Data collection in community group home 3 ceased in February 2008 due to a change in service provider who had not been involved in the original agreement to participate.

Exiting the Field

Gerson and Horowitz (2002) stated while there is rarely a clear and consistent deadline to the end of a qualitative research project, the time to leave is a process that should naturally emerge. It was unfortunate that the time to end engagement in community group homes 1 and 3 were decided by external factors but as Gerson and Horowitz cautioned, "…a project can end because the field site changes or disappears or because someone else says it is time to stop" (p. 214). For community group homes 1 and 2, I presented the house with a box of chocolates and a card thanking them for their time, honesty and patience.

DATA ANALYSIS

Transcription of Interviews

I was guided in my approach to transcription largely by the compelling passage by Walford (2001, pp. 92-95) titled *The Fetish of Transcription*. Walford argued an intrinsic seduction is at play when the qualitative researcher transcribes an interview in part due to the promise of large quantities of "hard" data. However, Walford questioned the validity of verbatim transcription as "…the tape recording is not an accurate record of the conversation" (p. 94). That is, the transitory conversation is rendered into a permanent and stable object that becomes re-contextualised each time it is perused, often in a totally different context to the original conversation (Graddoll, 1994 as cited in Walford, 2001). Walford disclosed the fact he has rarely fully transcribed any interview in 20 years of qualitative inquiry. Walford stated it is both a mind-numbing process and a distraction from what is actually being said. Instead, Walford suggested one listens to the recording and records topics of conversation and their changes by a counter marker; he then transcribes only those parts that are relevant to the research question. This is the procedure I used to record data from interviews.

The notion that recorded words in a conversation can hold a different meaning when read in a different context echoed the rationale behind the one female staff member who at her request was removed from the study. Other than being concerned about the researcher's capacity to uphold the promise of confidentiality, this participant felt certain she had been taken out of context at various points. When re-examining both the recorded conversation and the transcript, I felt the transcript was as accurate a record as I could produce. Upon reflection of the interview, it is clear the participant was right; English was her second language and although I had transcribed her words the context and meaning was lost somewhere between the conversation and the printed paper. Perhaps, also seeing words on paper at a later time reinforced to the participant she had, at least in her mind, controversially said too much.

With Walford's (2001) cautionary statements in mind, further reading confirmed verbatim transcription was firmly entrenched in the research traditions of conversation analysis and discourse analysis (Silverman, 2005) which this study was not employing. For studies requiring verbatim transcription, Heath and Hindmarsh (2002) described an orthography of symbols, time-lines, and numbers (representing humour, pauses, elongated sounds, rising inflection, in-breath, out-breath, intonation and so on) for transcribing data. While such orthography is not entirely impenetrable, it is nonetheless a terribly intricate and complicated procedure which, unless conducting a thorough discourse/conversational analysis, appears unnecessarily labour intensive. However, while verbatim transcription was therefore deemed inappropriate for this study, selected passages were transcribed verbatim.

Transcription of the interviews usually occurred within four hours of the interview by the time I commuted home, downloaded the digital recording, and gave myself some time to reflect upon the interview in is entirety including the context in which the interview took place. There were some interviews that were transcribed the following day largely due to the late hour that I arrived home. Each transcription took at least double, and usually treble, the time it took to conduct the interview. The transcription procedure consisted of listening to the whole recording to get a feel, followed by a step-by-step playback where selected passages were either recorded verbatim, were summarised in a sentence or, if deemed thematically irrelevant to the study, were not transcribed at all. For example, the following passage was recorded **verbatim** as there were many intertwining themes; words in parenthesis are the researcher's addition:

Researcher: *"As a sector are we good at this warmth and comfort"?*

Staff member: *"It is something I like and I am a very tactile person, they need it. Some of them (staff) are warm and loving and others treat it like a job. I have seen some of them (staff) put nappies on and shove it (erect penis) in and don't position it to promote comfort (dignity, respect). You've got to be gentle with them – gentleness and dignity as if it was your own child".*

This next example related to a simple theme the participant was trying to get across: that interactions are more about the individual as opposed to gender. The alternative was a verbose passage of conversation that added very little content.

Staff member: More about the *"individual"* whether male or female.

As a means of *member-checking*, all interview participants were sent a copy of the transcription of their interview with a letter thanking them for their participation and my contact details should they wish to discuss the transcription or their interview. The sole respondent was the female staff member discussed earlier who asked to be removed from the study.

Transcription of Participant Observation

Field notes were recorded as soon as possible after time spent in the house. There were no guidelines or limits about what to record other then the events which seemed prominent and my thoughts on those events. Verbatim excerpts from my field notes have been used as raw data in Chapters 7-9 to support and/or reinforce thematic development.

Constant Comparative Analysis

Data were analysed using the constant comparative method. While the present study was not intentionally driven by the need to generate theory, my interpretation of theoretical differences within the literature, described in Chapters 2 and 3, pushed this study toward a theoretical riposte. Coupled with perceived “comfort” in the logical manner of analysis using the constant comparative method, the logical analysis of data toward the development of theory made a compelling case for the constant comparative method.

Glaser’s (1969) summary of the constant comparative method stated that it offers a way to generate theory by the combination of a quantitative coding technique, plus the technique of “immersing” oneself in data to generate theoretically interrelated hypotheses. Glaser argued that the constant comparative method enables theory to be developed in a manner which is “…integrated, consistent, plausible, close to the data, and in a form which is clear enough to be readily, if only partially, operationalized for testing in quantitative research” (p.218). It is concerned with producing a range of theoretical properties and hypotheses about a phenomenon. Where theory about a phenomenon already exists, the constant comparative method can be used to elaborate and modify it against new data (A. Strauss & Corbin, 1998). A. Strauss and Corbin also stated that the method of constant comparison is a central feature of the research method grounded theory; “theory generation” and “doing research” emerging simultaneously in a structured manner.

A simplified summary of how to methodically carry out data analysis using the constant comparative method was described by McMillan and Schumacher, as cited in Leedy (1997):

> 1 read along, 2 stop after each sentence/paragraph, 3 what does it mean? 4 attach a tentative label, 5 write a summary to exhaust the meaning, 6 build a tentative sketch or model, 7 do it while it is hot instead of reading on, 8 accumulate lots of other little pieces, and 9 gradually seek order and integration into a larger pattern (p. 160).

Figure 5.3 illustrates my first developmental model using the constant comparative method, and depicts staff perception toward sexual matters and masculinity being heavily **contingent** or **conditional** on factors such as degree of disability. This continuum did not adequately explain, nor make sense, of every piece of data as contradictions abounded. But the notion of staff responses to sexual matters operating on an access-limit-deny continuum showed promise. However, it was only a summary of tentative labels framed into a tentative model which emerged from initial data analysis using the constant comparative method (N. J. Wilson, 2007a, 2007b).

ACCESS	**LIMIT**	**DENY**
SAFE	WARY	FEAR
ASEXUAL	NEUTER	SEXUAL
CONTROLLED	LIMITED	OUT OF CONTROL
LESS MASCULINE	NEUTRAL	MORE MASCULINE
PRIVATE SPACE	NEUTRAL	PUBLIC SPACE

Figure 5.3.

Emergent access–limit-deny continuum

Not content with the access-limit-deny continuum and the simple method suggested by McMillan and Schumacher, I returned to the data where a more nuanced analysis was made between the varieties of codes and their relationship with each other (Glaser, 1969; Grbich, 1999; Holloway & Wheeler, 2002; A. Strauss & Corbin, 1998). Grbich described the three types of codes used sequentially to build theory using constant comparative analysis; 1) *open*, 2) *axial* and, 3) *selective*[27]. Open coding refers to the initial line by line analysis of the transcript where a concept emerges; each incident is compared with other incidents. The important feature of open coding stated Holloway and Wheeler, is the accurate reflection, or illumination, of the data in each category, not the development of a preconceived notion. Table 5.3 provides a selected example of how data from the transcripts became an open code category.

Table 5.3

Example of formation of open codes

Example from transcript	Open code category
(Client B) is more feminine; soft, gentle calm, he becomes emotionally upset.	Expressing femaleness
Not comfortable discussing sex with men	A female boundary
Male staff offer a different kind of interaction	Male banter
Being a man is another world	Unique maleness
Better to have males around in case sex comes up	Positive qualities as a carer

Axial coding is a process where a category in open coding is analysed intensively (Grbich, 1999); connections are made between each category and emerging sub-categories. Silverman (2005, chap. 12) equates this stage to “saturating” the category with as many appropriate references that can be identified in order to demonstrate relevance of the category. An important feature of axial codes are their connection with

---

[27] Appendix 8 contains a tabular example depicting how the three types of codes build minor themes toward the final major theme/s.

the researcher's *a-priori* and *a-posteriori* perspective and with the empirical evidence as identified in the literature (Holloway & Wheeler, 2002). That is, categories do not necessarily need to belong to the researcher; they can be drawn directly from the literature if necessary. Table 5.4 provides a selected group of relevant open coded categories and how they were linked to form an appropriate axial code.

Table 5.4.

Example of formation of axial codes

Cluster of open-coded categories	Axial code category
Self-pleasuring; sexual	**SELF-DISCOVERY**
Self-pleasuring; non-sexual	
Stimulation from procedure	
Stimulation reliant upon others	

Selective coding provides the researcher with a validation of relationships between codes (Grbich, 1999). It is at this stage where the data, via the stages of coding, begins to be conceptualised into a theoretical framework (A. Strauss & Corbin, 1998). The conceptualisation Strauss and Corbin refer to centres around the identification of a *core category*, or a *core variable* (Holloway & Wheeler, 2002). That is, the variable relates to each and every category and is interwoven and identifiable throughout the data; the core variable becomes the storyline. Strauss, 1987 as cited in Holloway and Wheeler, claimed the following major characteristics of the core category/variable:

1) It must be the central element of the research related to other categories and explain variation
2) It must recur often in the data and develop as a pattern
3) It connects with other categories without a major effort by the researcher
4) In the process of identifying, describing and conceptualising the core category develops
5) The core category is usually fully developed only towards the end of the research (p.160).

The final stage of a grounded theory approach is the integration of the conceptual category/ies toward a theory which has *explanatory power* (Grbich, 1999; Holloway & Wheeler, 2002). A further draft framework was constructed where each axial code was framed into a selective code around the emergent notion or a core variable labelled "individual sexual development". Figure 5.4 illustrates this draft framework with the existence of only partial explanatory power but, despite its flaws, nonetheless a considerable development from the framework illustrated in Figure 5.3.

What was primarily missing from Figure 5.4 was an adequate explanation that "… helps toward specifying conditions and consequences, at every level of scale from the most macro to the micro, and integrating them into the resulting theory" (A. Strauss & Corbin, 1998, p. 161). That is, Figure 5.4 lacked the explanatory power that tied the numerous variables together into a cohesive theoretical framework. Therefore, I returned once again to the data and attempted to locate clearer links between codes and what those links might mean. Moreover, I also returned to the literature to utilise those facets of the literature which assisted the opaque series of continuums from Figure 5.4, to become clearer. The resulting, and final, framework titled *Conditionally Sexual* will be presented in the next chapter.

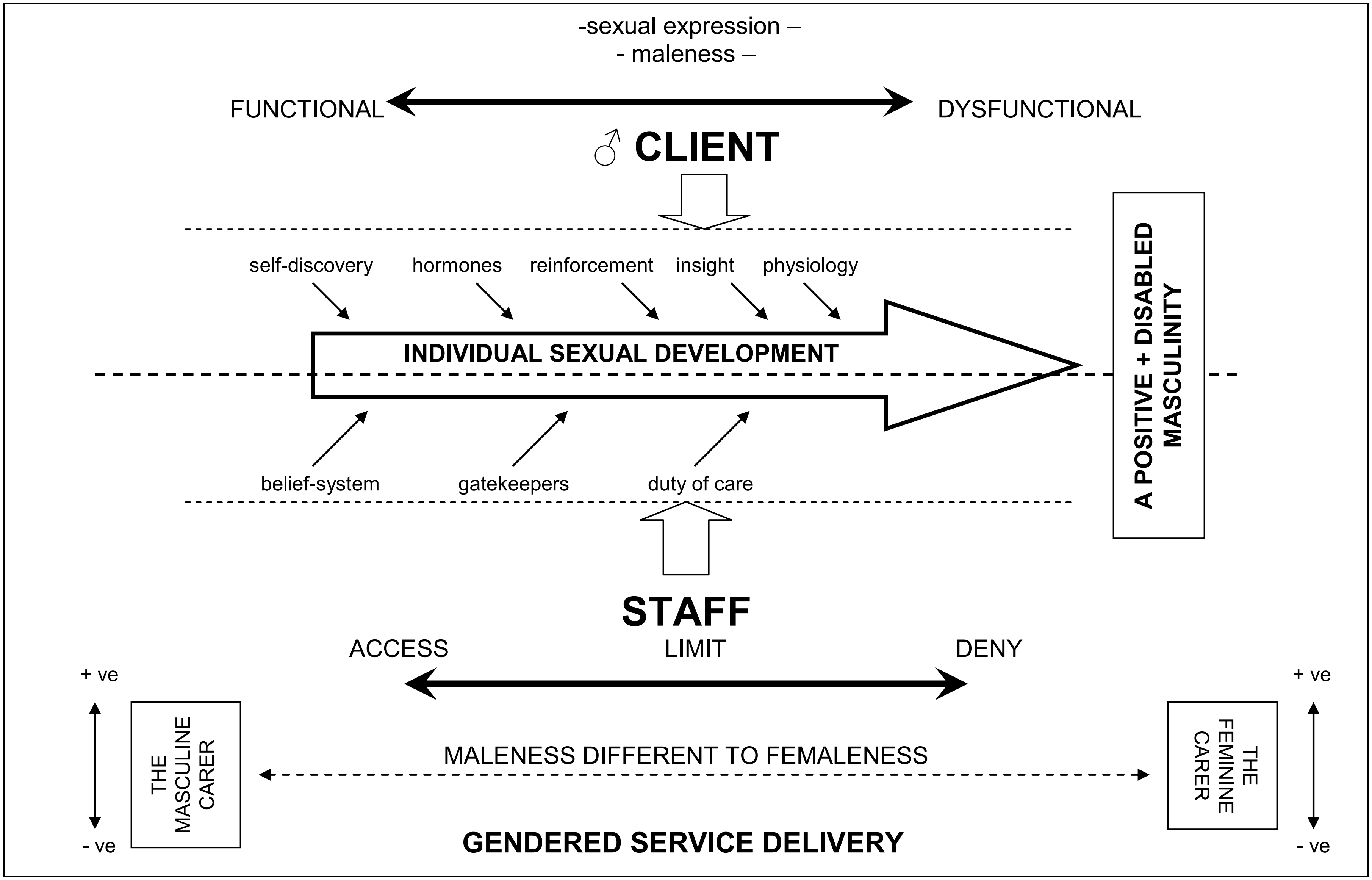


Figure 5.4

Individual sexual development, draft

SUMMARY

This chapter has described how the research process was conducted. In particular this chapter provided an in-depth summary of accessing the field, how the research tool was designed, and the process of collecting data from observation and interviews. Significantly, this chapter has also set out why the constant comparative method was the most appropriate way to analyse data. Furthermore, an account has been given of how the constant comparative method was progressively used to generate a conceptual framework presented diagrammatically in Figures 5.3 and 5.4. Figure 5.4 represented a significant structural analysis of the data but still lacked explanatory power. A final diagrammatic framework which illustrates the data and has the explanatory power that Figure 5.4 lacked, will now be presented in Chapter 6. Chapters 7, 8, and 9 will then deconstruct the three main interconnected themes of the framework.

CHAPTER SIX

CONDITIONALLY SEXUAL

This chapter will present the data and its analysis via a model and through textual discussion. The modelled representation of the data, illustrated in Figure 6.1, evolved from Figures 5.3 and 5.4 using the constant comparative method discussed in Chapter 5. The model, ***Conditionally Sexual***, represents the data, contextualised by the health environment, the service system, and socio-cultural perspectives of masculinity. The model was verified by three randomly selected interview participants as having an explanatory power that echoed their perspective.

Participants described the notion of men and teenage boys with a moderate to profound intellectual disability as being **Conditionally Sexual**. This notion, driven by intellectual and/or physical impairment, was entrenched not only in staff perception and the reality of impairment, but also in the historical taboo associated with sexual expression by people with an intellectual disability. Summed up by one staff member as *“It’s limited … a limited sphere of participation”*, **Conditionally Sexual** referred to staff responses such as “*education … depending upon cognitive function”; “masturbation … but only if that’s possible”; “understand feelings … if they are able”.* **Conditionally Sexual** was framed by three interconnected themes: **1) sexual development, 2) conditionally masculine** and, **3) gendered service delivery**. **Sexual development** was constructed by two variables; individual factors, and staff influence. **Conditionally masculine** was constructed by the underlying themes that masculinity was positive, mutable and unique. **Gendered service delivery** recognised a masculine and feminine perspective to providing care. These three interconnected themes will be discussed in detail in Chapters 7, 8 and 9 respectively.

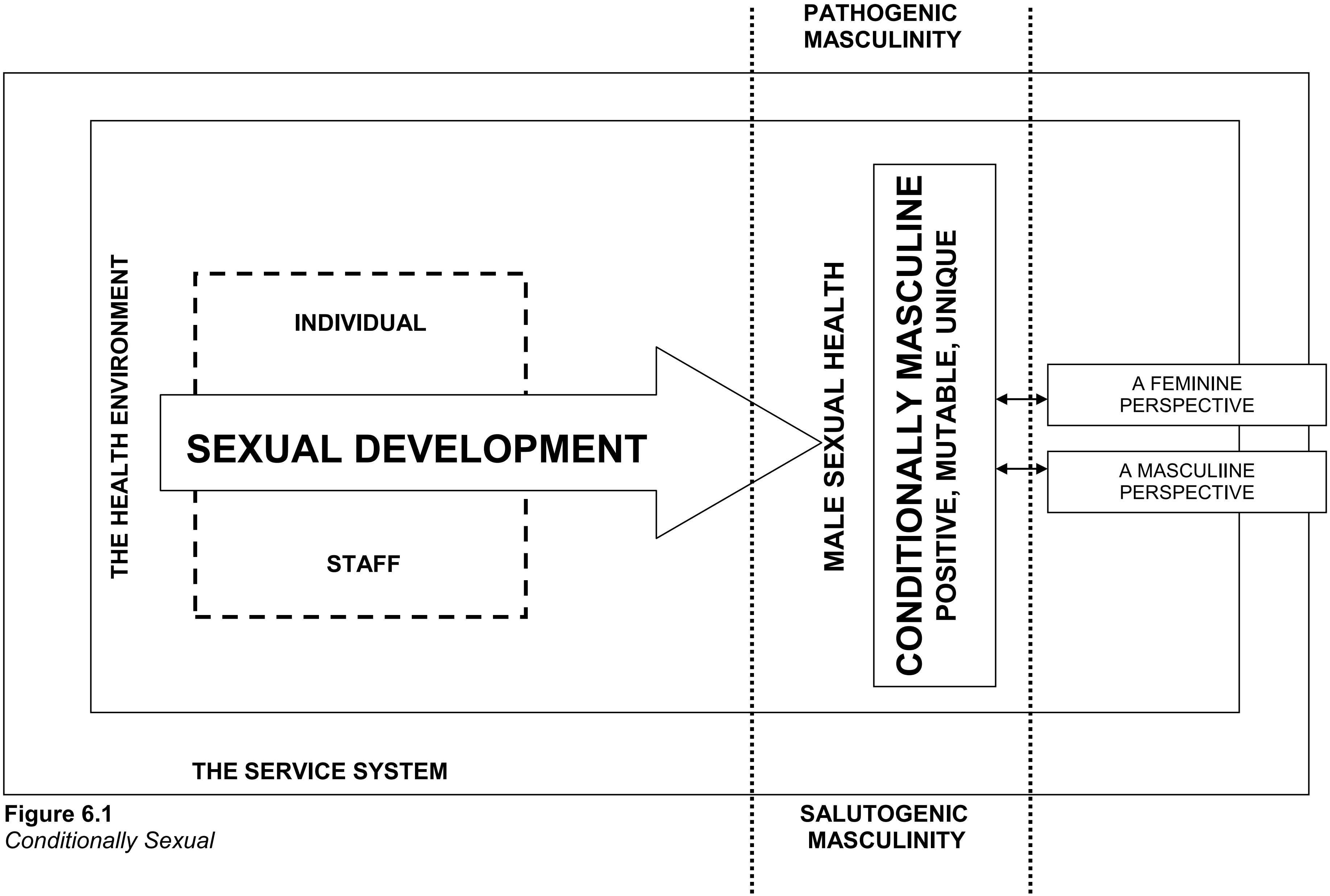


Figure 6.1
Conditionally Sexual

The following story is intended to illuminate some contextual aspects of the lives of the men and teenage boys with a moderate to profound intellectual disability from this study and the role support staff play in their life. It is intended to provide an insight into the meaning of **Conditionally Sexual** as portrayed to me through the data. This story, about Peter (a pseudonym), a 16-year old teenage boy with a profound intellectual disability, is constructed mainly from observation data, from some of the interviews, and from my own experiences. An acknowledgement must go to Chris Atkins for this ethnographic idea; Chris' summary of *Patrick's Day* (Atkins, 1998, pp. 127-132) in her doctoral thesis proved particularly instructive to my coming to understand quality of life for people with severe multiple impairments and the power of ethnography in seeking to understand more about vulnerable populations whose communication is limited. Peter's story is an attempt, through my eyes, to describe the context in which his sexual health might be experienced by him; whether this attempt is close to the truth or wide of the mark is open to conjecture. All names other than mine are pseudonyms.

SNAPSHOT OF PETER'S DAY

It is in the morning. I am sitting outside, under a covered patio situated just outside the double glass dining room doors. I am in my wheelchair slouched down without my lateral supports and feet straps secured; I am comfortable and I can move my legs about. It is an extremely hot day typical of Western Sydney in summer but I am protected from the sun by the patio roof. The heat however remains intense. I am dressed in shorts, t-shirt, shoes, ankle foot orthotics, and long socks. I am sucking my fingers, which I usually do, while I roll my head around and make noises; my finger nails are very long and have not been cut for some time.

Caroline is sitting next to me in her wheelchair; we are faced away from each other. There is no interaction.

We are both absorbed in our own world; no-one is talking to us, there is no music on, there is the sound of birds and distant cars, we are facing the brown Colourbond fence which is about 3 metres away. There is a narrow strip of green Astroturf between us and the fence. A neighbourhood dog barks occasionally.

Nathan comes out from the dining room and says hello to both of us; I acknowledge Nathan with eye contact, but without a smile or any other facial expression. Caroline performs her customary laugh and smiles at Nathan when he says hello to her.

Nathan goes back inside; I can hear him chatting with the staff and the others who live here with me.

After a while Nathan comes back out and wheels me inside the house for a drink. Mary, one of the female staff who has known me for five years, suggests Nathan sits the wheelchair next to Rebecca, who is sitting in her wheelchair, near the dining table. We are now faced toward the double doors of the dining room, looking onto the patio where I was sitting previously.

I start to cry and suck my fingers and roll my head around more than usual. Mary comforts me with a hug and kind words then takes off my shoes, socks and Ankle Foot Orthotics. Mary thinks I am a little too hot and by taking my footwear off I will feel better. I am still crying.

Nathan offers me my drink; he thinks I am thirsty and overheated from sitting outside so a drink may make me feel better. I can’t drink myself so Nathan gives me full support. I let Nathan know when I want my next mouthful as I open my mouth. I drink between cries; tears are running down my cheeks. The drink is cool and refreshing but still I am crying. No-one knows what is wrong with me. Mary gets a damp cloth and wipes my forehead and neck, again to try to cool me down. I continue to cry.

After my drink Nathan asks Mary if I can go back outside, Mary agrees so Nathan wheels me back to where I was before.

Nathan notices me sucking my fingers and wonders if my long nails are irritating the inside of my mouth; perhaps this is why I am crying. Nathan goes back inside then returns with nail scissors and plastic gloves on. Nathan cuts my finger nails and toe nails, talking to me about how long they are and how I might feel better after they are trimmed.

I am now sitting back where I was outside but with nothing on my feet and with trimmed nails. I am no longer crying and am happy enough to sit and suck my fingers and kick my legs. It is still very hot. I am happy again so I am left alone once more.

After about half an hour, Nathan comes back out again and tells me it is time for lunch. Nathan wheels me inside back to the dining table that looks out over the patio. Nathan slowly feeds me a tuna pasta dish that has been re-heated in the microwave. I eat it very quickly so it must be nice. Nathan then gives me two drinks of cool cordial instead of the usual one as it is a hot day; I drink these quickly also.

After lunch, Nathan, Mary and Margaret (another staff member who has known me for years) are discussing why I was crying and trying to decide amongst themselves what it was that made me feel okay again and stop crying. They have no idea why. I can’t tell them why. They try to include me in the discussion but it is one-sided. I must feel better as I am cooler, have been fed and watered, now have short nails, and most importantly I have stopped crying. I can’t tell them why: I stop crying therefore I am now comfortable and happy.

I don’t cry very often, maybe once a month or so. Once when I was crying it was because my testicles were compressed too tightly in my nappy while I was strapped in my wheelchair. My wheelchair is designed for a very secure fit so I can retain as good a posture as my bones and muscles will allow. I am usually secured across the shoulders, the waist, lateral supports next to my ribs, straps for my feet, and a large tray to keep my arms in a good position.

Mary and Margaret now take me to my room to change my nappy and then let me lay on a mat on my bedroom floor. When my nappy comes off I usually, straight away, try to feel for my penis; my penis becomes accessible during nappy changes. It only takes the staff about one minute to take off a wet nappy and replace it with a dry one. That's one minute about 4 times a day I get to access my penis if you don't count my five-minute daily shower. Staff control my access to my penis. I really like lying on the floor as I can roll around free of the restraints on my wheelchair. It does not take long for me to start kicking myself in the groin with my heels. The staff know I like this stimulation to my groin as I become more vocal than usual and my facial expressions tell them I am happy.

THE THREE THEMES OF CONDITIONALLY SEXUAL

1) Sexual Development

While Peter's story provides an ethnographic insight, it was but a brief snapshot of his life seen through my eyes and he was only one of the males living in the community group homes. All of the clients, whether male or female, have their own story too. Staff described sexual development as an ever-evolving and changeable feature of chronological growth over the lifespan. Sexual development was described as a central feature of being disabled albeit the development is conditional upon intellectual disability. Sexual development comprised variations in cognitive, emotional, physical, anatomical, hormonal, functional, and social development. It related to developmental milestones met and milestones not met. It was constructed against comparisons of normative societal expectation of self-exploration, sexual experimentation, relationship formation, marriage, and childbirth. The description of sexual development also extended to the influence of staff, the environment, the sector, and society towards people with an intellectual disability.

However, the influence of staff on aspects of sexual development was quite pervasive compared with the influence, for example, of society. Peter's story introduced the idea of an "accessible penis" and staff having complete control over Peter's access to his penis. This control is not sought or desired; it is not constructed by staff through their position of power, but by the powerlessness arising from Peter's intellectual and associated physical disability. Staff are forced to assume responsibility to either deny, limit or give access to the opportunity of self-discovery based upon their own personal and professional perspective. Institutional pressures, such as time, constitute other factors as do the needs of other clients. Indeed it is an unenviable situation, but one which confronts those in a carer – cared for relationship such as this.

2) Conditionally Masculine

The theme *conditionally masculine*, tightly interconnected with sexual development, allowed the study data to emerge toward greater meaning in depicting the men and teenage boys in this study. That is, male sexual health is about being both a sexual and masculine being. Staff referred to masculinity specifically as a conditional construct, as a divergence from the normative masculine ideals of strength, function, capacity, achievement, and physicality. In contrast, the men and teenage boys in this study fall short of these normative ideals and hence their masculinity remains conditional; their masculinity is shaped by impairment.

The concept of *Conditionally Masculine,* however, was not simply constructed through failure to achieve the normative ideal. Instead, *conditionally masculine* is constructed by acknowledgement that masculinity changes over time and context; it is not a fixed definition but a creation of different features. While masculinity can be shaped by any number of factors, conditionally masculine, although divergent from hegemonic exemplars, is simply a different masculinity still imbued with positive and negative ways to do maleness. For example, disabled male strength was viewed as both a positive and negative trait depending upon context. Disabled male sexual expression likewise is viewed differently depending upon context. A disabled masculinity was also constructed by the underlying principle that maleness is uniquely different from femaleness.

3) Gendered Service Delivery

Staff were not directly asked for their views on the clients' lived, or health, environment; the community group home. Data about the environment were collected at each visit to the community group home and included observations of the built environment, the geographical environment, the accessible environment, the support environment, and the personal environment. However, these data were not a comprehensive analysis of life in a community group home; they reflected a contextualisation of male sexual health.

The health environment was quite contradictory and impersonal at times, yet it retained the capacity for an intimate and empowering exchange. The environment was neither accessible, nor inaccessible. It was neither inclusive nor exclusive. There were aspects that were quite unpleasant and others very pleasant. It was neither male-unfriendly, nor was it male-friendly. The health environment was best described as a “compromise”; a compromise reflected in Shakespeare’s (2006) assertion that disability is a complex interaction with the environment. Shakespeare argued that because disability is connected to intrinsic disadvantage, it is not possible to entirely eliminate this disadvantage. The men and teenage boys who reside in the accommodation settings of this study have such significant intellectual and communication impairments that their capacity to enjoy full citizenship and membership of their local community is perhaps unrealistic. These males are in the community, but not part of their community. As Shakespeare reminded us, “…ending disablism … will not solve all the problems of disabled people” (p.65).

Summary

Sexual health for the men and teenage boys in this study is defined as the intersection between sexual development, conditionally masculine, and gendered service delivery. This notion has been labelled **Conditionally Sexual**. The model presented in Figure 6.1 represents the data and has been developed using qualitative data analysed by the constant comparative method of grounded theory (A. Strauss & Corbin, 1998). The model includes a summation of masculinity theory and how it intersects with sexual health for men and boys with an intellectual disability. Chapter 7 will deconstruct the notion of **sexual development**, Chapter 8 will deconstruct the notion of **conditionally masculine**, and Chapter 9 will deconstruct **gendered service delivery**.

CHAPTER SEVEN

SEXUAL DEVELOPMENT OF MEN AND TEENAGE BOYS WITH A MODERATE TO PROFOUND INTELLECTUAL DISABILITY

These day's sex and sexuality are both a public yet intensely personal part of life where, on the one hand, there can be strict codes about what's right and wrong, and yet, on the other, it seems that anything goes. Having a clear sense of what sexuality means for us as individuals, and being content with that, contributes to our enjoyment of happy and fulfilled lives. If the reality for most of us falls a little short of that ideal, then consider the situation for people with [intellectual] disabilities. For them sexuality is only mentioned as an „issue', a „problem' where a need to know is discouraged and basic rights can be subtly denied. (Drury, Hutchinson, & Wright, 2000, p. 3)

Sexual development is the first theme of men and teenage boys with a moderate to profound intellectual disability being *Conditionally Sexual*. Sexual development is both a perspective and an observable reality. It is observable in changes to size, behaviour, emotion, interaction, and physical features; it is also observable when these are absent. It is a perspective of those who work as a carer; a personal, gendered, and professional perspective constructed by morals, beliefs, ethics, feelings, fears, codes of practice, policies, and experience. Sexual development is neither sexuality as an exclusive socially constructed phenomenon or sexual health as an exclusive bio-medical reality. Sexual development hovers between constructed meaning and positivist truth; it is a biopsychosocial construct built from a combination of biological and genetic footprints, social factors and the emotional-psychological impact of the health environment. Disadvantage, because of intellectual disability, is intrinsic in sexual development. Sexual development is illustrated by the blue shaded area of Figure 7.1.

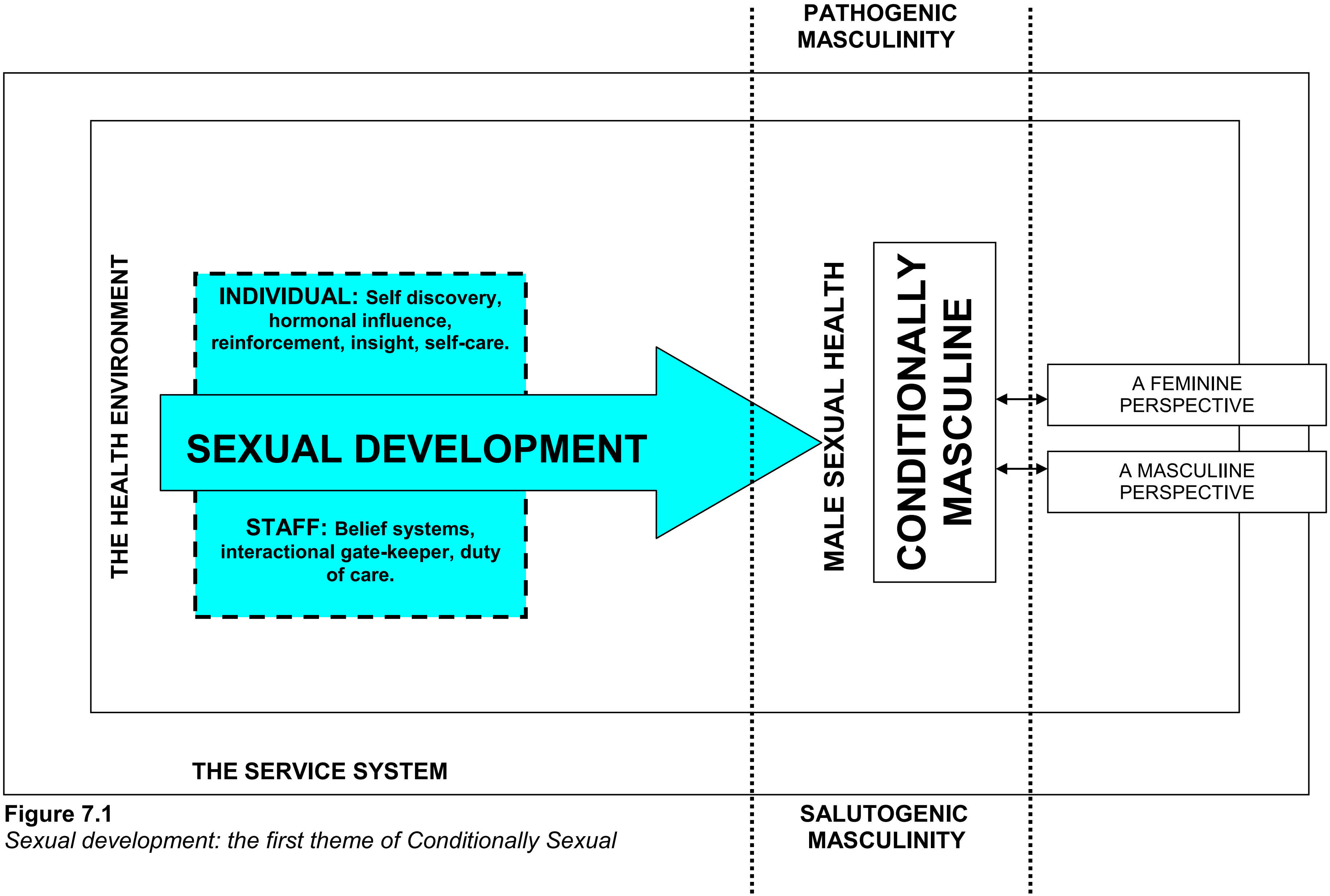


Figure 7.1
Sexual development: the first theme of Conditionally Sexual

THE INDIVIDUAL

Using the constant comparative method described in Chapter 5, five axial codes were identified from the data which related to individual sexual development. While each of these categories will be described below as separate sub-themes, they are in fact interdependent. These five axial codes are shown in Figure 7.2.

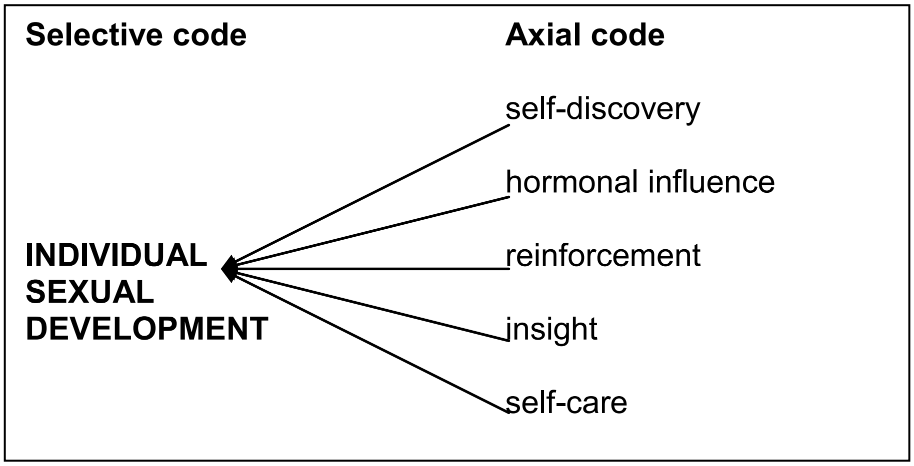


Figure 7.2

Axial codes for individual sexual development

1) Self-discovery: “It’s not a dirty thing … more exploratory”

Staff described a range of behaviours, responses, and tasks that were labelled as self-discovery; learning more about oneself. Self-discovery was not only limited to self-pleasuring and self-stimulation, but also to procedural tasks staff performed. That is, stimulation as the central action of self-discovery could be received either from oneself or from others. Therefore, not all self-discovery was defined as sexual in nature as some data were clearly described as non-sexual; on a sexual/non-sexual continuum.

The data presented a range of behaviours which staff described as sexual: masturbation, anal stimulation, kicking perineum, and masturbating in *"…not the usual way"* such as rubbing one's penis through trousers and rubbing one's penis against furniture. Less usual ways to masturbate are reportedly common where hand action is limited and a strong drive exists to find an effective method to self-stimulate (Joseph, 1991). One study by Kaeser (1996b), which included the sexual behaviours of 1288 adults with a severe or profound intellectual disability, reported a wider repertoire of less usual ways to masturbate including "… rubbing ones genitals against hard objects, such as sticks, forks, shoes, toilet seats floors, cars and washing machines … and banging one's penis against walls" (p.314). Where associated physical disability does limit movement, certain times during the day become opportune in the desire for self-discovery: *"… because he is not able to touch himself, because of the clothes that he has on and the limited dexterity he has, leaving him in the bath … and supervising from a distance … he does respond to that time … it's a needed and healthy time … like [the other male client] its hard to say if it's a sexual thing or an arousal thing"*. The range of sexual behaviours identified from the data were more limited than found in other studies; not found were behaviours such as kissing (McConkey & Ryan, 2001), anal intercourse (Kaeser, 1992), self-injurious masturbation (Robison et al., 1992), and, unfulfilling masturbatory technique (Shelton, 1992).

The range of sexual behaviours displayed was described from a positive viewpoint: *"… they have needs just like anybody else … you try to cater to suit their needs … respond to their individual choices … protection … rights … I suppose, giving them privacy"*. One younger female staff member stated sexual expression was *"… important in their life, I think it makes them an individual'*; another female staff member stated: *"… I* *don't think their needs are [any] different [to men without an intellectual disability]"*. There was no direct evidence of behaviours and/or opinions which reflected the pathological discourse described by Cambridge and Mellan (2000), probably because the behaviours of the clients' in this study were quite benign. Compared with her experience working with more able male clients, one staff member felt at this organisation sexual issues were *"… not a big thing at [organisation]"*.

One of the male clients, a teenager, displayed a range of behaviours which staff described as non-sexual self-pleasuring. Behaviours included gentle rubbing of the skin and hair across his body, this male client also elected not to wear much clothing irrespective of seasonal variation: *"he does lots of other things that are purely sensory focussed: scratching his arms, grabbing your hands to squeeze his head that kind of thing, so he does other things that he finds enjoyable"*. Staff felt these behaviours were not sexually motivated as there was no consistently observable origin, or trigger. Additionally, this male client would just go and masturbate if he wanted to. During observations there were ample opportunities to observe this male client perform such non-sexual sensory stimulation. Quite often he would lie on the ground in front of the TV with no shirt on and gently run his hands over and around his body; occasionally his hands would wander down his trousers which, from my perspective, mirrored the staff members description of non-sexual stimulation. He was simply hanging out watching TV and enjoying his own company in his own home. Indeed, Jourard, as cited in Coon (1986), claimed bodily touch confirms our embodied existence; "people need physical contact to increase awareness and sensitivity to the body" (p.587); such non-sexual touch, if needed by this client, is only going to be provided by himself.

The data also introduced the notions of non-sexual stimulation from care procedures; that is, not described within the context of consent or abuse. Non-sexual stimulation from a care procedure related to clients who were totally dependent on staff for personal care tasks such as penile hygiene: *"… he needs to be washed thoroughly, you push his foreskin back … each time I shower him he gets an erection … so you gotta wait, wash the rest of him wait till it [erection] goes down"*. One older female staff member referred to a teenage female client appearing to derive non-sexual stimulation when female staff attended to her intimate hygiene needs; the female client's verbal responses and facial expression indicated to the female staff she was deriving some form of stimulation/pleasure as they were wiping her perineal region. The female staff found this professionally troubling as they realised their actions were potentially causing a sexual reaction, however framing it as non-sexual stimulation gave the staff an element of security. This issue relates to both males and females and indeed, what should staff do? There is very limited guidance or discussion within the literature except in terms of the consent/abuse dichotomy. Viewed solely from the perspective of the client as intellectually and functionally dependent upon a powerful carer (e.g., Cambridge & Carnaby, 2000) this dichotomy remains at the forefront of the interchange. However, such a perspective also places the carer in a powerless position where their non-sexual action potentially becomes sexualised based upon the clients' response viewed within the framework of this dichotomy.

Cambridge and Carnaby (2000) suggested addressing this issue via open discussion of individual support needs; such a discussion may often only reinforce staff empathy or discomfort with the erection. This approach, however, only focuses on how staff might react in a safe and valued way; there is limited appreciation of the issue for the client, as self-discovery, and what the client response (e.g. erection) might be communicating. That is, the issue is rendered staff-centric; staff are forced to respond reactively instead of working with a proactive approach toward a focus on what the client might want (Hingsburger, 1994). Quality of life work for people with profound and multiple intellectual disabilities might offer one solution to ensuring a client's need for self-discovery is respected. In such work there is an emphasis on interactions with clients using their limited repertoire of responses to identify likes and dislikes, emotions, thoughts, fears; their subjective quality of life (Atkins, 1998; Lyons, 2005). One staff member touched on this idea claiming; *"... I'd love to know how he feels … I'd love to see how his mind works"*. However, there is currently no philosophical or ethical framework to guide staff in reacting to an erection in a meaningful manner; a response which takes into consideration their subjective sexual development and staff safety. Instead, as one participant suggested about sexual issues: *"… it's dis-encouraged in the industry, because it's, sort of, easier not to go there"*. This philosophical and ethical hiatus toward sexual issues has been described as a professional inertia (Kaeser, 1996a) that leaves these clients and their subjective sexual development, via the right to self-discovery, in an indeterminate state.

Some male clients who were more physically and intellectually able actively sought physical contact with female staff which was framed as another form of self-discovery: "… *he … knows that females have got breasts and he'd like to cuddle, and put his head into your breasts … in his own little way he maybe knows that females are a little bit different to males … I don't think it's sexual … I just think it's like a cuddle, getting some motherly comfort …. that doesn't bother me, as long as he doesn't hurt me that's fine"*. Another female staff member mentioned a male client in his early twenties who attempts frottage on some of the female staff from behind: *"… lately he has had, I would say sexual behaviour … we have a female client here, he'll grab her on the boob, or grab her on the butt … occasionally we've have had [female] staff bending over and he'll walk up behind them and [staff member motions frottage action] … but not in a dirty [sexual] way … it's more in an exploratory way … I don't think he has the capacity to understand „dirty' in the way that normal social circles govern that … it's self-discovery and probably trying to discover what's going on, you know, with the opposite sex"*. Another male client, a teenager, displays different behaviours of self-discovery: *"... occasionally we've had a few people say he'll get down on his hands and knees actually up against this [staff member motions to chair/her leg] … and rub his groin … kind of doggy-style, and I think that's purely instinct because he is severely intellectually disabled'*. The extent to which these behaviours are viewed as exploratory, as opposed to inappropriate, largely rested on the degree of intellectual impairment: *"… inappropriate touching maybe from their behalf, [inappropriate] because they don't understand" NW: inappropriate touch as in sexually inappropriate? "That all depends on the views that they would have I would assume … what they feel or think that is happening in their mind … I don't see it as that [sexual intent]"*.

Certainly, other research has found the greater the level of disability the more tolerant female staff are of such physical contact (D. Thompson et al., 1997). There are two pivotal points here; the first that such a sympathetic view may not be shared by incoming staff which may confuse male clients. Second, it has been suggested a deprivation of love and warmth within service settings can lead to problems as well (Cambridge & Mellan, 2000), so if the behaviour is not sexual, is it simply an expression of love and warmth? Either way, there is no resolution that may guide staff or help the male clients. Staff should foster an environment of warmth, but are staff setting a male client up to fail by allowing them to attempt frottage from behind them and simply casting it aside as a form of exploratory self-discovery?

2) Hormonal Influence: "It's more an arousal thing"

Hormonal influence on sexual development was framed within the recognition of a biological sex-drive, natural variations in hormone levels, and hormonal changes across the lifespan. Hormones were referred to, to illustrate both excessive and limited sex drives; hormones were framed causatively as they gave staff a degree of explanatory power for client sexual behaviours and staff's response to them.

Staff described the influence of hormones to the sexual health needs of the men and teenage boys in this study. For example, a male client who tended to wear few clothes became frequently aroused because of an intrinsic teenage sex-drive and easy access to his penis due to limited clothing; as a result his hormonal urge *"… is there to be aroused"*. Other participants suggested *"… they have the same [hormonal] feelings but … do they understand what these feelings are about? … you know, they obviously feel the same requirements that we would but they can't tell us, they don't know what it is".* One younger female staff member linked this lack of insight into hormonal urge as feelings that can be displayed physically when a male client may try to inappropriately touch female staff: *"… they do, they want to touch, they want to do this [touch me], but I brush it off … and leave well enough alone"*. Hormonal urge was also used as an explanation to trivialise the frequency of young hormonal males sustaining regular erections: *"… he's got an erection 98.9% of the time so it's not such a big thing for us"*. While this teenage male client was given the scope to respond to hormonal urge, other males with a similar urge might not be afforded such understanding: *"… different sexual needs as well come into it … someone might be overly sexually active … he's discouraged more because they're [staff/the sector] a little bit afraid of what he might ... he might cross boundaries"*.

Staff seem to be suggesting sexual behaviours can be contextualised physiologically via acknowledgement of a basic sex-drive; Wheeler and Jenkins (2004) stated a strong sex-drive, or sexual desire, can be behind some sexual behaviour constructed as challenging. While this is in itself not an unusual proposition, it is less usual for sex-drive, or recognition of biological factors, to form part of the sexuality discourse discussed in Chapter 2. For example, framed by their assertion the sexual behaviours of males often result in an aversive response from others, Cambridge and Mellan (2000) recommended opportunities for males to "talk about" and explore "emotions and feelings" as one way to contextualise sexual behaviours. While this recommendation has obvious limitations for males with poor communication skills, staff are suggesting a hormonally-driven sex-drive perhaps goes beyond "emotions and feelings". The data are suggesting need/urge can be a source of an observable behaviour/action; this pathway is being constructed by staff within a positive and normative frame.

Hormonal change was also intrinsic to individual sexual development. Changes in the frequency and potency of erections across the 24-hours, including morning erections stimulated by male hormones and nerve reflex, are one sign of hormonal changes during puberty (Watters & Carroll, 2001). One participant felt *"… first thing in the morning seems to be a key time for these guys [getting an erection and masturbating] … it's normal, my brothers did that … out of respect I just close the [bedroom] door"*. For another male client night time was evident: *"He has to have his quiet time … quite often* *you're on night duty you can hear him, awake in his bed [masturbating], I just let him go … lets face it, it's a normal thing, a comfort thing … he's a male and he's … [doing what] boys do".* For older males, the influence of hormones was less visible: *"… he's an older man now … so they have less sexual [needs] … for a younger person, I think, it's much more of an issue"; "… I don't think he has a wide scope of sexual needs, his [older] age and his disability, probably, preclude him from conceiving any kind of sexual relations, or desires, or whatever".* There was also concern raised about potential future growth when younger adolescent males become bigger and stronger men: *"… I think we should be addressing all those [sexual] issues …. we should be looking at the fact they will have sexual needs [as they grow] and how are we going to address that ... would it be safe to promote that or should we sort of hide it behind the cushion"*?

3) Reinforcement: "If something makes you feel good, it feels good".

Reinforcement was described within a biopsychosocial context; where a physiological and/or emotional dividend from sexual actions provided a reinforcer. Staff also described a range of interpersonal interaction, such as hugs, that, for some males, was reciprocated and subsequently reinforced by staff as a non-sexual interchange of mutual regard.

On a physiological level, reinforcement referred to the perception of derived comfort, release, intimacy, sensory stimulation, touch, and pleasure: *„…if it feels good, let him do it'.* The opportunity to *"feel good"* as a result of masturbation also had wider benefits; *"If you let him have his free time [to masturbate] his behaviours are better, the behaviour of putting his hands down his nappy and up his bum …. he has had the opportunity to work out his frustrations [by masturbating]"; "For someone that is … low* *functioning … doing something like that [masturbating] will make them feel good and will get rid of anger … the way you're feeling, the bad feelings"*. This suggests there is some kind of a physical/behavioural release to be gained from successfully masturbating which extends beyond the cycle of sexual arousal, plateau, orgasm, and resolution described by Cerver (2000). The suggestion by staff here is that a potential reinforcement exists for successful masturbation leading to calmer day with fewer challenging behaviours. *"A lot of behavioural issues may stem from a number of factors, [unmet] sexual health [needs] could be one of those factors"*. An older female staff member provided an interesting comparison in her own life: *"If something makes you feel good, it makes you feel good – for the day, or for the evening, or for that shift … if you bought me flowers, that would make me feel good and I wouldn't have a bad day"*. Previous institutionalisation was also suggested as a factor in developing, then reinforcing, a sexual drive: *"a lot of them have been institutionalised all their life … [he] has been institutionalised all his life maybe that's why he always has to stimulate himself … their background probably reflects their behaviour now … apparently he has done that [masturbation] since he was a little kid … that's what makes him happy"*.

"Cuddles" and *"hugs"* were generally described as a positive and essential form of interpersonal interaction; there was a desire from most of the men and teenage boys in this study to seek physical contact: *"[He] loves physical affection"; "[he] loves cuddles and I don't have a problem whatsoever with giving him a cuddle"*. There also existed a belief that a certain diagnosis could predispose one towards affection: *"well, with the Down syndrome, they sort of want more of the cuddling, kissing and [being] affectionate"*. While there was a belief that mutually responding to hugs was a basic human need, there was also concern about the messages staff might send when this was denied. For example:

"the slightest show of affection for instance, normal things, you might come up to a guy and [motions physical contact/arm around shoulder] „how was your weekend'…. I've been in situations where contact was absolutely forbidden even if you just did that [arm around shoulder] … that is very negative ... [it's] detrimental to proper expression of a relationship … they recognise us as a significant other, they look up to us". A younger female staff member described the difficulty in being affectionate when a Government official who visits the house clearly stated it is wrong: *"… lately, [he has been] trying to get hugs from staff, he's always coming up and wrapping his arms around you … it's important for him, I suppose, to have some sort of … human contact … but um, the Community Visitor has come here and said „no', we've got to, sort of, push him away ... [then] with an email from his mother she said give him a hug for me"*. One older female staff member expanded on the need for human contact quite eloquently: *"They [clients] need it [cuddles / comfort]… they haven't got the parental contact, so they get it from the staff … and I think it's lovely, I don't mind it at all … it's also rewarding for the staff … that tactile comfort … not physical love, but like parental contact"*. However, the physical affection described by staff was generally initiated by the men and teenage boys in this study; staff were responding to that need and reinforcing it as an appropriate and mutually agreeable human interchange.

A slightly different scenario also emerged where one of the older male clients would often receive too much physical affection from female clients he lives with: *"… two in particular … they both dote over him you know, you know they'll come up and give him kisses and cuddles …..at times [he] will push them away and you know that … okay, he's had enough"*. During several interviews where this topic arose, an opposite hypothetical was put to the staff: what did they think might occur if it was two male clients being overly affectionate with a female client? The responses suggested a more aversive stance where the interaction may be viewed more as “harassment” with a range of punitive behavioural interventions the likely outcome. Clearly, physical contact between clients and staff can be problematic and fraught with difficulty. For example, teaching people with an intellectual disability appropriate self-protective behaviours is one way to minimise their vulnerability (Long & Holmes, 2001). While such strategies might be useful for people with an intellectual disability who can exercise a degree of autonomy over their relationships with others, for those who experience less autonomy, the theoretical ideal that all contact with the vulnerable should be avoided, diminishes their right to non-exploitative human intimacy to a lesser status. Furthermore, there is also the critique that hugging adults just because they have an intellectual disability reinforces their characterisation as the “eternal child”; Melberg-Schwier and Hingsburger (2000) suggested such a lack of cautiousness is underlined by the perspective the adult with an intellectual disability is not a “real” adult (p.28). While some staff did refer to the notion of the eternal child, this characterisation was not affiliated with giving hugs. Instead staff discussed mutual warmth and regard as the cornerstone of an ongoing therapeutic relationship.

4) Insight: “I suppose they do [have sexual health needs] … I’ve often wondered …. but, I find that hard to comprehend in someone that’s as intellectually disabled as [him]”

Insight referred to both understanding and recognising the emotive self plus feelings of inadequacy and frustration. The capacity for insight appeared as the fulcrum for the next stage of sexual health need; the point between cognitive incapacity and capacity.

A lack of insight was suggested as a reason why *"… someone that is low-functioning … unfortunately might find out the wrong way about sex … maybe when they're in institutions, or other group homes, because of the more higher functioning men [clients]"*. That is, a lack of insight infers vulnerability and, in turn, the need for protection as a vulnerable person. There was also a concessionary perspective toward their behaviours: *"… if he was … considered normal, I don't think he would behave in such a way [grabbing females on breast, bum]… I say that because his parents are church-goers and he would show much more restraint because he is autistic … because they don't understand … other people"*. Therefore, a lack of insight can get a person with an intellectual disability into trouble, just as it can get them out of trouble. For example, one male client, a teenager, who has started to grab female staff on the breast was excused due to the level of his insight: *"He does just grab you on the breast … but I think he doesn't know any better"*.

Education was mentioned again as a concessionary, or conditional, construct: *"…he has a lot of sexual need, he masturbates … but don't educate him to a level where he really wouldn't understand"*. Along this theme, it was felt any client would need to provide the first step or sign that they were ready to experience the next developmental level, or degree, of sexual expression: *"… if they can recognise it for what it is, sexual feelings are something you can't concoct … if it's not coming from the person themselves, there is no use imposing it on them …. you wait for their question … everything in life comes when we are ready for it … usually you see some kind of display of readiness, or eagerness in the form of a question, or some sort of action ... [if there's] no indication, leave it alone"*. Therefore, without cognitive insight which enables understanding and affords the person some autonomy, there was a fatalistic assumption that education was perhaps not required. In addition, where a person's disability also extended beyond cognitive impairment and included limited communication and function, their capacity to express such a need also lessens: *"… depending on their level of disability … may determine their level of functional ability … and their sexual health situation …. the more functional you are [it is] highly likely that your sexual health needs will be met ... [those who are lower functioning, their disability is] a barrier to being sexually active"*. Where developmentally appropriate cognition, function and communication were not taken into consideration, unrealistic desires might result from too much, too soon: *"... for people in mind-encaptured bodies it provides, it [e.g. exposure to pornography, media images etc.] could easily lead to them increasing desires that they can't have, which increases frustration, which increases a heightened sense of them feeling inadequate and not part of the community … you mix all that with minds that are unable to analyse things …"*.

This notion of impaired insight, because of impaired cognition, function, and/or communication, presents a real conundrum for staff. For example, the individual planning processes in each organisation were heavily focussed on age-appropriate life domains. Some female clients living in the houses underwent regular bodily hair removal, had make-up applied, dressed in fashionable clothing, had their nails painted, and experienced therapeutic massages. Yet, if we accept the argument described above, their level of cognition suggests they were not developmentally consenting participants in these age-appropriate gendered activities. However, if the notion of feminine hair removal and make-up is one way of sexualising female clients without their implicit appreciation, treating age appropriate sexual expression differently appears at odds with the stated aim of individual planning.

5) Self-care: "…the most important thing could be hygiene".

The final sub-theme of self-discovery related to male self-care referred to hygiene and preventative health checks. None of the staff mentioned testicular examination and only one female staff member mentioned a prostate check, partly in response to her husband recently undergoing this procedure. This lack of preventative health focus echoed the research findings of Servais (2006) who asserted "…there appears a dearth of research on sexual health status and practices of men with an intellectual disability" (p.55).

Data concerning penile hygiene were relatively comprehensive: *"… they can't look after themselves so the most important thing is, I guess, their [penile] hygiene"*. In particular, males who were incontinent and required incontinence pads needed to be *"…kept really clean, you gently push the foreskin down… the boy's get mucous from being in nappies… they're sweaty … you really gotta make sure you wash them properly because they're now growing pubic hair and they get faeces caught in them"'*. One male client who wears an incontinence pad 24-hours a day suffers from the occasional abscess, or infected hair follicle, on the shaft of his penis. Described as pimple-like lumps, they are apparently quite common and are no different to the same lumps found elsewhere on the body (Watters & Carroll, 2001). One female staff member did suggest time out of incontinence pads each day to breathe was beneficial but *"… time constraints, you know, what are we going to do if they make big messes? … because we don't have the proper equipment we don't do that"*. One male client suffered from recurrent penile infections: *"… he gets staph a lot … and thrush on his penis because he's not circumcised … we have to pay particular attention … because he's obese and he gets rashes and sores and quite a number of staph infections … it gets infected"*. In their study of personal care Carnaby and Cambridge (2002) found support staff did rate the more intimate tasks, such as penile hygiene, more negatively than less intimate tasks; such a preferential continuum did not appear evident in these data. However, in their other article on the topic, Cambridge and Carnaby (2000) reported staff viewing intimate personal care as either “routine” or an opportunity to provide the type of “empathic” quality care they would like to receive should the need ever arise; this more accurately reflected statements made by staff in the present study.

STAFF INFLUENCE

Using the constant comparative method described in Chapter 5, three axial codes were identified from the data which related to staff influence over individual sexual development. While each of these categories will be described below as separate sub-themes, they are interdependent. These data are closely linked with additional data covering the gendered differences between staff which will be presented in Chapter 9. These three axial codes are shown in Figure 7.3.

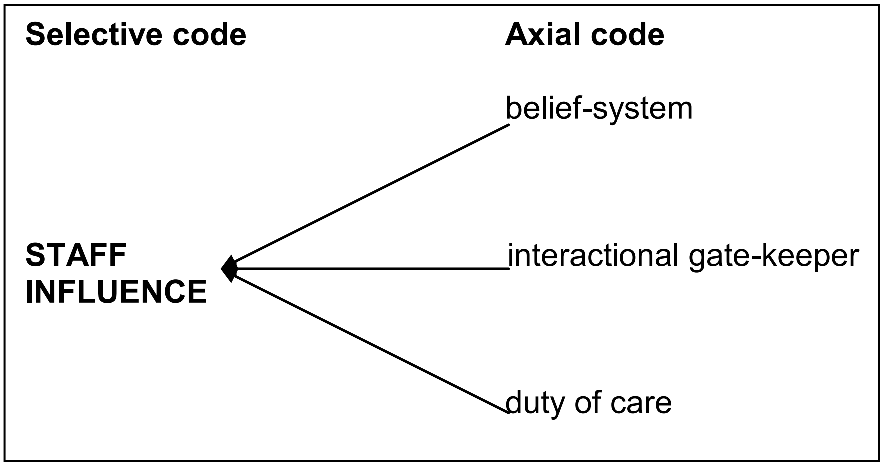


Figure 7.3

Axial codes for staff influence

1) Staff belief-system: "There is still a lot of restraint … people are still afraid of the subject [of sexual matters]"

More than any other sub-theme, this collection of data incorporates staff offering something deeply personal about themselves; it involves some of their feelings, morals, fears, views, and perspectives of male sexuality. This sub-theme suggested the views and opinions of staff can impose another barrier. In addition, a picture drawn from unique sex differences started to emerge when staff focussed on their own beliefs; that a feminine perspective might be different from a masculine perspective.

One younger male staff member suggested *"… they [female staff] feel potentially intimidated by it [one male client's sexual expression], and that combined with his continuing strength, he's continually getting stronger, so it kind of verges on, what will he become with all these issues amplified?"* While no female staff used the word *"intimidated"*, there was a definite anxiety about male sexual expression when combined with physical strength: *"When the boys get older what will we do then? They're getting older ... they're different to the females and they have different needs, like the independent time [to masturbate] that the girls don't necessarily need … these young men are … getting to an age when it does need to be addressed"*. The male participant who suggested some female staff feel intimidated felt this was evidenced by *"… female staff, I think, are more inclined to use his wheelchair, or use his room, or use the commode … to restrain"*. This method of managing male sexual expression and strength was evident during observation sessions where most female staff used the forms of legitimate restraint as suggested. In contrast, male staff actively sought to give this one particular male client ample time to freely mobilise; when this young man freely mobilises it resembles a primate-like gait on all fours. The following excerpt from my field notes, in Box 7.1, provides some context to the use of legitimate restraint.

Box 7.1

Field notes: controlling physicality

Client C spends the entire first part of the shift in his wheelchair strategically placed in the middle of the dining room where he has no capacity to reach or grab any object. He has nothing to play with nor any thing to occupy or engage him. The staff are busy with afternoon tea, cooking dinner, folding washing, reading notes, answering phone etc.

As the staff walk by client C they do acknowledge him and do stop to interact, albeit briefly, with lots of positive „good boy, you are a good boy', and so on. From my observation I can't see what choice he has but to „be a good boy' as he can't move, can't hold anything, can't do anything. His only choice if he was bored would be to somehow communicate distress as he has no other way of attracting attention.

I wonder whether this strategy used by staff is one of restraint or one of convenience or one of taking control where they fear they may otherwise lose control? Certainly he has been restricted, whether this constitutes restraint is another issue, all he can do is stick his hands down his pants ……..? The staff are not doing anything wrong as such; they are busy, they are active, they are not mistreating him but something is definitely missing.

Staff member A feeds client C his dinner where he spends a fair bit of time spitting at and on her. Some of this spitting is actually deliberate and is quite a sight to watch. She deals with it very well and takes a kind hearted view of it, but he is really letting her know he either does not like her, does not like the food or is generally unhappy. He does not end up eating much.

After his meal client C goes straight onto the commode; as usual the door is ajar so staff can keep an eye on him. He opens his bowels and masturbates as he does every night. Again he is restrained to the commode: other than the male staff telling me in an interview they make sure client C uses the toilet so he does not get restrained, no one else does this as far as I can tell.

Client C then goes into the bath where he performs his usual acrobatics and flings water everywhere having a great old time. When he is done he gets himself out the bath.

The potential use of pornographic material provided another diverse range of responses reflecting divergent staff belief systems. One younger female staff member felt using pornography was part and parcel of *"…being a guy"*. An older female participant felt *"R-rated videos, maybe porn to a certain extent"* might be a useful aide for some males with an intellectual disability. One younger male participant felt regarding pornography that *"providing illicit material … I think I would not want to go down that kind of path ... it's a whole new kettle of worms … it could have positives associated with it, but I can see a lot of negatives associated with it"*. Several male participants with a mild intellectual disability in the study by Yacoub and Hall (2009) reported viewing pornography regularly although this practice was curtailed for one participant as it was apparently offensive to a female (it is not clear in the article if this female was another client, a visitor, or a staff member). Certainly, the use of pornography has been caught up in changing social attitudes towards the exploitation of women (Cambridge & Mellan, 2000) however its potential efficacy as an assistive tool *"… if you were not able to engage in a sexual activity"* is unlikely to be ever assessed for men and teenage boys with a moderate to profound intellectual disability because of ethical and moral outrage provoked by their vulnerability.

Staff expressed a range of fears which were uniquely sex-differentiated; male staff reported a general fear of accusation and female staff reported a general fear of male strength. These fears reflect the gendered themes expressed elsewhere (Dobson, Carey, Conyers, Upadhyaya, & Raghavan, 2004; McConkey et al., 2007). While most of the discussion surrounding these fears will be presented in Chapter 9, two specific points directly link to the theme of sexual development and will be discussed below. One of the younger male staff, when asked what he though the sexual health needs of his male clients might be, believed he was *"… not allowed to think about it [any sexual issues] … a lot of it stems back to … a child protection meeting [mandatory training] … [which reinforced] they were clients, not your friends, they're clients so you should never put your arm around them, give them a hug …. and she [the trainer] really instilled fear in us that if you were to do things like this, you were a devious person and were you getting pleasure from it? I think they have sexual needs but they're not being met"*. Fear, triggered by this notion, drove this staff member to deliberately distance himself from clients and any sexual matter out of fear: *"I think my line of thought is that we are encouraged to distance ourselves … as a result of that I am not looking out for sexual needs, I am really just focussing on getting the basics done …. I am terrified of someone saying … „that looked a bit funny' … [for my post-university life] I have to be cleared to work with children"*. Monitoring your own professional interactions while at work instead of reacting more naturally reinforces distance and the theme "I'm a support worker, not your friend" (McVilly, 2000).

A young female staff member expressed a fear of males: *"… well, [the fear] probably comes from my past, I have been in an abusive relationship before … the fear of, a bit of a fear of males and violence, being in that situation before in my life"*. Another female participant relayed an experience from a previous job in the UK which further illuminated the notion of female fear. In this situation, a group of male clients' sexual needs were causing significant problems for them and their staff team: *"… before, where I used to work, we looked at the prospect of perhaps taking some of them to prostitutes ... there was quite a lot of differences of opinion with that … the Psychologist said „what they've never had they're not going to miss' … [another view was] if they [staff] did take them to prostitutes then they were „creating a monster' because that person then knew,* *they had enjoyed what they had and other girls and female staff were then vulnerable … they ended up, they didn't do anything?"*. Although there has been an ongoing philosophical consensus toward the sexual rights of people with an intellectual disability "to develop meaningful relationships" (e.g., Aylott, 2001), this example highlights how practice and philosophy remain distant bedfellows. Two distinct viewpoints highlight the challenge faced for males with an intellectual disability. To wit, although sexual surrogacy for males with an intellectual disability remains contentious for some when framed by male dominance over vulnerable women (e.g., Jeffreys, 2008), others argued surrogacy, or facilitated sex, for people with disabilities is constructed by them within the parameters of nothing less than access to sexual rights (Earle, 1999). For people with a physical disability and no cognitive impairment, although not without difficulties, such sexual matters remain less contentious.

There is a body of literature which suggests the individual attitude of support staff toward the sexuality of people with an intellectual disability impacts heavily upon their capacity to enjoy meaningful sexual outcomes (Griffiths et al., 2004). Essentially, this body of work is heavily focussed on rights and suggests support staff need to be comfortable with their own sexuality but, as Griffiths et al. remind us, as do the preceding paragraphs, there remain gaps between attitude, philosophy and practice. Viewing people with an intellectual disability as asexual beings has often been cited as evidence of a condescending attitude which may lead to denial of rights. While some of the staff in this study did echo this view of asexuality at times, their responses to the sexual health needs of the male clients were always based upon promoting the client's best interest, often with limited guidance to support them.

2) Duty of care

Staff believed they have duty of care to assume an educational role, to plan for the future, to adhere to occupational health and safety policies, and to complete relevant documentation. Only one of the organisations had a policy relating to sexuality which is significant in its scope for telling support staff what not to do, but extremely limited in telling them what they can do. An excerpt is provided below in Box 7.2:

Box 7.2

Excerpt from human relations and sexuality policy

"HUMAN RELATIONS AND SEXUALITY"

It is not the role of staff to:

- Provide any specialist service for which they are not qualified. For example, where people have human relations needs that require intensive intervention. This should be provided by qualified practitioners trained in specialist techniques.
- Make decisions on behalf of people and their families. Every person is entitled to have an advocate help them during any decision making process.

The role of staff does not encompass such actions as:

- Sexual positioning of a person,
- Physical assistance with masturbation,
- Assistance to purchase sex aids and pornographic materials when sale is restricted,
- Assistance to acquire the services of a prostitute.

Note: Premises owned or operated by [organisation XYZ], for example, residential houses are not permitted to be used for the purposes of providing the services of a prostitute or an escort agency worker. [Organisational] vehicles must not be used to transport people to a brothel or location for the specific purposes of obtaining sexual contacts. It is not the intention of this document to imply moral judgement on any of the actions, instead it is to reinforce that staff must work within the law, and policies and guidelines of [Organisation XYZ].

Several staff mentioned sexuality education was important and a part of their role. However, no participant could cite an example of a sexuality education plan they were implementing nor did any of the staff recall ever attending any sexuality training. Two staff recalled implementing a behaviour intervention strategy for inappropriate masturbation in past jobs, both were reactive strategies written by a behaviour intervention specialist. With such limited guidance, the lack of an educative role or narrative was not surprising. As one staff member reminds us: "*… if you don't know what you are doing you shouldn't touch it"*.

The growing emphasis on risk assessment, under the umbrella of occupational health and safety law, now involves most areas of practice. When pressured with the demands of the job and set timeframes, doing the basics well while being cautious of risk may become more important and may present an obstacle to offering meaning: *"… is this job about extra [working] hours … or is it more about what can I achieve with the guys today, what can I facilitate, what can I try that's new? … at what point do you draw the line between OH&S [risk] issues and providing activities that are actually helpful to the guys?"*. That is, by fulfilling duty of care the staff have achieved a professional requirement, but this can be at the expense of an individualised focus on the little things that enhance life satisfaction. For example, despite one male client only having bath time to masturbate and staff knowing that he likes this time, it is not offered due to *"… time restraints, convenience … you can't leave him unsupervised [due to risk] so they [male clients] don't have personal time to do it [masturbate]"*. Meaningful service delivery is almost paralysed by the emphasis on risk minimisation. Becoming more focussed on time and convenience is partly because *"… the job is intense … having stopped doing [the job] full time … I was able to reflect on how draining it can be on your mind … its very easy to just become „okay, I've got 7 hours I've got to do these things' … it's more intense in these situations, its very physically demanding, its very hard when you are dealing with people [clients]* *who … take an hour to feed … it all becomes in the „too hard' basket, it kind of becomes about efficiency"*.

3) Staff as interactional gatekeeper: "… the different backgrounds and ages of people [staff] definitely reflect what informal policies are put in place".

Thus far, the theme of staff influence has covered a range of topics which have concluded with the following proposition: despite staff being motivated by a variety of beliefs and perspectives which includes a view that the industry prefers to avoid the topic of sexuality, the supporting practice from staff is generally performed from an empathic stance aimed at, where possible, promoting the personal preferences of the male clients in their care. This leads on to the next sub-theme which describes how staff performed this empathic stance; they are expected to be an "interactional gatekeeper".

Staff described a part of their role as monitoring; monitoring affection between clients, between clients and staff, and monitoring self-exploratory behaviour between the public/private domains of the community group home. The monitoring role was framed by a differentiation between "appropriate" and "inappropriate" interaction. For example, *"…he will play with himself, as I'm cooking in the kitchen he is sitting on the chair …. not masturbating in the real sense [rubbing penis through trousers] … it wouldn't be offensive so I don't make a big deal about it"*. Another of the staff felt this approach from staff was *"… because [he] is very placid… no one is bothered by it ... if he was more aggressive it could present [staff with] more problems'*. During observation this man was observed to rub his penis through his trousers; none of the other clients seemed to notice it, the staff didn't react to it, and eventually he stopped. The following excerpt, Box 7.3, from my field notes describes the approach to another male client who often rubs his body also while in a public space:

Box 7.3

Field notes: Staff role as interactional gatekeeper

TV LOUNGE
Client stays where he is, in the loungeroom with all other clients sitting in their wheelchairs. He is dressed only in a pair of shorts over his nappy. I go in to sit and observe. Client continuously stimulating himself by rubbing his hands and fingers over his body; legs, arms, groin, neck. Other clients paying no attention to him; he is paying no attention to them. No interaction to observe at all between clients. Staff A and Staff B both come in to check on clients; Staff A covers Adam's groin with a pillow, sighing; „doing what boys do'. Staff B laughs. Client takes no notice. They leave and client carries on regardless. „Neighbours' is on the TV and client is watching attentively whilst constantly rubbing himself all over. It does not appear that he is actively masturbating; Staff advise he does this in the bathroom when on the commode. This goes on for over half and hour. The evening continues the same; no interaction between clients and client peacefully watching TV whilst rubbing himself.

DISCUSSION WITH STAFF ABOUT PUBLIC/PRIVATE SPACE
Staff advise he does this every night but he has progressed from his room to taking his pillow to the lounge and watching TV. Staff advise some staff have a problem leaving him to rub/stimulate himself in lounge whereas they leave him to it; he is doing no harm, it is more stimulatory rubbing and no one pays any attention, client also seeks no interaction from anyone for this behaviour; I conclude it is purely a self- absorbed stimulatory repertoire. Staff advise if a parent comes along then they will feign surprise with his actions and remove him to his room.

SUMMARY AND CONCLUSIONS

This chapter has brought to the surface a range of complex and interdependent sub-themes which has been described as sexual development. Implicit within sexual development are the importance of developmental stages and their association with cognitive capacity and insight; disadvantage due to intellectual disability is evident. Perhaps most significantly, sexual development, while clearly a biopsychosocial construct, is described less by social scripts and more so by a combination of biomedical factors, genetic footprint (e.g. Down syndrome), cognitive and physical development, emotional maturity, and staff influence. This is most significant as a number of high-profile authors have written about sexuality and intellectual disability where the role of social scripts has been at the forefront of their dialogue and research observations (e.g., Löfgren-Mårtenson, 2004; McCarthy, 1999; D. Thompson, 1998; Wheeler, 2007). This research explored sexual health for men and teenage boys with a moderate to profound intellectual disability, while the other research has focussed on people with a mild to moderate intellectual disability. Therefore, intellectual capacity appears to be an important prerequisite in order to take on board the social scripts central to sexuality as a socially constructed phenomenon.

While these data do not refute the current discourse discussed in Chapter 2 which comprised an oppositional dichotomy between medicalised symbols of the past and social construction founded upon rights, they point to an acknowledgement that both perspectives have something to offer. For example, Conditionally Sexual recognises that the men and boys in this study have rights … but up to a point. This point appears constructed by the combination of individual sexual development and the influence of support staff. These men and teenage boys have a right to self-discovery, a right founded upon hormones, reinforcement, insight, and self-care, but rights experienced within the context of gendered service delivery dynamics governed by limited policy and procedural guidance. This limitation forces staff to assume the role of interactional gate-keeper, while bearing in mind their duty of care, leaving staff with little to guide them but their own belief system. This also adds to the evaluation of attitudinal research concerning sexuality and intellectual disability (e.g., Griffiths et al., 2004); attitudinal research tends to conclude staff attitude has a significant impact, which it clearly does, but perhaps fails to appreciate the wider picture that staff often have little else to go by. In a way, such a narrow focus on “staff attitude” suggests the staff are yet another symbol of oppression to the lives of people with an intellectual disability. These data highlight that staff are performing admirably, often with ethically and morally challenging issues, within an inadequate philosophical structure.

The conundrum that staff are placed under are illuminated very clearly for example, by the data on penile hygiene, pornography, prostitution, legitimate restraint, touch, hugs, and masturbation. There are two key missing ingredients in the way these males’ lives are experienced: the value of an intimate and therapeutic relationship with other people, and the value of human sensuality. That is, the focus on human sexual health is not geared toward what feels nice and what is fun, it is problem-led within a service-centric risk-hierarchy. There also appears limited appreciation that sexual health also extends to fostering meaningful human relationships; beyond the physical/genital body to the psycho-emotional person.

Chapter 8 will now examine the data which sought to explore the intersection of masculinity and intellectual disability. This intersection continues to build on the notion of men and teenage boys with a moderate to profound intellectual disability being Conditionally Sexual. That is, their masculinity is just as pivotal as their sexual health needs to their life experience; the two are not practised separately. Male sexual health and masculinity are one and the same broad entity. Although Conditionally Sexual is the one lived experience, these data are presented separately for the purposes of providing greater explanatory power to the framework introduced in Chapter 6.

CHAPTER EIGHT

CONSTRUCTING THE CONCEPT OF *CONDITIONALLY MASCULINE*

> *The lives of men with less-normative bodies, such as those with disabilities, provide an instructive arena in which to study the intersection of bodies and masculinity. Depending on the degree of their deviation, men with less-normative bodies contravene many of the beliefs associated with being a man. Yet little has been written about the intersection of less-normative bodies and masculinity.* (Gerschick, 2005, p. 368)

Conditionally masculine is the second theme of men and teenage boys with a moderate to profound intellectual disability being *Conditionally Sexual*. It is a concept which differs from the historical and stereotypical portrayal of the *diminished man* (McDonagh, 2000) mentioned in Chapter 3, and from constructs of normative masculinity. Conditionally masculine is less a socially constructed notion but more a biopsychosocial perspective; a perspective which appreciates the disadvantage intrinsic to limited capacity, function and communication, as well as location on the social gradient. It is also a construct which appreciates the influence of structural inequality described by Holter (2005); masculinity being conditional upon the interpretation of masculinity by those providing the support. An interpretation communicated by dress, grooming, hygiene, choice, activity, relaxation, and socialisation. Conditionally masculine relates to the perspective of staff who work in the community group homes; their gender, skills, communication, training, and background. It also relates to organisational culture, and access to community participation and integration. Conditionally masculine is illustrated by the blue shaded area of Figure 8.1.

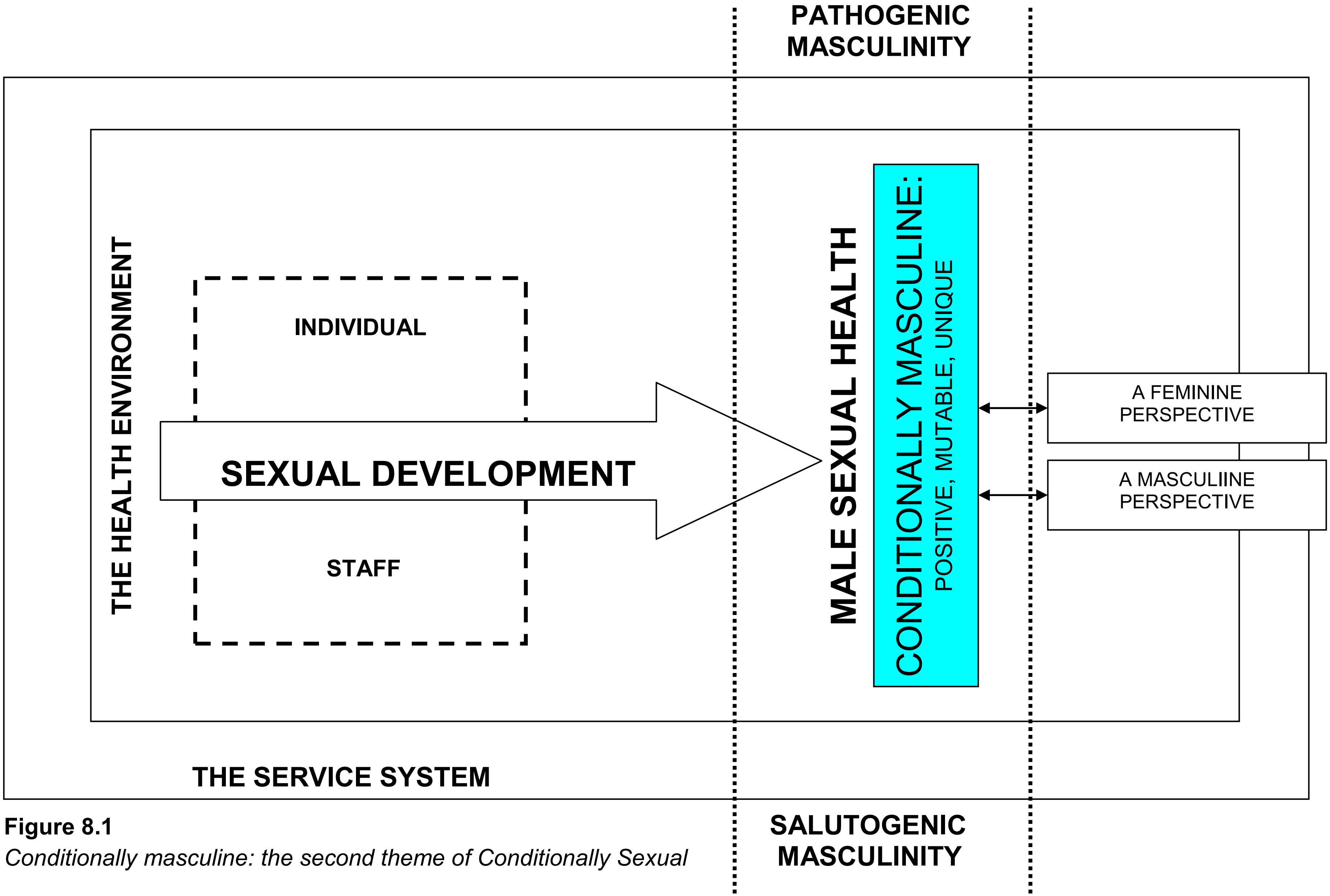


Figure 8.1

Conditionally masculine: the second theme of Conditionally Sexual

A POSITIVE CONSTRUCT

Using the constant comparative method described in Chapter 5, two axial codes were identified from the data which related to conditionally masculine. While each of these codes will be described below as separate sub-themes, they are interdependent and are shown in Figure 8.2.

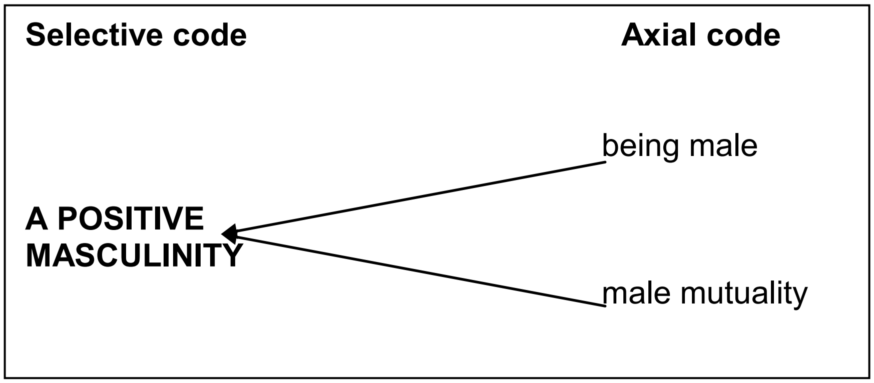


Figure 8.2

Axial codes for a positive masculinity

1) Being male**:** ***"I do respond to males in a more masculine way … [for example] a male baby will get thrown in the air, where a female [baby] will get held close and rocked … [it's] a little bit rougher with males".***

Staff described a range of data which were labelled as "being male". These data included doing maleness, expressing maleness, feeling maleness, looking male, and expressing femaleness. The inclusion of expressing femaleness indicates conditionally masculine is not a dichotomous masculine/un-masculine construct; it is a construct operating on a continuum of masculinity inhabited by expressing femaleness but not being female.

A range of physical behaviours and activities, most related to sport and physical games, described how doing maleness was linked with physicality. Examples included:

"…taking [client C] on a four wheel motorbike"; "…rollerblading or playing with a ball…"; "…swimming, physical stuff, outings, letting [client C] out of his chair to run around the house"; "Richmond Air Base or trains"; "bowling, swimming, barber, a truck show". Sport provided one key metaphor for being male, a metaphor which is reflected in the literature. Reinforced by the popular media, where sporting heroes bodies are commoditised to promote the "vast merchandise of manliness" (Segal, 2007, p. 104), being male and displaying masculinity often connect through sport. Connell (1995) likewise stated sport has become the "… leading definer of masculinity in mass culture" (p. 54). However, the practice of conditionally masculine is not entirely constrained by sport; it was also acknowledged this physicality, and being male, was an individual thing, not all males were into sport: *"… [more independent males] go to the pub and play pool, go and watch the footy, the cricket … [client A] not into any of that sort of sport, but if you put a musical on he will sit and he does the tap dancing … and he just loves performing".* Underlying this difference was an implicit male physical drive of energy that needs to be expressed: *"… a young energetic boy who likes to run around and I like to give him the freedom to do what he likes [express that energy]"*. Box 8.1 contains an excerpt from my field notes which depicts the freedom to express energy once "released" from a wheelchair.

Box 8.1

Field notes: The release of male energy

Once out of his chair Client C ran around on all fours up and down the corridor, into his room, climbing all over the bed and bean bags in his room, banging on the lounge room door where one of the female client's family were visiting. Very energetic stuff. At one point he stood erect by leaning back on the table and banged his chest and grunted just like Tarzan in the movies; one of the care staff called it his silverback gorilla routine. Great description and one that appears valid. He started to annoy a second female client by throwing her toys away and so on. He also climbed over the female staff wanting hugs for comfort as well as a „physical' joust. Laughing all the time.

Male physicality was only one way of being male and expressing maleness but central to that expression was the underlying assertion that maleness sounds and acts differently from femaleness. That is, *"… [males] have a different way of expressing [themselves] … whether we are softer or whether we are rougher, I don't know"*. For example, the single male client in his early twenties who had a moderate intellectual disability would echolalically swear in order to express maleness: *"… he wants to be a man … he has started to swear… his favourite word is „fuck a duck' … but he doesn't equate the word „fuck' with sex"*. This example reflects masculinity as a socially constructed embodiment where the client's expression has been shaped by his perception of male social scripts. Connell (1995) referred to the historical understanding of such imprinting of gender as a neutral body taking on board social symbolism to practise masculinity; socially nurtured masculinity. Crying, together with emotional expression, was another factor which defined expressing maleness; *"… [Client C] is more like a guy [whereas client B] is more feminine … he's softer ... more gentle, more calmer, he probably gets more emotionally upset … every male probably does cry … some males cry because it's how they are, whereas others might only cry when something really gets to them"*. For client B, expressing femaleness was a part of his maleness; although he expressed a range of more feminine emotions his underlying maleness was just defined differently. It recognised masculinity as *"… very much an individual thing … you can have soft masculinity and you can have high [more dominant] masculinity … I pretty much work [with] and accept who they are"*.

Maleness was also defined by how it looked, which essentially incorporated dress and grooming. One male client apparently desired *"… a Ned Kelly*[28] *beard"* so staff allowed this: *"… [he] is really into growing a beard … he wants to be a man"*. Although this is only one example, it is clear the social symbolism influencing this male client differed to the way maleness is often commoditised by mass culture. In retrospect, it would have been useful during data collection to further explore how grooming like Ned Kelly became a masculine ideal for this client. Nonetheless, male grooming was defined differently from female grooming which was described more as beautifying: *"… he's a young adult, all his clothing are man's clothing … I suppose cutting his hair [short] like a man … I suppose you don't do the [male clients'] hair like [you do] the female client here"*. Significantly, the additional attention given to the female client related to *"… it makes her feel more on par with the rest of society … looking through magazines, „I want to be like that' … she has got two sisters and she wants to be like them"*. While not related directly to masculinity, these data do mirror the desirability of a gendered hegemonic ideal; in this case equalling a normative ideal. One younger male staff member generally felt *"… more effort was put into female grooming than into male grooming"*. This factor probably reflects mainstream society, where the range of grooming products for women generally outnumbers those for men, notwithstanding the merchandise of manliness now available, and the greater numbers of female staff who are perhaps more attuned to the grooming needs of other females. For example, during one observation session my help was enlisted to wet-shave a young man as the female staff stated they lacked confidence in their competence to adequately and safely perform this task. Carnaby and Cambridge (2002) did find shaving was one of the most disliked personal care tasks although their reported data did not differentiate between staff by gender.

---

[28] Ned Kelly was an infamous Australian outlaw who was partly renowned for his prominent beard.

Being male also incorporated feeling maleness. One older female staff member felt *"… men, yes, they think about sex more than women do, women will think about sex when they have to but men think about sex a lot more … it's important men are given a lot more time [to masturbate] … more often, more frequently"*. This quote suggests the presence of a difference between the male and female body; that males have a distinctly different repertoire of fundamental need. Another example of feeling maleness related to interaction between clients: *"… when [the female clients] fuss over him, his chest swells, he perks up a bit"*. Extending this theme, this same male client, the older man, was *"… appreciated as, he's the man of the house, but not in that blokey [dominant] type of way"*. A biological basis of feeling male was balanced by the idea of imprinting normative male social scripts.

2) Male mutuality: "… a level of acceptance in being one of the boys".

Staff described the belief in a positive male mutuality; that *"… being one of the boys"* was not only a part of being a male, but a constructive piece of maleness. Male mutuality was about positive role models, male warmth, belonging, and male banter and was based on the interaction males offer each other. Unlike mutuality based upon shared interests, or commonality, as described in friendship research (e.g., McVilly, 2004), mutuality was described as an innate gender-specific understanding. Male mutuality will also be described in Chapter 9 where the interaction between male staff and their role as models to male clients will be discussed in greater detail. Perhaps in relation to the level of intellectual disability, examples of male mutuality between the men and teenage boys in this study were limited, if not absent. For example, in the two community group homes where there were two male clients, no staff mentioned any specific male to male interaction and nor did I observe any.

Male warmth was described as *"… a beautiful male bond"* between a male client and certain male staff. Staff suggested the men and teenage boys in this study know the difference between male and female staff: *"… they need that stimulation of the different genders … they need the difference … [he] gets all excited [when males are on shift] … he does like males"*. Expanding on this theme, male bonding was suggested as one positive outcome from the presence of male staff: *"… when [male staff member] comes in he gets excited, you know another male around …. [male staff will] interact with him …. men sort of bond and protect each other"*. Bonding was how this female staff member, who was Aboriginal, went on to describe her understanding of traditional Aboriginal men's business, separate to women's business; male bonding as a necessity for not only male collegiality but also for wider socio-structural stability. In addition, the brother of this client played a significant role in his life: *"… he's got a brother … slightly older, and I find that he is very fond of him … but I see the distinction [between male staff and his brother] … he longs for contact with his brother… you can see the genuine feeling behind that"*.

McConkey et al. (2007) suggested the unique qualities of males working in the care sector need to be indentified; this notion of male warmth, male collegiality, or male bonding, is one quality integral to the well-being of men and boys with an intellectual disability which has been clearly identified by the data. However, this notion, described in critical studies on men and masculinities as *collective masculinities*, has usually been associated with negative outcomes such as war and violence (Connell, 2000). A more productive viewpoint is found in what Connell has labelled the "pop psychology" of masculinity theory; here male collegiality is presented as mandatory to the development of manhood (Biddulph, 1995). Biddulph argued that developing into a man includes fathering, equal terms in relationships, locating a sacred sexuality, engaging with your children, learning to have male friends, finding heart in your vocation, and freeing your wild spirit. This collegiality however requires an intimate and lasting relationship where meaning underpins interaction; this basis is often lost when the interaction is a purely professional one (McVilly, 2000).

Interaction between males that helped define collegiality was also referred to as male banter; the verbal and non-verbal communication between male staff and male clients. For example, one male staff member described coming on shift and gently punching a male client on the shoulder as a part of his verbal greeting which the male client responding to positively. This interaction, or banter, was not described in the usual context of activities, such as sport or work. It defines a deeper emotional investment between males which, on the surface, is often defined as unemotional (Robertson, 2007), but belies the fact *"… males have a different way of expressing themselves"*. Just because male interaction appears superficially unemotional does not mean emotion is absent. For example, banter includes reassurance: *"… again at bed time, if there is too much hassle, too much running around the house, too much demand on him, too much noise …. you lower your voice and settle things down … I go to his bedroom … I linger on for ten minutes or so and just talk to him, and I feel that [it calms him down]"*. Expanding this further, this same male staff member felt this man *"… without a male [staff member, he] would probably be very much lost … after 1:1 with him … he has a much better mood"*. Box 8.2 describes some observations from the field which further illustrate male banter.

Box 8.2

Filed notes: Male banter

We are all sitting around in the loungeroom late Sunday morning. Two of the clients are lying on their mats on the floor. Client C is ambling about the house, in and out of the loungeroom, on all fours with a mischievous grin on his face. He loves the freedom to roam as he pleases within a space he is comfortable in.

Client C started to annoy a young female client by throwing her toys away seeming to know it would elicit a reaction from the staff. The young female client was not at all pleased with this intrusion upon her solitary play. Client C would also intermittently climb all over the female staff who were sitting on the lounge; he wanted hugs. These hugs seemed to be based upon the need for comfort as well as a much rougher „physical' joust; he is laughing all the time.

A little later on, still in the lounge room, when another female client's family had gone, client C started to climb all over me. He wanted both hugs and a physical rumble; he loved the physicality of the contact and he loved the "rougher" way I was mucking around with him. Being physical with him in a caring but rough manner. "Rumbling". He would run off then come back for more. This lasted for about 20 minutes.

Because I had started to develop a good relationship with the staff and the clients I was not concerned with the physical nature of his interaction with me – however, if there were others there that I did not know or others who I perhaps felt less secure about, I would probably not have allowed client C to interact with me in that way.

The often physical nature of male interaction, or banter, as illustrated in Box 8.2, despite the positive manner it has been described, represents an ethical dilemma for male and female staff (this will also be deconstructed further in Chapter 9). The recently published *Australasian Code of Ethics for Direct Support Professionals* (McVilly, 2007) states physical interaction between staff and clients can be an important medium to build relationships of trust and support. But, this is further qualified with a cautionary statement that physical interaction can also give rise to "misunderstandings". What the data in this study are suggesting is the presence of gendered interaction, which can be physical and/or intimate in nature, that should be added to ethical codes to further qualify practice, to enhance understanding and appreciation of the gendered nature of some interactions.

For example one male staff member stated: *"… I don't think I'd respond to [Client B] in nearly the same way as I would with [Client C] because [Client C] is so much more boisterous … but I'd adopt a more gentle tone when I'm talking to a female [client]"*. In this example, Client B has more complex physical disabilities than Client C in addition to a greater degree of intellectual disability.

A MUTABLE CONSTRUCT

Using the constant comparative method as described in Chapter 5, two axial codes were defined which related to mutable masculinity. These two categories will be described below as separate sub-themes and are shown in Figure 8.3.

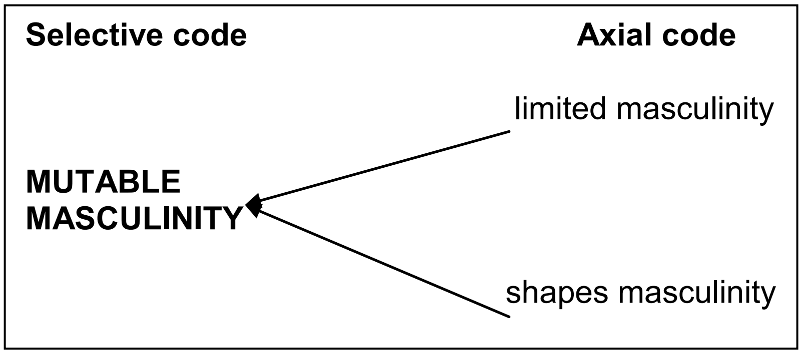


Figure 8.3

Axial codes for mutable masculinity

***1) Limited masculinity*: *"… [He] is not less of a male … I don't know how, I just think it's more difficult for him to express [masculinity] … there is something less going on in that area [masculinity]"*.**

Staff described a range of data that defined masculinity as a limited construct. Essential to this definition are the limits imposed by cognitive and/or physical impairment. The notion of "perpetual childhood" was also linked directly to cognitive impairment. Data presented previously under the sub-heading “being male” mentioned one male client in his early twenties who desired a Ned Kelly beard. This same young man *“…he does have his own vision of what a good masculine role model is … he wants to be a fireman, he wants to get in the fire truck, and put on the [gear]”.* This young man was the sole client with a moderate intellectual disability; he had greater capacity to take on board cultural images, through for example mass media, and relate their interpretation to his own masculinity. While not articulated with intellectual disability in mind, Hearn (1992) referred to the way modern masculinities develop not only by the relationship between modernism, masculinities and sexualities, but also by a **consciousness** of these factors. These data start to portray the importance of consciousness, or the brain, as they relate to the construction of disabled masculinities. That is, limited consciousness limits the shaping and practice of masculinity by the self. Equally, the epitome of embodied masculinity, and hence the parameters of its limits, was further defined by energy, function, power, strength, and size; or as Connell (1995) asserted: masculinity constituted through bodily performance. Masculinity is a verb; males “do” rather than “discuss” (Caesar, 1999).

Staff described a continuum illustrating how greater limits, embodied through greater degrees of disability, equate to limiting the practice of masculinity. Figure 8.4 summarises this perspective of masculinity, limited by disability. There was also a perspective that the older man with Down syndrome, described as *“cute”*, personified a limit to masculinity because of his diagnosis; Chapter 7 presented data which portrayed persons with Down syndrome as having a cuddlier, and hence less-masculine, disposition. One staff member stated *“… I don’t see him [male client with Down syndrome] as being as that much of an issue [masculinity] with him as it is with some of the younger clients … and older ones who are more able to [develop a] rapport with me,* *and to do things together … because of the Down syndrome, I don't see him as masculine, to tell you the truth, as other [male] clients"*. Additionally, staff mentioned the limits low staff numbers can often have on social opportunities to do male things; defined in being male as outings, sport and physical activities outside the home. The issue of staff rostering and its contextual and often limiting impact on masculinity will be discussed further in Chapter 9.

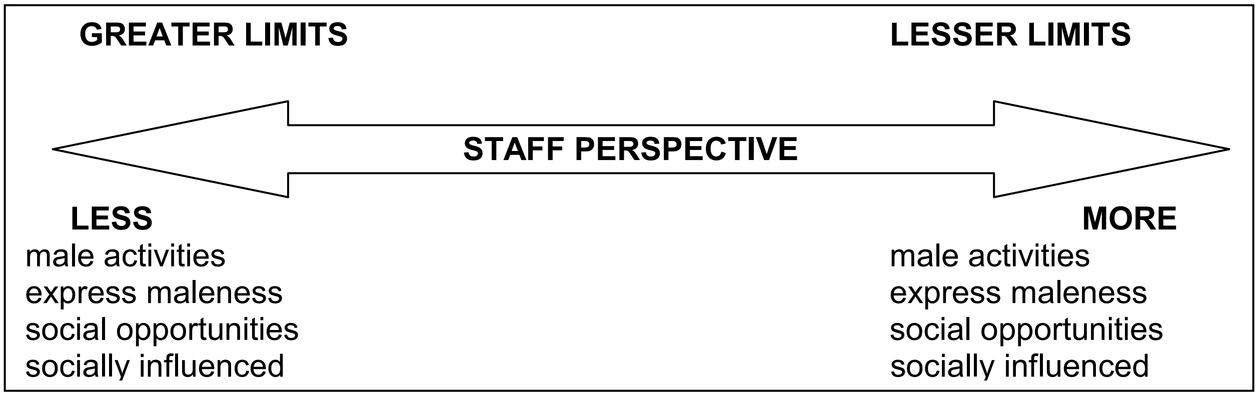


Figure 8.4

Staff perspective of masculinity, limited by disability

Three pieces of data from interviews with staff are particularly instructive toward deeper understanding of the concept of conditionally masculine and how masculinity relies upon consciousness; that masculinity is also cognitively constructed. First, masculinity requires more instruction and support the greater the degree of cognitive impairment; second, masculinity should be modelled by care staff but within the clients' cognitive limits; and third, that masculinity is less influenced socio-culturally the greater the cognitive impairment. For example, while the media were recognised as a key factor in constructing masculinities, one of the teenage boys, who has a severe intellectual disability, was less influenced: *"…because they don't interact with the media … they are less influenced … by the media … that's a huge issue … because he never watches* *television or reads a newspaper I think that's really where the difference lies … out in the community they [other males with less cognitive impairment] notice more than I would say that [he] does"*.

In contrast, data presented earlier showed the young man with a moderate intellectual disability was influenced by images of Ned Kelly and firemen which would presumably have originated from at least one media format. Furthermore, the female client talked about by staff when referring to grooming had a mild intellectual disability and was purportedly influenced by her sisters' image and by those of other women. The greater the disability, the more staff are required to encourage masculinity: *"… I like to [encourage] … you give them a bit of a sense of pride in being male … you might pull him up on his dress … [encourage positive behaviour by saying] don't do this or that"*. Staff working with the teenage boy with a profound intellectual disability, the most "disabled" of all the men and teenage boys in this study, felt his masculinity was *"… harder [masculinity] the less proactive the client is … the kind of things that he is able to express his masculinity through are more limited and more chosen by external people [staff] and not by himself"*. This teenage boy required greater input from staff: *"it's harder for [him] because he's less interactive … he's very reactive and less proactive in what he does … often … it's a one-way conversation … trying to give them the benefit of the doubt … the flavours of those conversations have to reflect their age and their different flavours of masculinity"*.

Box 8.3 contains a summary from my field notes which, although not directly related to the practice of masculinity, describe the limited interactional context associated with limited cognitive function. It is important based on the data that highlight masculinity partly through interactional and cognitive mediums. Twelve months earlier this older man had some expressive and receptive communication skills, was able to independently navigate around the house, and would seek out others for interaction. Following a cerebrovascular incident related to epilepsy and coupled with advancing dementia, the man's life, and hence masculinity, had been altered significantly because of his increasingly limited cognition. While these notions remain more conceptual at this time, valid parallels might be found concerning males with an acquired brain injury, dementia, other degenerative conditions, and men who are ageing, directly affecting their capacity for autonomy through limited interaction and cognition. That is, conditionally masculine is experienced via limited autonomy, which in turn is defined by impaired cognition, caused by damage to the brain.

Box 8.3

Field notes: The interactional context of limited cognition

Lounge room: Client A is brought a drink which he consumes over the next ten minutes. There is no interaction from him when being given the drink other than an acceptance of the cup in his hand. When finished his drink he gets up out of chair and walks around the back of the chairs looking for somewhere to place the cup. He places it on the ironing board. He then wanders back and forth behind the armchairs seemingly trying to figure out how to get back to the front. He eventually takes the more difficult option and climbs over the arm of the chair sitting back down.

He then stays seated for a good forty minutes. During this time Client A looks at his hands, gently chews on his finger/thumb, and assumes a hunched position. At different times the room is full then at others it is empty bar me. He makes no attempt to interact with anyone.

On several occasions a female client smothers him with kisses and cuddles to which he seems to not respond or acknowledge. The female client says various things such as: "you poor boy"; "I will look after you"; "I love you"; "Come here my big pussycat". He does not interact back.

He is handed a sock which the female client states is his – he accepts the sock and spends some time just looking at it and turning it over in his hands. He then gets up out of the chair and wanders towards the front door. He seems to be looking for somewhere to put the sock but does not know where. Eventually the sock is taken off him and he resumes his seat in the lounge. Still no interaction.

These data point to the important role of staff as a masculine surrogate to what would otherwise be masculinity expressed with full autonomy. That is, as autonomy diminishes, the need for a masculine surrogate increases. Importantly, while the masculinity of the men and teenage boys in this study are diminished because of their limited cognition and the related experience of powerlessness, their masculinity is not constructed within a hierarchy of power as framed by analysis such as Connell's (1995). That is to say, although the men and teenage boys in this study, on the surface portray the requisites for a subordinated masculinity as defined by Connell, there is limited, if any, evidence of domination by others due to a gendered hierarchy. For example, Connell defined characteristics of subordinate masculinity as: existing in the presence of dominance, practised through oppression and discrimination, experienced as exclusion and through abuse and violence, and symbolised by a blurring with femininity. One significant critique of Connell's analysis of masculinity asserted by MacInnes (1998) is its confusion between symptoms and cause. Indeed, it could be argued the symptoms of discrimination, dominance, and exclusion can be found across all facets of western society and are equally as much a symptom of gendered power as they are of capitalist reality. Just because the men and teenage boys in this study practice masculinity partly with a masculine surrogate, it does not imply they are automatically subordinate to that surrogate.

Limited cognition also affected the way some staff perceived the stalled developmental milestones of some males with an intellectual disability where the term *"childlike"* was used. This term however was not used in the mythological sense of the "eternal child" that needs protecting (Griffiths, 2007). For example, one of the older female care staff commented viewing males with an intellectual disability as childlike is

“…a habit … [I’ve known the clients] since they were little people … they haven’t grown up and moved out of home and had their own life ... I’ve gotta be honest with you, I always see them as kids, it doesn’t matter about their age, or how they have developed, you sort of think of them as the kids in the house … I think that’s because of their intellectual disability”. Therefore, while society is usually structured via a developmental approach to behaviour that is based in chronological age (Peterson, 1989), it differs for people with an intellectual disability. People with a cognitive impairment progress more slowly through the stages of development and their ultimate level of development will be at a slower rate than their chronological age (Jenkinson, Sparrow, & Shinkfield, 1996). Importantly however, these data, while recognising the limiting effects of cognitive impairment, also do not support the personal tragedy model typified by pity and humiliation (Stratham & Timblick, 2001). That is, references to *“childlike”* do not reflect the model of pity but are articulated to reflect the reality impairment has to development: *“I see both of them as young men … they’re adults … but I also see them as their child-side… because they’re not … in their brains they haven’t formed to an adult … they can still do the things that a grown man could do but their capacity in their brains, when they talk to you, are as children”*.

2) Shapes masculinity: “…in his behaviour management plan … „don’t do that because blokes don’t do that”’.

Masculinity is also subject to being shaped. Staff, and the systems/interventions they support and implement, can influence, reinforce, and characterise masculinity. Masculinities are also shaped by institutional systems, political factors, and practices (Connell et al., 2005). The men and teenage boys in this study are additionally subject to policies and procedures, legislative frameworks, and organisational systems which will be discussed briefly in Chapter 9. Family background might also shape masculinity, for example: *"[Client A] his family background… his brother's a priest … there's all that that comes into it all, his background …. he wouldn't have been exposed to that [e.g. sexualised images of women] at any stage"*.

Staff in community group home three described a behaviour management plan for one of the younger men where a positive affirmation of appropriate manhood was used as a response to negative, or puerile, behaviours: *"If [he] does something wrong … I might say „you're the man here, that's not what a man does'"*. Examples of puerile behaviour given included making siren noises or going to hit someone where the formal response was *"…„don't do that because blokes don't do that' … I see that as forcing [him] into a [male] role … in saying that, he wants to be a man"*. This strategy also formally extended into other areas of this young man's life when behaviours did not present a challenge; where staff felt appropriate they would model, or shape, toward a masculine role: *"I take [him] to the video shop and try and direct him to, sort of, boyish videos … sometimes, you know, he wants „Angelina Ballerina' which is very girlish … that's his opinion and that's his choice … which is fine, but I do suppose I direct to guy movies … boy videos"*. These actions essentially reflect the professional expectation of staff to promote age and culturally appropriate activities (McVilly, 2007). Importantly, there were no male staff employed in this setting; the absence of male role models given their strategic importance to behaviour will be discussed further in Chapter 9.

Masculinity was further shaped by personal grooming the greater the physical impairment, although the gamut of masculine grooming was quite narrow compared with feminine grooming: *"I suppose you don't do the [male clients'] hair … [whereas the* *female client] we dye her hair and do her makeup"*. Further, a young male staff member stated *"…we [staff] make decisions for them with what kind of clothes they wear … I see more effort put into female hair than I do put into male hair … when I used to work on Wednesday mornings, getting people ready for school, I received a comment from one of the teachers that she always knew when I was working because [Client C] came with his hair done … just a bit of gel to mess it up, trying to be age appropriate and situation appropriate"*. Grooming for masculine appearance not only extended to personal hygiene tasks but also to age-appropriate dress: *"… [they're] very handsome young men … I make an effort to make sure they're clean, they're washed, they smell masculine, they're dressed nicely, and co-ordinated … I try and dress them to their age group … I'm very conscious that when you put nappies on you're not putting pads on to look abnormal at the front [all bulky]"*. It was also recognised that not all males were that interested in the results of extensive grooming: *"… you can fix [Client B's] hair up nicely but you fix up [Client C's] nicely and he will mess his up"*. At a very basic level these data are described as staff performing their supportive role with personal care. On a slightly deeper level, these data support masculinity being constructed toward a normative canvas where society imprints social symbolism on a neutral body (Connell, 1995). These data are however not on par with the way less-normative masculinities arguably shape themselves to a normative ideal through practices such as tattoos, body building, extreme sport, and penis enlargement (Gerschick, 2005).

UNIQUE: MALENESS IS DIFFERENT FROM FEMALENESS

Two axial codes were identified which described masculinity as a unique construct; that characterize maleness as different to femaleness, they are illustrated in Figure 8.5.

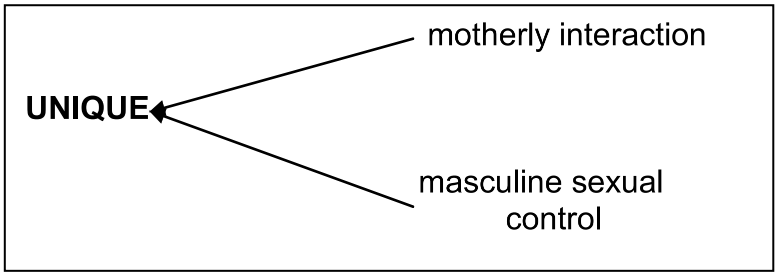


Figure 8.5
Axial codes for unique: maleness is different to femaleness

1) Motherly interaction: "…[he] sees females perhaps more in a motherly role".

Significant from these data are the repetition of the adjective *"mothering"* to describe the way the men and teenage boys in this study perceive female staff in the absence of any comparable and consistent adjective to describe male staff. One older female staff member felt this was partly to do with parenting: *"…as parents yourself, and you are, sort of, in that caring role, looking after kids"*. Another female staff member felt female staff were *"…a bit more motherly with clients compared with male staff … females are softer in their approach"*. Whether these data were more about the female care staff perception of themselves is unclear; however there were no significant data collected during observations to support the sub-theme of the men and teenage boys viewing female staff in a motherly manner. That male staff did not cuddle clients, male or female, as much as female staff seemed to be more about male staff anxieties concerning physical contact with clients, as opposed to a perception the men and teenage boys in this study had toward female staff. Alternatively, perhaps male staff simply cuddle less, period. Although there is no empirical evidence, assigning behaviours such as cuddles to the adjective *"mothering"* may validate the role as described in attribution theory; where a cause is found to explain, and respond emotionally to, events (Hatton et al., 2004). These themes will be explored further in Chapter 9.

2) Masculine sexual control: "…once you [a male] have an erection … there's not a lot you [males] can do about that … women have more control".

Male sexual control was described by a female staff member as unique: *"with guys, I think sexuality is a fairly big component in their lives and I think with these guys [clients] it is probably no different … there's a lot of behavioural issues, a lot of challenges that these guys face"*. This assertion, based on sex-difference, has some support in the literature; McCarthy (1996) presented data showing males with an intellectual disability were twice as likely to be referred to sex education as a reaction to a problem than females with an intellectual disability:

> Men with learning disabilities are identified as having more problems and/or causing more problems, with their sexuality more often than women are, most of the problems relating to sexual aggression and violence. It would be surprising if this were not the case, as it reflects the picture of men and women's sexuality in society generally (p.268).

Additionally, the term "challenging sexual behaviour" is also more readily applied to males with an intellectual disability (Cambridge & Mellan, 2000). As one older female staff member suggested: *"…there's a place for sex with women … it is a little bit different than men"*. The issue of less control in males was described as emanating from consciousness by one female staff member: *"…they [male clients] have less of a capacity to understand control … there is that feeling that they are not in control of their thoughts, that they could go too far"*. These data appear to be suggesting "limited control" is a sex-specific variable driving male sexuality.

SUMMARY AND CONCLUSIONS

This chapter has raised some sub-themes which not only break new ground in the area of research in intellectual disability and masculinities, but also offer a fertile source for future research in intellectual disability, and critical studies on men and masculinities. On a broader level, these data have supported some of the accepted wider themes in critical studies on men and masculinities which were presented in Chapter 3. These are that there is no single masculinity, but masculinities; that masculinity is a changeable construct geographically, culturally and historically; and that masculinity is an embodied construct (Adams & Savran, 2002; Connell, 1995; Connell et al., 2005; Gerschick, 2005).

Significantly, this chapter has presented data which illuminates how degrees of cognition can contribute to changes in masculinity. It is in these data that the construct of conditionally masculine starts to emerge; the notion that masculinity is not only conditional upon cognition, but also the role of surrogates in performing conditionally masculine. Conditionally masculine recognises the limitations of disability upon expressing maleness, but not upon being male. As was presented in Chapter 3, the hitherto generally accepted analysis of masculinities is found in Connell's framework of hegemonic masculinity (Connell, 1995; Connell & Messerschmidt, 2005; Robertson, 2007). Here, masculinity is described not as fixed roles, but as configurations of practice between the categories hegemonic, subordinate, marginalised and complicit. Hegemonic masculinity is the dominant construct which is rooted in patriarchal, or gendered, power. The significant point in Connell's framework is the role played by autonomy and communication to participate as agents of practice between categories.

In contrast, conditionally masculine offers a different perspective as autonomy and communication, and therefore capacity to navigate the categories of gendered power in a framework of hegemonic masculinity, are cognitively diminished. The masculine surrogate would be the agent who performs the negotiation of any hierarchy. Gendered power, and subsequently the accepted analysis of hegemonic masculinity, does not appear as relevant to men and teenage boys with a moderate to profound intellectual disability as the emerging theory of structural inequality as articulated by Holter (2005). That is, internal and structural factors appear to have a greater influence over conditionally masculine than do factors associated with gendered power.

For example, the young man in this study with the least degree of cognitive impairment partly practised his masculinity via some cultural symbols which held meaning for him: the fireman, Ned Kelly, and echolalic swearing. None of the other men or teenage boys in this study displayed any meaningful connection with social-cultural symbols of masculinity. Outside of an innate bio-genetic male footprint, they practised their masculinity conditionally; conditional upon staff. The staff become a surrogate; the client's body the object of practice, the surrogate embodied as the key agent of practice. This presents some problems to theory as the innate bio-genetic notion harks back to the nature (biological) versus nurture (sociological) debate, or sex-role theory, which Connell (1995) asserted has limitations. As Connell stated, if biological determinism alone is wrong and social determinism alone is wrong, how can their combination, depicted as sex-role theory, as a compromise suffice? However, these data do point to the limited impact of social scripts the greater the degree of cognitive impairment, yet to state conditionally masculine is absent from social influence at this point would be incorrect as consideration of the environmental nuances of community group homes is yet to be discussed (see Chapter 9).

Unique to this research within the intellectual disability literature is the emergence of positive themes such as **male mutuality** and **male banter**. Whereas examples of mutually celebrated femininity have been published in the literature regarding female health concerns (J. Brewster, 2005; Women's Health Goulburn North East, 2002), this same celebratory tone does not exist for men and boys with an intellectual disability. In fact, the notions of gendered mutuality and banter reflect themes within the mythopoetic analysis of masculinity which is derided by the proponents of hegemonic masculinity. Furthermore, codes of ethics for staff working in the care sector are often very prescriptive in their definition of professional conduct which does not foster harder to define but important concepts such as mutuality, bonding, banter, and warmth. That is: *"…a delineation between clients and staff where you aren't really meant to cuddle – they aren't your friend, [we provide a] professional relationship"*. Instead, relationships between staff and clients are meant to be supportive (e.g. McVilly, 2007) but what does this mean in a qualitative and gendered way? Additionally, such codes urge caution against intimacy via the limiting of professional versus personal responsibilities, yet intimacy in the guise of male warmth was acutely defined as appropriate and life-enhancing within this study. This leads to the question: how should supports be structured to offer the physical intimacy and meaning in relationships without the fear of misunderstanding in the interaction? That is, how can male staff safely foster the *"…beautiful male bond"* described within these data?

Chapter 9 will now deconstruct and contextualise the data already presented in Chapters 7 and 8. Chapter 9 will explore the issues of a gendered care environment and will cover differences and similarities between male and female staff, the built environment, structural issues in community group homes, and the role of policy and training in the gendered care environment.

CHAPTER NINE

GENDERED SERVICE DELIVERY

> *Left alone, a seedling will grow into a tree and a tadpole will turn into a frog.*
> *But a human child does not turn into a functioning adult without lots of help.*
> *To learn to be the gender you are, you probably need thousands of hours of*
> *interaction with older, more – mentally – equipped members of your own gender.*
> *In our society, girls get this contact from women on a day-to-day basis,*
> *but boys rarely get it from men. (Biddulph, 1995, p. 13)*

Gendered service delivery is the third and final theme of *Conditionally Sexual*. It is a theme which attempts to triangulate data already presented and offers deeper insight into how male sexual health and masculinity are inextricably linked to service delivery. That is, service delivery is not an optional extra in the lives of the men and teenage boys in this study; it is a vital cog in the experience of quality of life. Gendered service delivery explains how important unique male and female caring roles are to people with an intellectual disability. Gendered service delivery clearly describes masculine and feminine perspectives to performing the caring role. Gendered service delivery also contextualises the gendered lives of the men and teenage boys with a moderate to profound intellectual disability and is depicted by the blue shaded area of Figure 9.1.

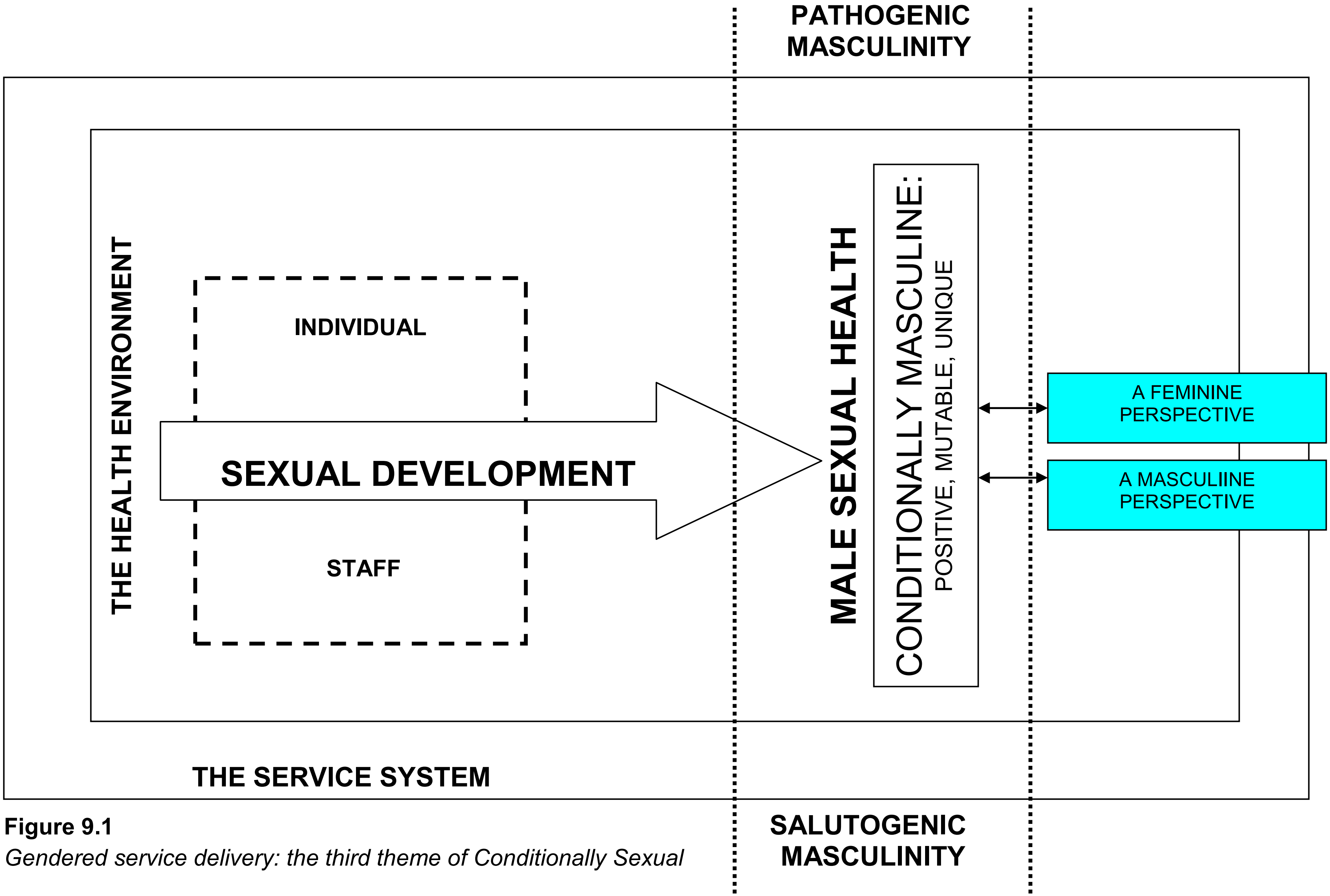


Figure 9.1

Gendered service delivery: the third theme of Conditionally Sexual

A GENDER CONTINUUM

Staff were asked during interviews about their perspectives on the concept of gender as it related to their role as paid staff and their interactions, specifically, with men and teenage boys with a moderate to profound intellectual disability. Responses ranged on a continuum between those who felt gender, as a broad concept, was less important, to those who asserted it was a critical aspect of their role. There were no significant patterns of responses from staff based upon their own gender and/or age. The meaning of gender as described by staff essentially reflects the diversity of views that might be expected from a range of different people in the community generally: 1) that gender was less important, and 2) that it was more important.

1) Gender Less Important

Gender was considered a less important issue for a number of reasons. The first was described as the challenge to find the time to provide unique gendered supports: *"… [the sector] tries, I think people try, but I think you tend to put convenience in there, where - okay we can all go there so that's what we all do … to get the most out of it, it is very hard [to focus on gender- specific activities], I think with the work ratio ... it is virtually impossible"*. The second reason depended on staff themselves; their own perspective influenced by their life experience. For example, one female staff member stated: *"…I tend to work better with the males I think, because I am that sort of personality, a bit of a tomboy … I'm not really into dressing up and putting makeup on … I like working with the guys. I grew up with four boys so I understand men well"*. Another female staff member, who declared a past abusive relationship with a male partner, was also influenced by her past and, while she stated gender was *"… not really"* important, she still held a certain gendered perspective toward some males with an intellectual disability: *"… when I went* *for the other job I was a bit wary that they were all males … just a fear that they were, you know, adult males, a fear that they were stronger than me … that I'm a female and I'm not as strong … I don't really feel that here … I don't feel vulnerable here being a female, but there I did"*. Thirdly, there were those who simply felt personality and identity were more important things to consider than gender: *"Identity is, probably, more important, probably than gender … in terms of my working, again its very individual … its around, I think acknowledging all interests, individual interests … if the guys are all sitting around watching the footy, a collective interest"; "…they all have their own identity … they all have their own little characters"*. These three points, and in particular the last, begs the point whether masculinity is even a part of ones identity.

Some responses referred to the existence of gender equality between staff; male or female clients were not factored into responses. That is, the role of staff was best performed as a neutered one. For example, a younger female staff member stated gender was *"… not important …I don't see that [gendered society] at all … [we're] all equal"*. A young male staff member was more equivocal in his response which was then qualified with a statement that appeared closer to his inner belief: *"…all the needs of the service users here can be met irrespective of [staff] gender … that said … there is something special about hanging out with someone of the same gender, it is a different interaction, but exactly what it is I can't put my finger on it … but I do have a bit of a sense that maybe we [males and females] do play slightly different [gender] roles, but I don't like admitting that because it heads down a dangerous path!"*. Likewise, an older female staff member presented a statement that reflected a gender-neutral capacity to follow a job description, but was also qualified later in the interview with an underlying belief in gender differences: *"Once you're at work, I don't think there is a lot of difference between the* *male and female personally … I think you've got a job to do you come in you do your job; [however] men and women are fundamentally different … you could sit and chat to a male for hours, I could sit and chat to a female for hours …. we have got different interests and different things we enjoy doing … [as for] the equality bit, I think the men should be doing the housework and things like that"*.

2) Gender Important to Role

For those staff who felt gender was an important part of their role, it was articulated only via a fairly broad expression. For example: *"Yes, I think definitely, very important, I suppose … they're different because they're gendered"*. The older male staff member, the only male staff member working in community group home one stated *"… gender roles are very crucial in society, the whole functioning [of society]"*.

Perhaps the most interesting theme emerging was the difference between equal employment opportunities and the clearly defined gender-based nuances of interaction and role performance. These data build upon the data presented in Chapter 8 which questioned how male banter, warmth, mutuality and bonding can be fostered in an environment of where intimacy between clients and staff is suppressed. Further to this, the codes of practice, which guide role performance, also err more toward the principles of gender equality via an emphasis on gender-neutral language (e.g. McVilly, 2007; United Kingdom General Social Care Council, 2002). Yet, deeper questions than those raised in Chapter 8 emerge: how can a person-centred approach be limited to the needs, opinions, values and beliefs, incorporating ethnic, cultural, and religious sensitivities, without mention of gender? Does a gender-neutral job description deny true person-centeredness? As Walsh (2007) stated: "gender is expressed at the intersection of personal and public domains – where the individual's identity becomes visible in the society where she lives and grows to maturity" (p. 591). The issue of gender was further elucidated in more specific discussion with staff about the differences and similarities between male and female staff; phrased as gendered caring roles.

GENDERED CARING ROLES

The roles of male and female staff were discussed in interviews, and further clarified during observation sessions, within the context of service delivery to male clients. The analysis of data using the constant comparative method saw the differentiation between a **feminine** and a **masculine** perspective toward role performance. There was no reference to an androgynous model able to traverse traditional masculine/feminine situations (Coon, 1986, Ch. 18); but there was a strong representation of a masculine caring role and a feminine caring role. These data depicted not only powerful societal gendered stereotypes, but also stereotypes of a differently gendered capacity to perform a caring role. Significantly, these data were generated not only from interviews but also from observation. Qualitative methods, such as interview and observation, although little used in researching disability support staff, facilitate the emergence of the latent phenomenology of staff experience and role conflict, such as friend/carer/parent (Hatton et al., 2004).

A Feminine Perspective

Two sub-themes were identified which characterised a feminine perspective to performing the caring role to the men and teenage boys in this study. The main sub-theme simply describes femaleness as different from maleness. The second sub-theme portrays how a feminine perspective incorporates caution toward male clients. These two sub-themes are interdependent and are shown in Figure 9.2.

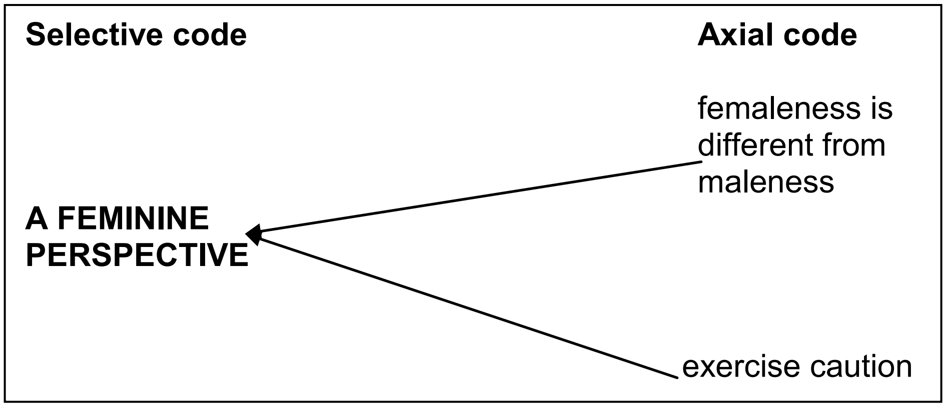


Figure 9.2

Axial codes for a feminine perspective

***1) Femaleness is different from maleness**: "… female staff are happy to give affection and cuddles …".*

Staff described a number of ways that doing femaleness, performing the role of the feminine carer, was in contrast to doing maleness via the role of the masculine carer. These included unique female qualities, defined female boundaries, a female perspective on male sexuality, plus a different interactional style from male staff.

Attributes the feminine carer possessed, ostensibly in greater abundance than the masculine carer, were described by several female staff. For example, female staff described themselves as being *"…more gentle, in general, than male staff"*. This gentleness was further described thus: *"… obviously, you know, women are more, I don't know, loving and nurturing …. not to say that some men aren't"; "I think, possibly, the female staff can be a little bit softer in their approach than maybe the male staff* *sometimes"*. One female staff member described one of the effects of these attributes: *"…I think females are, you know, melancholy him a bit more, we like soften him up a bit more"*. That is, gentleness and nurturing was one way to soften the behaviour of one of the teenage boys. These described intrinsic attributes reinforce the cultural assumption that caring is seemingly a characteristic of being born female (Bogle, 2007); that caring is the essence of womanhood and women's learned tendency (E. H. Thompson, Jr, 2005).

Similar to the data described in Chapter 8 titled "motherly interaction", there were no clear data collected during participant observation to support or to undermine the assumption that the adjective "motherly" was absent, but perhaps more that interpretations of mothering differ from person to person. During observation sessions, I was left with the impression of female and male staff who displayed gentleness just as I was left with the impression of male and female staff who also displayed a harsher style of interaction. However, these impressions were not documented in field notes as observable behaviour; they were my subjective impression of individual staff personality that I took from spending time with them. Hatton et al. (2004) commented how staff behaviour, so central to staffing research, has been surprisingly under-explored. Certainly, interpreting the behavioural parameters of vague notions such as *"mothering"* is fraught with difficulty and may, in part, point to one reason why it has been under-researched. Specifically, measuring behavioural characteristics, such as softness and gentleness, without the overt influence of subjective bias presents a significant challenge. However, female staff are using the adjective *"mothering"* in positively describing some of their attributes as carers so, as a notion, it has legitimacy.

Female staff also described defined and gender-specific boundaries that the female carer may preferentially adopt during interactions with the men and teenage boys in this study. Importantly, these are self-prescribed boundaries and do not relate to a gender-neutral job description. Two detailed examples were provided; responding to male sexual health issues and supporting one of the teenage boys to kick a ball around the yard. These boundaries were, in part, a reflection of the informal policy in each setting that male staff do not support female clients with personal and intimate care; the *"informal"* or *"in-house"* policies were not documented. That is, these data suggest an unwritten policy that has unofficially endorsed additional service delivery interpretations based upon staff gender.

Kicking a soccer ball around the garden was one preferred physical activity of this teenage boy that could be achieved without going on an outing where additional staff would usually be required. Furthermore, as he was visually impaired, such an activity within a fenced yard represented a form of exercise with minimal risk of absconding or injury. Yet, female staff no longer encouraged this form of exercise: *"… we had one male staff here that wasn't such a good worker, but he did go out there and play soccer with [Client E] and I thought that was good and maybe [the client] needed that, to be out there and playing soccer with the boys"; NW: Do you see female staff out with [Client E] kicking a ball around?; "…I think we all probably tried in the beginning but he wasn't as interested when it was the girls out there kicking a ball with him … now it seems like he's too lazy and can't be bothered to get off the lounge"*. Another female staff member stated: *"we've had male staff coming out and kick the ball around outside with [him] which is something that we could do, but being girls we don't do that, because it's socially not acceptable for us to do that"*. Whether the lack of motivation was staff or client-led remains unclear; the absence of observation data from this setting does not allow for the triangulation required to affirm deeper conclusions. However, it is pertinent to recognise there were no male staff working in this house at the time of the interviews.

Female staff stated feeling less comfortable regarding most issues concerning male sexual health; such feelings have been reflected elsewhere, although usually in relation to challenging sexual behaviour (e.g. D. Thompson et al., 1997). For example, one female staff member mentioned how, compared with male staff, female staff would tend not to want to hear about male sexual exploits: *"… I don't want to know what you did! … but the male staff was quite happy to sit down and let him brag about his [sexual exploits over the] weekend"*. Another female staff member stated *"… I suppose I just don't feel comfortable really [dealing with male sexual health] … with the female clients I would, I do, but with the male clients I feel like it's a male to male [thing]. It's probably best … because we [female staff] don't know so much, then its best to have males around"*. This feeling was repeated by one other female staff member although she recognised the role of all staff in supporting individual need: *"… as a female you just like to think that the male staff are gonna deal with that sort of thing [sexual health], but that's not always the case because the majority of staff are female … if it [a sexual support strategy] was put in place … then you just do it [whether male or female]"*.

A specific example of a sexual health matter referred to male penile hygiene where *"… there's a new cream that [he] has to have on his foreskin, which [some of the female staff] they're freaking out about it … but I say it's his cream and put it where you have to do it".* Concerning the young man, another female staff member stated *"… I am sure that there is an element of [female staff feeling] embarrassment …. we've got quite a number* *of young girls who don't want to see that [infected penis] … and they're quite within their rights to say „no' as well, but it doesn't help with his hygiene"*. Interestingly, this same staff member felt the teenage boy living in the community group home received better attention as he was less physically developed: *"… I think [Client E], because when he is naked he appears as a boy, and not a man, and people are more likely to clean him more thoroughly …. [he] appears as a 12-year-old, he hasn't got much pubic hair ... the perception of people who work in this house [all female staff] is that he is a child … [whereas Client D] he's quite large… has got chest hair, hair on his face, hair down there, because [he] is so big, he sweats a lot … he pongs when he comes home … I can see why people won't want to get close to that"*. Creating inequitable gendered boundaries which limit healthy outcomes for the young man and teenage boy in this example did not seem to matter to the female staff. As McConkey and Ryan (2001) asserted, staff have a powerful role to play regarding the sexual issues of clients in their care and these data demonstrate the power of unofficial, but house-sanctioned, gendered boundaries.

A distinctly female view of some facets of male sexuality was expressed by some male and some female staff. Female staff discussed how their view of male sexuality was framed by *"worry"* plus the consideration of *"trust*"; male staff described how a feminine view might *"over-analyse"* some aspects of male sexuality. This notion of gaining female trust triangulates with data presented in Chapter 7 under the sub-heading "self-discovery"; where the female staff member trusts the male with an intellectual disability, physical interaction was framed as exploratory. Although it was not raised by the data or in the context of this study, one hypothetical conclusion might be that a lack of trust renders some physical interaction as non-exploratory or, more significantly assaultive. For example, during a recent intellectual disability conference symposium on client sexuality, Kyrkou (2008) described a young man with an intellectual disability who was to be investigated for sexual assault after he had allegedly grabbed female staff on the breast. It was not until the young man's mother pointed out he was attracted to their name badge, not their breast, the non-sexual nature of his touch was realised. This presents a salient reminder of how a feminine perspective might over-analyse the context of an interaction; a suggestion that the potential for trust to be lost or gained depends upon the nature of the analysis. However, these remain hypothetical assertions.

One older female staff member asserted *"… I think most females don't trust men completely because that's who they [females] are … you have heard lots of stories and lots of things [about male abusers] over the years"*. This same female staff member continued by stating *"…I don't completely trust any man unless its someone I've known for a long, long time … I find it hard to trust … because, a lot of things have happened to me, over, in my life"*. During this interview I did not seek further clarity on the life events she was referring to but I was left with the clear impression she had experienced significant problems in a past relationship with a male. A younger female staff member who openly declared being involved in a past abusive relationship with a man talked more specifically about her worry about male staff. For example: *"… then we've got the thing with [the female client] as well, she takes a liking to male staff and you know, as much as it shouldn't, it does worry the girls as males do night shift on their own … and we do worry" NW: So the female staff worry about that? "I think I do, in as much as I probably shouldn't and should give people the benefit of the doubt and what's the difference between the girls working with the boys … but I've talked about it with other girls that work here and we feel the same … It's [female client] and the way she is promiscuous, she does come running out here naked … wanting a boy friend, wanting to get married … we* *do worry, you know, how the male staff that are here are gonna deal with that"*. No other female staff referred so openly to the issue of worry or trust about their male peers. However, Thompson et al. (1997) did mention one of the ways female and male staff differed was that "… men lacked women's wider awareness and fear of men's violent sexual behaviour" (p. 585).

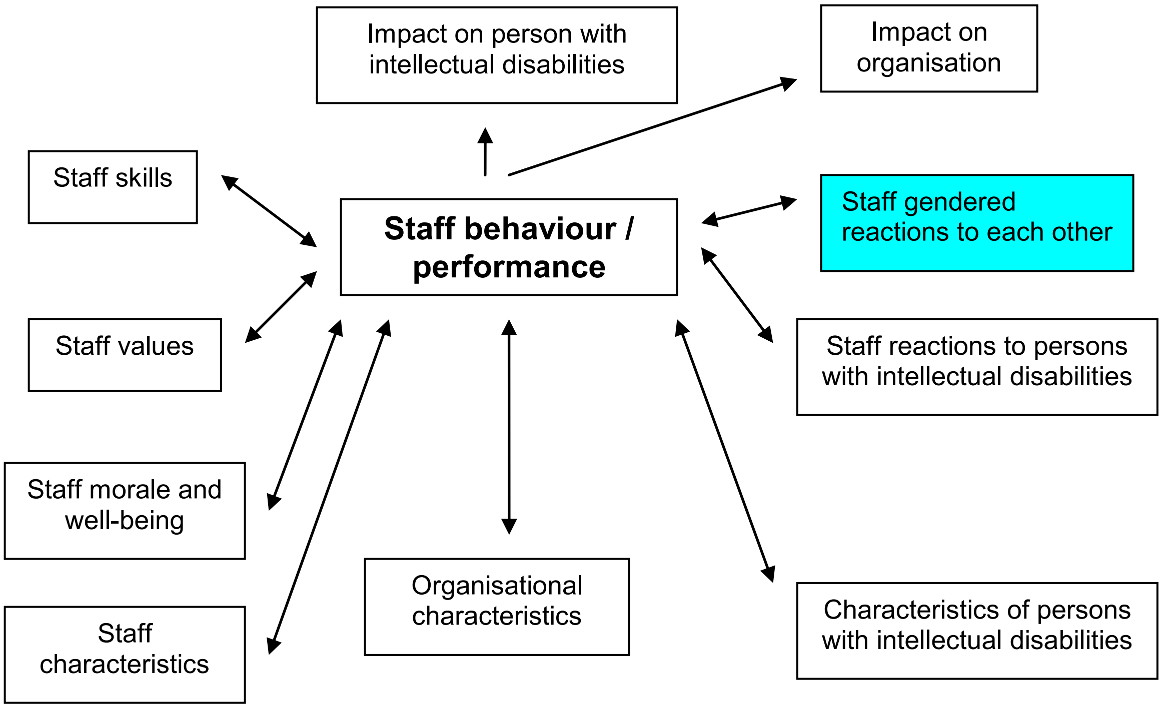
Over-analysis of male sexuality referred to both the cause of masturbation and male staff showing an interest in male sexual health issues. One younger male staff member stated *"… that interpretation of things [masturbation as more sensory, not sexual], that I have [as a male], is going to be different to female service workers, I think, who do see it [masturbation] more as an offensive kind of thing … and so that influences how they treat him … so [some female staff should] just don't try to read into it"*. Therefore, while female staff might feel less comfortable talking about male sexual issues, female staff might also over-analyse their male peers if and when they address the topic. One female staff member suggested that females do tend to be more observant than males which may mean male staff *"… are more reluctant to dig too deeply [into sexual issues] for fear of what others might think of his interest in the [topic]"*.

These data, where male and female staff have reflected upon their gendered reactions and views of each other, represent an area that has received limited attention in the research literature. Hatton et al. (2004) in their review of researching staff described the range of core constructs which make up staff behaviour and performance; the absence of gendered interactions within the literature is highlighted in Hatton et al.'s (2004) Figure 5.2. Therefore, in addition to "staff reactions to persons with intellectual disabilities", the present study's data suggest another core construct which might be titled:

"staff gendered reactions to each other". Figure 9.3 illustrates the suggested adaptation, shaded in blue, to Hatton et al.'s core constructs of staff behaviour and performance.

Figure 9.3

Amended core constructs of staff behaviour and performance



Furthermore, these data point to the value of qualitative approaches in triangulating some of the quantitative data concerning staff gender (e.g. McConkey et al., 2007). For example, if male staff are reluctant, as the data above suggest, to raise sexual issues on behalf of men and boys with an intellectual disability, the right to gendered advocacy for those with greater degrees of intellectual impairment appears to be restrained by anxiety, or perhaps concerns about a false accusation of unwarranted interest in the sexual matters of a vulnerable person. No data suggested female staff having to exercise a similar concern.

The feminine carer was able to adopt a different style of interaction from the masculine carer which encompassed both service delivery and the degree of physical warmth. One older female staff member reflected on how same-gender personal care policies represented a more recent phenomenon: *"… I don't know what it is but … females can do males [intimate and personal care] but there's this no-no about males doing females ...and doctors appointments and all the rest of it … and I find that very strange … 20 years ago … a male [staff member], he done the girly monthly thing [menstruation], the shower, the bath, and nothing was thought of it … but there's more thought of it today, I think"*. A meta-analysis of research into gendered care tasks by Miller and Cafasso (1992) found female care-givers were more likely to carry out personal care tasks but they do urge caution in generalising from results as the difference, although significant, was categorised into care-giving to a spouse or child; a completely different interactional context from the paid care of a non-relative. Data from the present study suggested the gender-difference in providing personal care is perhaps more related to female staff less concerned about physical intimacy/distance: *"… females can get away with a lot more than males, we [male staff] seem to be under a lot more scrutiny … as far suspicion of impropriety or some sort of a pay off … you're forever in situations where you can compromise yourself"*.

2) Minimising male temptation: "[Male clients] are more prone to be attracted to a woman [female staff] … it's [attraction] just a natural part of life".

Female staff described a number of pragmatic issues which had the effect of minimising the temptation for assault and/or abuse by men and boys with an intellectual disability. The main logistical issue is seen when female staff are less likely to work where the men and boys have known challenging sexual behaviours: *"… that's probably why they don't like to put females in that house in particular, because of the issue [sexual] with the male clients there, they [male clients] don't know their boundaries"*. Another female staff member avoided talking about sexual issues *"… I just don't like, to sort of, I suppose, I am just more careful around sexual areas when I am working with men, I don't like to, sort of, put any ideas in their heads, or to encourage them in anyway by talking about it … I'd hate to think that they would get some sort of idea about anything [sexual]"*. While the potential vulnerability of female staff to the sexual behaviours of men and boys with an intellectual disability has been explored elsewhere (D. Thompson et al., 1997), it is of interest that none of the men and teenage boys behaviour in this study was ever described as directly sexually challenging toward female staff. As has been discussed at length in Chapters 7 and 8, and supported by Thompson et al., the perception of minimal risk toward the sexual behaviours described was linked directly to the degree of impairment, and hence limited sexual insight, of the men and teenage boys. Notwithstanding this fact however, the stereotypical perception of unbridled male temptation remained.

One of the older female staff mentioned how their manner of dress may directly affect potential responses to them: *"I suppose with female staff … there is always an issue around how we dress, how we present ….. it's the risk to us and I think also too it's probably fairer for the guys as well we are working with, there is no point us coming to work with a low cut shirt and a mini skirt … and maybe to a certain extent I don't know* *how some of the male clients might respond to that, react to that … in a sense it could be a bit of a turn on … if its seen as provocation. In all fairness for the guys … and also around challenging behaviour … we have to be careful with what we wear”*. Although none of the staff wore a uniform, the dress of all staff was noted during the course of the present study to be very practical and reflected the intensive nature of the required care tasks; jeans, shirt and closed shoes were standard dress.

A Masculine Perspective

Three sub-themes were identified which characterised a masculine perspective toward performing the role of carer to men and teenage boys with a moderate to profound intellectual disability. The first sub-theme further describes the way that maleness is different from femaleness, the second and third sub-themes articulate more clearly how male staff perform a caring role. These three sub-themes are portrayed in Figure 9.4 and, although illustrated separately, are interdependent notions.

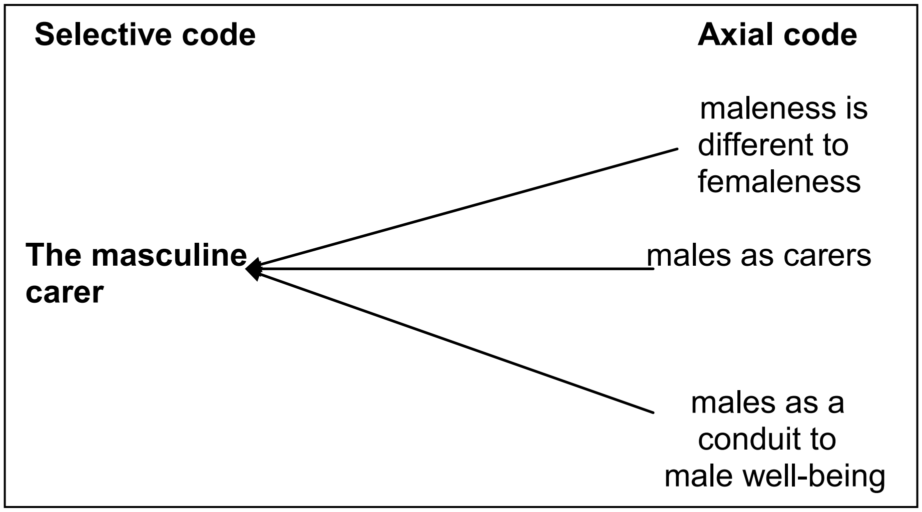


Figure 9.4

Axial codes for a masculine perspective

1) Maleness is different from femaleness: *"…[being a male] its another world I suppose".*

Just as masculinity, as described in Chapter 8, was partly constructed by male physicality, function, and activity, a masculine perspective to caring was also framed toward a tendency for physicality. That is, male staff were more predisposed toward *"… a focus on male clients and doing male things, such as swimming".* Male staff were more likely to *"… do blokey things than if I had put a casual female in the house"*. An example of blokey activities was described thus by a female staff member: *"It is quite important that they do have a bit more time with the guys [male staff] because they [male staff] do different things … recreationally … a guy might want to go to the football, I mean I would probably want to go shopping"*. One female staff member described a male peer as *"…not such a good worker but he did go and play soccer with [client D]"*. E. H. Thompson Jr. (2005) described how, through the dominant constructs of masculinity, male caregivers perform their role from a safe emotional distance; engaging in more physical, sports oriented, social activities may be one way to do this. Likewise, research exploring fathers' caregiving role found fathers provide less direct care and were less affectively close to their child, but were equally as likely to participate in social activities (Essex, Seltzer, & Krauss, 2005).

In addition to physicality and activity, a masculine perspective on caring was supported by other broad notions such as bringing a more relaxed perspective toward the role. That is, not relaxed as could be described by claiming male staff were "laid back", but relaxed in their perspective of maleness. *"A male worker's a bit more relaxed than a female … males can relate to [Client D], they're males … how they talk to him, they call him mate"*. Adopting a "friendship" approach to caring, as opposed to a feminine “maternal relationship”, was also found in Paterson’s et al. (1996) study of male nurses; an approach formed by an amalgamation of both masculine and feminine characteristics. Being more relaxed also described a male perspective toward male sexual expression, a female staff member stating: *“…a male staff member might understand a bit more how important that [masturbation/erection] was for a male client”*. This idea of openness has been found elsewhere; Löfgren-Mårtenson (2004) also stated male staff were “more open” toward sexual expression between clients. Furthermore, another female staff member felt male clients appeared to respond positively to a relaxed, open approach to caregiving: *“[male clients] are more prone to be asking a male staff member [about sexual health issues] rather than asking a female … who they were really comfortable with [more likely to be a male staff member]”*. One of the male participants in Yacoub and Hall’s (2009) study stated he could talk to other men about sex but not to “ladies”. This suggests male staff have the capacity to be a conduit to positive outcomes for male clients which will be explored later in this chapter.

An additional broad notion which described a masculine approach to caregiving was the way some male staff might alter their natural actions and conversation in the presence of some females. To a certain extent it is obvious that we all alter what we do and say depending upon who is present, but these data point to a process of alteration which encompasses performing a masculine perspective. The last paragraph in Box 8.2 where a male client wanted to participate in rough play/rumbling with me epitomises how I carried out the type of action which will bring about alteration in behaviour by the masculine carer. A male staff member described his behavioural alteration thus: *“… most of the scrutiny [of male staff] will be done by females, but there’s also policies, rules, instruction manuals, full of saying …” this is how you behave” … I don’t believe in that* *because I think we are all very individual ... the variety of our relationships comes in ... it robs the whole system [interaction and relationships] of human richness, it becomes a predictable thing. I reckon that you can't function like that [holding back]… when I have someone [female peer] who is that way inclined, who is likely to misconstrue … I will tailor my behaviour, you know I will scrutinise my behaviour more thoroughly, so as not to give them any reason for being that way [wary]. I can see that being the natural me …. which I have a clear conscience … this other person might, from what I know about them, might think otherwise … they might cause me trouble … its not a very pleasant situation … I prefer to curb my impulses to a degree in front of that person to have a peaceful shift"*. The central point appears as a reflection of data presented earlier which described the way female staff might worry about male staff, over-analyse some aspects of male behaviour, and pre-emptively limit trust in their male peers. The alteration of male behaviour in tandem with a lack of female trust, forces the perception of "maleness equating to risk" to perpetuate into a tacit self-fulfilling impasse. Although not mentioned in this study, the idea that accused staff might be guilty of suspected abuse until proven innocent, may also weigh on the minds of male staff as they alter their natural interactional style (Jones, 2007; Manning, 2008).

***2) Males as carers*: *"[It's] better to have males around in case they [male clients] want to talk about [sexual] things that they don't feel comfortable with talking to females"*.**

This axial code provided a broad summary, solely from a female perspective, of the wider qualities that male staff bring to the role. No comments from interviews with male staff or field note entries were assigned to this category; this category emerged through the eyes of female staff. Although Kramer's (2005) summary was written with unpaid male caregivers of family members in mind, one salient point referred to the tendency for the role of these male caregivers to be constructed via a lens of female experience. That is, their role was constructed, and subsequently measured, against prominent maternal stereotypes of the feminine carer. Two straightforward conclusions to this detail spring to mind; either males are not communicating their role perception, or they are not being asked. Alternatively, and less confidently, perhaps male staff don't have a view or don't feel the need to have an opinion, but perhaps this just further feeds stereotypes such as the clichéd male communication style.

Supporting with challenging behaviours was one common quality of the masculine carer: *"…male staff are more appropriate when there is a risk of [challenging] behaviour … I've seen male staff who have quelled a situation that was just escalating … a male staff member has come on board and there has been a bit of a dialogue between the client and [male] staff ... there's been a simmering, there's been a reduction, [in challenging behaviour] … I think male staff … can play a fairly good role with male clients"*. This notion has support from other research, although in this instance the female staff member is referring to a reduction in challenging behaviour due to male presence and communication as opposed to physical strength, as suggested elsewhere (e.g., Wilcox et al., 2006). In addition to providing support with challenging behaviour, some male staff were purportedly *"good role models"* and were better to have around the house to talk about sexual issues. Other positive qualities included supporting with male-specific health *"appointments"*, and male staff were more inclined to pay attention to genital hygiene: *"it is something they [male staff] can relate to, they [male staff] do have a foreskin and you [males] have to clean up there, they [male staff] would probably be more hands on … because of the problems men experience there [genitals/foreskin]"*.

Female staff were also quite unequivocal as to the qualities male staff brought to the domestic side of the role, simply that male staff were in general *"… not very good with housework"*. A female staff member recalled one male staff member who was *"…lazy in the house, I suppose it was a gender type thing, with the housework and cleaning … he would sit and watch TV with the client and not do anything else except get out there and kick a ball around when [Client D] was getting disruptive … as far as the housework went he thought it was women's duties I suppose and didn't do it"*. This theme was also reiterated by other female staff: *"we've had some good male staff here … they are not very good at the house work and not very good at cooking but they are very, very good at taking [Client D] somewhere"*. One of the younger female staff suggested this apparently poor domestic quality intrinsic to male staff might be more about female staff seeking perfection: *"the male staff will just get in and do it, whereas the females want everything to be perfect [vacuuming, cleaning etc]"*. When asked why the sector did not employ as many male staff, one older female staff member felt the role was *"… too, perhaps, hands on. Yes, you would get males but you won't get the males that would want to do the washing, the bathing, and the cleaning, I couldn't see my husband wanting to do that … and especially not young men"*. One of the younger male staff made the comment that male-orientated jobs would often be waiting for him on a Saturday morning such as *"… light bulbs … fixing stuff …. fixing the computer, that's a big one"*

Whereas these data can be analysed for their stereotypical and gendered roles around the house, the female staff don't seem to have a gendered axe to grind. Instead, the female staff are placing a higher value on domestic duties than on other aspects of the caring role in the community group home. That is, if a male staff member were more adept and/or willing to perform domestic duties they would possibly incur praise as opposed to critique. The unanswered question remains: is going on an outing less valued, or less important, to the lives of people with an intellectual disability than ensuring the ironing has been done? Does a clean floor, with its obvious occupational health and safety benefits, enhance well-being and quality of life more than a trip to the park to kick a ball around? O'Lynn (2007b) suggested if caring, as a concept, is examined through the lens of gender, then its association with traditional and sociological theories of labour division will predominate. However, the other side of this gendered view also asks why are traditional male roles, outside the home, any less caring? That is, can it be argued that toiling outdoors with a group of men and boys with an intellectual disability and negotiating the geographic and architectural obstacles that socially disable, is a less caring and worthy endeavour than staying in the community group home and ensuring the washing, ironing and cleaning are done? While these questions remain unanswered, the data have shed some light on the gendered dynamic and identity issues faced when one gender ventures into a field dominated by the other gender (Laberge & Albert, 2000).

Reflecting upon why there were so few males working in the sector, a variety of opinions were proffered by female staff. One related to the stereotype of male nurses being gay: *"I mean, I'm not passing comment on males who do work here, but a lot of them are gay, we have a lot of gay men come through this house, because it is seen as a gender specific [female] work place … people see any hands-on work [caregiving] as socially gender-specific [a female role] … gay men are socially seen as feminine … a larger proportion of male care workers are gay because of that"*. Similarly, another female staff member reflected upon the traditional and stereotypical view of caregiving as a female role: *"I think … a lot of males, more macho types go out and find … [more traditional male] jobs, I think the majority of people see it [care work] as a female type job,* *I guess we don't have a lot of long-term type male people have we?…. the guys [2 male staff] in the house here are probably going to be gone within a year"*. This last comment referred to the two sole male staff members who were studying at university and were using the job as a temporary income earner: *"… the field is more girls than men ... I think that the guys that do come in here, they do it more as a casual job rather than a serious field [career] …. [he] is more down here for the extra money"*. Economic realism was offered as another reason why males might not stay within a paid caregiving role: *"… its not a high paid job and they're not going to make [enough to] support a family, and raise kids, and buy a house on what they're going to earn in this type of job"*. In their review of career intentions of support staff, Dempsey and Arthur (2002) also found male staff were less inclined to see their career within the disability sector, although level of pay was not a statistically significant factor in choice to stay in or leave the sector.

***3) Males as a conduit to male well-being*: *"... he [Client C] does blossom with a male staff member ... he is so well behaved with a male staff member"*.**

The notion that male staff could provide positive outcomes for the men and teenage boys in this study was expressed very clearly, in particular by female staff. This assertion is hardly surprising for the same reasons female staff have provided unique supports to the health of women with an intellectual disability (e.g., J. Brewster, 2005). Indeed, Kyrkou (2008) clearly articulated how mothers and sisters of girls with an intellectual disability were vital to the early teaching process for menstrual care. Furthermore, the growing realisation that male teachers can offer not only positive role models to boys, but also offer a different teaching style (Biddulph, 1997; Donnelly, 2005) provides additional weight toward arguing that male staff in disability services might also have this aptitude. Indeed, McConkey et al. (2007) reported that some male clients in their study "…expressed a wish to have men as support staff and they reportedly responded better to them" (p.190). Staff provided specific examples of the way male staff are able to provide a different style of care, support and interaction, plus examples highlighting the results of this different style. Many of these examples have already been presented while illustrating other salient points not only in this chapter, but also in Chapters 7 and 8. Therefore, in order to avoid repetition, a summary of these examples are presented below in point form.

Promoting Maleness:

- male clients given more frequent opportunities to masturbate more frequently
- male clients given more time in the bath/shower
- greater engagement in sporting and outdoor activities
- male staff more understanding and tolerant of sexual issues
- male staff are more relaxed and easygoing
- rough, but gentle at the same time
- male mutuality, male banter
- male staff more likely to advocate for male clients
- male staff understand the importance of masturbation to male clients
- male staff provide more supportive supervision when males clients masturbate
- male staff offer a different stimulation, touch, feel, and smell
- male staff are useful during episodes of challenging behaviour
- male staff better at supporting with penile hygiene
- male staff give male clients greater freedom to move around unencumbered by legitimate restraints.

These examples provide some ways the role of the masculine carer positively differs from that of the feminine carer. In addition, sections of the data have characterised the results of positive male role models and positive masculine interaction. For example, male mutuality (described in depth in Chapter 8) articulated a style of interaction that resulted in male bonding and male warmth which, for one of the teenage boys, contributed to valued and celebrated maleness: *"… he has really blossomed from that [1:1 with male staff] … he does blossom with a male staff member … he looks up to the guys, he really, he loves being with men"*. Another female staff member described the excited and happy response and facial reaction in another teenage boy when a liked and trusted male staff member came on shift one day: *"… it was beautiful, a beautiful bond with [the male staff member] … a father figure, a male figure … I think it's just a relationship that he has, he obviously knows the difference between male and female"*. Another female staff member added to this theme by suggesting male staff of a similar age to the men and teenage boys might also be valuable: *"… he [Client E] does enjoy male companions [staff] … he just enjoys the company … normally when they [male staff] are younger too, not so much the older ones … a similar age, early 20's I think it is just that little bit more in common … when you've got someone [a male staff member] around their age, I think you find it, its like wow!, you know"*.

Community group home 2 featured a wall of over 30 photos hung prominently in the living room. Staff proudly referred me, and other visitors, to the wall of photos which acted as a repository for memories of specific and significant events for all of the clients and their families. A series of photos showed one of the teenage boys, who requires a wheelchair for mobility, on a seaside holiday with a young man from another community group home and two male staff. Staff were exuberant and touched by these holiday photos which show the teenage boy involved in a variety of activities which most staff admitted they either would not have had the confidence, or imagination, to suggest. One photo shows him on the back of a speed boat, another of him rolling in the shore break, another of him covered in sand. Staff saw these photos as evidence of the positive contribution male staff can make to men and boys with an intellectual disability: males promoting maleness. One of these photos is reproduced in Figure 9.5[29]; staff claim it as a celebration of maleness, a depiction of “unauthorised” male physicality and spontaneity achieved without a risk assessment, behaviour plan, or written consent for a potentially perilous activity.

Figure 9.5

Promoting male well-being

---

[29] Consent procedures regarding the reproduction of this image, which reveal the client’s identity, are located in chapter 5.

THE BUILT ENVIRONMENT AND STAFFING

The design of community group homes tends to reflect architecturally normative suburban ideals, with a few modifications such as ramps and wider doorways to accommodate wheelchairs, modified and efficient bathrooms, plus latches and doors to minimise identified risk. However, whether gendered support needs should be an additional consideration to service design remains unknown. For example, can male physicality be adequately expressed within a small suburban block where the garden is too small to even accommodate a medium sized trampoline? For men and boys without an intellectual disability this may not present as an issue as access to the local park and other activities can be achieved with minimal parental supervision; picture the soccer mums and dads chatting on the sideline, or sitting in the car park, while their kids burn energy running around a soccer field.

The entire front gardens of all three community group homes were unfenced which necessitated the front doors to be locked at all times in relation to client safety. Community group home 2 is situated in suburban western Sydney and all clients rely on a wheelchair for mobility, yet there are no footpaths anywhere nearby, there was also no town centre within walking distance, or park, or any other recreational facility. Community group home 3 is set on unkempt acreage in a semi-rural/bushland region that is unfenced at the front and the risk of clients absconding is very real. In relation to the geography of each setting and client support needs, the built environment, while not hostile, is not entirely safe, nor easily accessible. Staff to client ratios exacerbate the inherent problems of the built environment. For example, Monday to Friday community group home 1 has a staff ratio of five clients to one staff outside of the morning personal care rush. It is not possible for one staff member to safely go out with all five clients. Community group home 2 has five clients who use wheelchairs, two staff on shift, and one van designed for three wheelchairs only. Community group home 3 has three clients, two with challenging behaviour and one who is at risk of absconding, who are supported by one staff member.

The built environments and the support structures do matter and, while they are not male unfriendly, they could not be defined as male friendly. Data from field notes in Box 9.1 describe my first visit to community group home 3 where, before getting out my car, I knew, due to the uninviting appearance and my past experience that this house catered for people with difficult behaviour. It is a bland and sparse environment where male inquisitiveness, energy, enthusiasm, drive, and physicality is contained and when expressed, has little option but to disrupt routines constrained by limited staffing, limited resources, and within small enclosed rooms.

The ratios of male to female staff differed across all three settings with a common theme of limited numbers of male staff. This was most stark in community group home 3 where there were no male staff at all to support the two male clients. Their absence was most notable for the poor personal hygiene and ongoing penile infections of one client, and the limited physical exercise of the other. This was contrasted by the attention the female client received in that house with her weekly beauty regime of makeup and hair dyeing. Most of the female staff did reflect upon the paucity in numbers of their male peers, but were also quite pragmatic about the reality and chose not to dwell on it. The work of one male staff member in particular, from community group home 2, whose influence resulted in the blossoming of male clients, presents a telling view of the value of same gendered supports.

Box 9.1

Field notes: The built environment, community group home 3

17th May, 2007

Wow, what a place this is. On about an acre of fairly unkempt grounds in the middle of outer-suburban Sydney.

The house looks terrible from the outside. It does not even look like a normal residential house from the outside with a defined porch, windows, path, garden, lawn, other architecture etc.

Not sure what it looks like, maybe resembles an industrial type setting without the evidence of industry? Also visibly reminds me of the house at XXXXXXX in my previous job which cost thousands to constantly replace bits of the house!

Inside is quite sparse and it reminds me of several units at an institution I worked at from days of old. The kitchen is locked up and it even has the appearance of being a locked/secure commercial kitchen. For example, in comparison, one of the other houses has a gate on the kitchen to minimise risk but at least it still looks okay and feels good.

The entrance way houses a solitary couch, on its own and in bad shape. No pictures, decorations, or nik-naks.

The dining room is empty but for a table and two chairs (there are meant to be three clients!!).

Carpet quite dirty with many marks over it.

I would not like to live or work here, my goodness. What a stark environment.

Compared with other houses, this place is very remote. Middle of nowhere. Where on earth did they find this place?

Spent time chatting to Manager about the house, the clients, the staff, the research. This place should be fun.

Staff Training

Staff were asked during interviews about the types of training they had received since working in the care sector and whether they could recall any training that may have focussed on gender-specific themes. Only one staff member had received any form of sexuality and disability training and this occurred 20 years ago. McConkey and Ryan (2001) reported low levels (11%) of direct care staff training in sexuality and disability. Two of the staff mentioned physical intervention training that may have touched on some gendered issues, but they were unable to recall exactly what the gendered issues may have been. One staff member mentioned the child protection training where his role perception as a male staff member altered following the training. There is currently no formalised or accredited sexuality and intellectual disability training course offered in NSW and, in reality, without direct links to a state-wide policy framework the benefits, if there were some, may be short lived.

Policy

Box 7.2 contains the only sexuality policy which was available to staff in community group homes 1 and 3. Staff working in community group home 2 had no specific sexuality policy at all to support and guide their practice. A number of staff in all settings mentioned the acceptance of an informal policy that male staff do not support female clients with intimate personal care. Staff working in community group home 2 had the benefit of a personal care policy which stated a same gender policy for personal care was aspirational when possible and that staff should actively pursue this. This policy was also explicit that all staff still had a duty of care to provide intimate personal care to any client where this was urgently required, irrespective of gender.

SUMMARY AND CONCLUSIONS

Data presented in this chapter have triangulated the data presented in Chapters 7 and 8; they have given a richer contextual meaning to sexual development and the concept *conditionally masculine* in addition to offering some new insight into staffing in disability services. These data have identified that stereotypical sex differences and gendered caring roles remain quite strong. Moreover, these data have portrayed the complementarity of these gendered roles and how the masculine and feminine carer offer unique supports to the men and teenage boys they support. Male and female staff were simply asked to reflect upon the way they interact with one another and work with the men and teenage boys. These data represent a deeper insight into staffing research than has been possible using quantitative or the limited qualitative techniques described by Hatton et al. (2004).

The masculine and feminine carer operates within the same geographies of care but negotiates and interacts with the landscape in uniquely gendered ways. For example, gendered differences between physicality and interaction varied from a relaxed and activity-focussed style of interaction in the masculine carer, to a more nurturing, and controlled style in the feminine carer. Conversely, intimacy for the masculine carer was more of a risk than for the feminine carer, for whom intimacy was more permitted during role performance. Figure 9.6 illustrates some of the gendered phenomenology of how the masculine and feminine carers perform their differently gendered role. For example, how the masculine carer can be a conduit to maleness whereas the feminine carer is concerned by maleness; the masculine carer is comfortable with male sexual health whereas the feminine carer is uncomfortable. Significantly, Figure 9.6 depicts gendered role performance on a continuum, not as an oppositional dichotomy, a gender-neutral job description lies at the centre of the continuum.

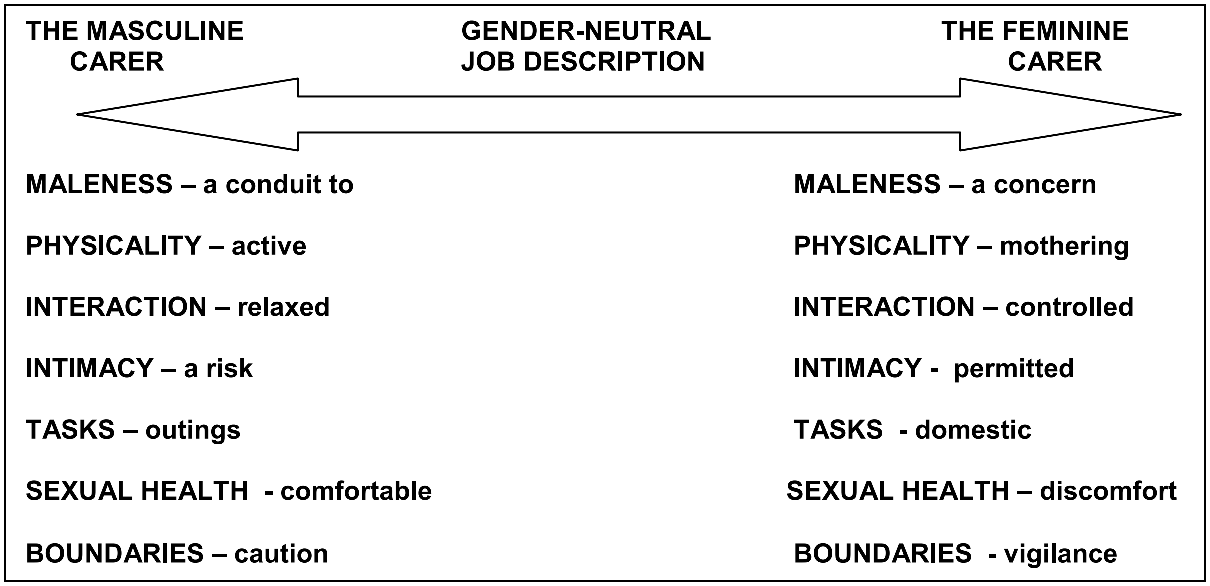


Figure 9.6

Performance of gendered caring roles

Chapter 6 introduced a conceptual model, **Conditionally Sexual**, which depicts a contextualisation of the sexual health needs of the men and teenage boys with a moderate to profound intellectual disability in this study. Chapter 7 deconstructed the first theme, **sexual development**, which presented one part of male sexual health as an interchange between individual factors and the influence of staff. Chapter 8 deconstructed the second theme, **conditionally masculine**, which articulated another part of male sexual health as a construct of masculinity that was positive, mutable, and unique. Chapter 9 deconstructed the third theme, **gendered service delivery**, which illustrated how the gendered service setting influences male sexual health outcomes. Importantly, these data suggested male sexual health goes beyond the genital and is a unique interaction between the individual, masculinity, and the gendered environment. The final chapter of this thesis, Chapter 10, will provide an overview of the study with a specific focus on the purpose of the study, the attendant methodology, and the key findings of the study. Chapter 10 will also consider the scientific rigour of the study through a review of key criteria in qualitative inquiry. Finally, it will consider the theoretical and practical implications of the study including a propositional conceptual framework for male sexual health.

CHAPTER TEN

A REVIEW OF THE STUDY, AND FUTURE IMPACT ON POLICY, PRACTICE, RESEARCH, AND THEORY

This chapter will reassess the purpose of the study, its findings and implications, and the attendant methodology. Specifically, it will evaluate to what degree the stated aims were met as the study evolved over its four-year duration. This chapter will consider methodological issues with a focus on scientific rigour and research reflexivity. In addition, it will discuss the implications of the findings for policy, practice, research, and theory. In conclusion, a propositional masculine health environment will set the scene as one future consideration for researchers exploring the sexual health needs of men and boys with a moderate to profound intellectual disability.

PURPOSE OF THE STUDY

The aim of this study was to identify the sexual health needs of men and teenage boys with a moderate to profound intellectual disability. Justification for the study was based on several points. First, little was known about the sexual health needs of men and boys with an intellectual disability and what research had been conducted tended to focus on men with a borderline to mild intellectual disability. Second, the sexual expression of these men and boys was mostly conveyed within the literature as problematic; little work has been presented which recognises sexual expression for this group of males as healthy, fun, pleasurable, therapeutic, and a developmentally appropriate experience. Third, the historically taboo nature of sexuality and disability was framed by notions that people with an intellectual disability were either asexual eternal children, or over-sexed deviants. That is, as a result of their limited cognitive capacity, people with an intellectual disability are depersonalised, dehumanised, neutered, and seen as “the other” (Parmenter, 2001). Finally, my own perspective consisted of two points: 1) that the sexual health needs of all people with an intellectual disability had been dominated by the topic of risk and abuse, and, 2) that social perspectives presented as “whole truth” do not provide the entire story of the sexual health needs of this unique group of males.

On the one hand, the stated aims of the research were exceeded. However, on the other hand, the research may have posed more questions than it answered. The aims of the research were exceeded by the theoretical contribution to the critical studies on men and masculinities, sexuality, and the nature of gendered care relationships. While more is now known about intimate male hygiene as one health determinant (N. J. Wilson, Cumella et al., 2009), the study highlighted how male sexual health tends to be focussed on the penis as “confrontation” as opposed to a broader understanding of sexual health that incorporates factors “beyond the phallic”.

THE FINDINGS

Conditionally Sexual represents a new perspective to frame the sexual health needs of men and boys with an intellectual disability. Conditionally Sexual suggests sexual health needs for this group of males are a combination of three factors in a constant interchange between the person and their environment: 1) individual sexual development, 2) masculinity, and 3) service delivery. While most of the staff tended to contextualise sexual health by the penis and its changing states, this limited contextualisation was a reaction to the challenges staff face within their role performance. Staff did present a wide range of issues when defining sexual health needs, but often framed them via the penis. For example, sex-drive was represented by the frequency of erections, hormonal change by the presence or lack of erections, sexual need through masturbation, reinforcement through the masturbatory response cycle, and insight by phallic awareness. A broader conceptualisation of male sexual health could materialise by a reflection of the frameworks endorsed by the World Association for Sexology, and the World Health Organisation as outlined in Chapter 2.

1) Sexual Development

The literature described in Chapter 2 indicated how the dominant sexuality discourse has focussed more on sexual rights, as part of a wider social constructionist and symbolic narrative, than it has on a broader biopsychosocial perspective of sexual health. Sexual health instead, is located by the dominant sexuality discourse as a reproductive and bio-medical concern. While sexual rights are a fundamental goal for all humans, Conditionally Sexual reflects the historical constant outlined in Chapter 2 that people with diminished cognitive capacity have always experienced restricted rights depending upon the degree of in/capacity. Conditionally Sexual recognises the legal determinants for capacity and consent, which in the current sexuality discourse tends to be trivialised by the symbol of rights. Further, Conditionally Sexual recognises developmental stages of sexual expression, another factor often overlooked by the current sexuality discourse.

2) Masculinity

The literature in Chapter 3 surmised that a focus on structural factors is more helpful in understanding gendered inequality than a focus on gendered power. Conditionally Sexual has illustrated that maleness is not ameliorated by impairment, but is a notion that can differ experientially because of impairment. Conditionally Sexual offers a perspective of masculinity yet to be acknowledged by critical studies on men and masculinities. Conditionally Sexual highlights the role of cognition in the experience of maleness and hence its importance as one other facet when suggesting masculinity is an embodied experience.

3) Service Delivery

The literature in Chapters 2 and 3 pointed to a limited appreciation of the gendered roles staff play. Chapter 2 highlighted the prevailing focus on abuse, risk, and staff attitude toward the sexuality of people with an intellectual disability. Conditionally Sexual shows that such a focus renders the discourse staff-centric which: 1) forces staff to assume responsibility for sexual matters and, 2) reduces sexual matters for males with an intellectual disability toward a problematised and reactive position. Conditionally Sexual has additionally highlighted how gendered roles influence service delivery and the way male sexual health matters are perceived.

Summary of Findings

Conditionally Sexual therefore is an innovative concept as it has uncovered a contextualisation of male sexual health that is not limited by an ideology centred on rights. Conditionally Sexual also breaks new ground as it incorporates a theoretical union between disability, sexuality and masculinity. Conditionally Sexual has shown that the gendered roles of staff are a pivotal medium for the experience of gendered health outcomes. Conditionally Sexual can be summarised thus: **The sexual health needs of men and teenage boys with a moderate to profound intellectual disability are the union of developmental sexuality and masculinity, in an environment where gendered supports allow a sexually healthy male to emerge.**

METHODOLOGY

While ethnography was selected as the most appropriate methodology to answer the research question, some methodological issues, and limitations, which include my own bias, need to be acknowledged. The primary issue relates to differences in theoretical perspectives which have become central to the emergence of Conditionally Sexual and the discussion within this thesis. The secondary issue relates to my own learning curve as a researcher and how the numerous methodological challenges forced me to question myself both professionally and personally.

Review of the Literature

According to Grbich (1999) a literature review has several purposes. Concerning the topic of the present study these purposes were to:

1) establish knowledge of male sexual health in the intellectual disability literature,
2) locate the theoretical/conceptual basis of male sexual health,
3) identify any gaps in the literature, and
4) draw any implications that may relate to male sexual health.

The process of conducting a literature review is straightforward. It is much more difficult to negotiate the dispute between those who stress any review of the literature in qualitative inquiry invites undue theoretical influence, and those who argue without a review of the literature time can be wasted conducting research that already exists (Holloway & Wheeler, 2002). Influential to my decision to conduct a wide ranging review of the literature was the realisation that as humans we are all influenced, one way or another, and conducting research is no different provided that, as researchers, we declare our colours from the outset and recognise the influential role of the literature (McVilly et al., 2008). That is:

> The gendered, multiculturally situated researcher approaches the world with a set of ideas, a framework (theory, ontology) that specifies a set of questions (epistemology) that are then examined (methodology, analysis) in specific ways. … Every researcher speaks from within a distinct interpretive community, which configures, in its special way, the multicultural, gendered components of the research act (Denzin & Lincoln, 1998, p. 23).

A literature review, combined with my own *a-priori* perspective, influenced the research instrument and analysis, and therefore contributed to the scientific rigour of the present study. The literature review traversed theoretical and conceptual thinking in disability studies, sexuality studies, sexology, critical studies on men and masculinities (which incorporates appreciation of gender studies), men's studies, primary health care, men's health, and quality of life. Concerning the topic of enquiry, the literature review established there was a limited focus on the sexual health needs of males with an intellectual disability and their wider health needs. Further, the literature was conceptually driven by a focus on male social pathologies and failed to incorporate mainstream theoretical contexts in male health promotion (N. J. Wilson, 2005).

The literature review also set the scene for an appreciation of the ongoing theoretical trichotomy between a pre-modern relativist stance, modernists who attack biological reductionism, and post-modernists who are primarily concerned with deconstruction (Storkey, 2000). Appreciation of the historical and scientific location of each perspective proved to be an important point. That is, the contesting of sexology by writers concerned with queer theory, sexuality studies, and social constructionism (e.g. Foucault, 1978; Gagnon & Simon, 1973; Weeks, 1986, 1991) has created a dichotomy between what Allen (1992) calls "sex research" and "sexuality studies". You either become a sex researcher (seeking truth) or you study sexuality (seeking meaning). A similar dichotomy, based upon perspective, has also been drawn in studies relating to intellectual disability and masculinities. For example, as Shakespeare (2006) stated, disability studies are based on the social model which asserts society disables, and is set against the bio-medical model's allegedly reductionist view of impairment. Critical studies on men and masculinities refers to the socio-cultural study of masculinities which emanated from feminist theory and the subjugation of gay men (Connell, 1995); while men's studies embraces manhood from a rejection of post-modernist and feminist perspectives of patriarchy (Biddulph, 2000). This revelation was most important as the insight enabled me to limit bias from the literature to the present study; I was able to start identifying the *a-priori* perspective of other researchers which gave context to their findings. That is, I could appreciate different author's findings within the context of their particular approaches without necessarily opposing them.

The literature review significantly influenced the structure and the content of the semi-structured interview schedule. Chapter 2 concluded that sexual health as a biopsychosocial construct combined the strengths of sexology and of sexuality studies and acknowledged the notion of a healthy sexuality. Chapter 3 argued that any research seeking to explore male health must also consider issues of masculinity. Hence, interview participants were asked about their perspectives of sexual health and masculinity as they are inextricably intertwined.

Ethnography

The research method of ethnography was used to explore the topic of enquiry. Principal to this choice of method was the need to uncover the perspective of a unique group of males whose ability to accurately articulate their own feelings was limited due to their cognitive impairment. Perhaps most striking of all were the staff gendered perspectives of each other and the manner in which staff opened up, divulging some profound and personal narratives. Some of this was a challenge to respond to, so at times I was required to become an “empathic” and “passive” listener as opposed to “listening for information” (De Vito, 1988). One pertinent example related to two female staff who referred to past abusive relationships with male partners. On another occasion, I was honoured to respectfully listen to a female Aboriginal staff member who opened up about some of the contemporary issues confronting Aboriginal males, a topic usually referred to as *men’s business*.

Observation in the community group homes proved unpredictable and required a degree of flexibility on my behalf. For example, the health status of the older male client in community group home 1 deteriorated significantly during the process of inquiry which meant observation was sporadically performed in between often lengthy hospitalisations. Furthermore, the change in auspice of community group home 3 meant observation was limited to preliminary visits and time spent in the home while conducting interviews; the intention was to spend more time simply observing. While disappointing at the time, such requirements for adaptation and change over the length of ethnographic studies are apparently quite common and the researcher needs to adjust, and move on (Janesick, 1998).

Scientific Rigour

Scientific rigour in qualitative inquiry can be measured by a number of criteria (Morse, 1998), but mainly consist of appropriateness, adequacy, auditability, and verification. Walford (2001) also suggested theory is a vital part of any data analysis.

During each stage of the present study adherence to these criteria was followed as much as possible:

1) Appropriateness: Firstly, the semi-structured interview schedule was informed by the literature in both the mainstream and intellectual disability areas which ensured the data were appropriate to the research question. Secondly, the pilot study ensured the semi-structured interview schedule met its required aims. Thirdly, purposeful sampling ensured the data referred to males with a moderate to profound intellectual disability living in community group homes.

2) Adequacy: The amount and nature of data collected during the 18 interviews were adequate as saturation started to occur at around interview 15. Although the observation data were limited, changes within the field dictated this limitation so adequacy was dictated by circumstance rather than choice.

3) Auditability: The use of a tabular format for data analysis (see Appendix 8) ensured an audit trail is visible between the data, codes, and the final theme.

4) Verification: Invited feedback of the interview transcripts from interview participants provided the first stage of verification. Second, discussion and questioning during observation sessions with staff were used to verify topics and themes, and my interpretation of what was happening in the field. Third, member-checking of interview transcription and of the model Conditionally Sexual (Figure 6.1) ensured interpretation of the final themes had both explanatory power and reflected reality and meaning. Finally, dissemination of the model Conditionally Sexual at both formal conferences and informal university-run colloquia reinforced another level of validity for the interpretation of the data.

5) Theory/methodology: Adherence to ethnographic methodology provided a certain amount of scientific rigour. Use of the constant comparative method to analyse data provided further scientific rigour.

Ethics

The two main ethical considerations were: 1) the conduct of interviews and observation sessions, and 2) whether the intrusion into people's living and working space caused any undue interference or stress. Certainly the quantity and quality of data on a potentially challenging topic suggests interview participants felt sufficiently at ease and were not threatened by my presence or conduct. Observation sessions were conducted at a time which suited the all of clients living in the community group home, staff, and their daily routines. For this reason, the level of intrusion was minimised as my presence was dictated by the natural rhythms and patterns of the clients' lives. On the few occasions my presence was inconvenient I was advised of this over the phone prior to the visit and the visit was cancelled.

An additional ethical issue for some qualitative ethnographic research is the eventual number of actual participants and the extent to which consent has been ascertained. For example, female clients plus visitors to the houses during data collection ranged from a visiting mental health nurse, therapeutic dogs and their handlers, families of other clients including young siblings under the age of 16, casual staff, and an electrician. None of these other people gave their informed consent yet they influenced the natural setting, although, none of these people ultimately appeared in the final analysis and description. On some occasions I described to visitors what my presence was for and the nature of my study. By providing positive encouragement for the purpose of the study at the same time as not objecting to my presence, they gave tacit assent for my presence as a researcher. However, the quandary still remains for any naturalistic fieldwork research and delineating those who must consent, those who tacitly assent, and those who literally have no idea.

Reflexivity

Having declared my *a-priori* perspective in Chapter 4, the question of reflexivity refers to how I considered these preconceptions over the duration of the study and my reaction to participant's accounts (Holloway & Wheeler, 2002). In terms of methodology and procedure, in hindsight, and with more confidence, I should have started observation much earlier to see what unfolded in preference to staging and sequencing the different types of data collection; interview, observation, and collection of artefacts. While less to do with preconceived ideas, this hesitation was more to do with needing to feel in "control" of the process, largely due to lack of poise. A second reflexive issue occurred about half way through the study when my PhD supervisors pointed out I was presenting an oppositional and reactive position between my own biopsychosocial comfort zone and other perspectives. Through interview participants' responses to their views on their peers gendered roles; it enabled me to better appreciate the value in gendered perspectives, such as radical feminist accounts (e.g., Jeffreys, 2008), that I previously may have rejected out of hand for their hostility towards males.

During the process of data analysis, I came to realise the importance of the nature of the disability service system in Australia, in particular the standardisation of community group homes on the people with an intellectual disability who live in them. That is, I was seeking a person-focussed and salutogenic research agenda, but realised this was actually constrained by the rigidity of the service system. The men and teenage boys in this study receive a “service” based on the community group home model as opposed to being supported to “live” a life with meaning in a model that allows this to materialise. No matter how much additional data may have been collected, this constraint on a meaningful life presented as a constant. In contrast, my experiences working in the UK where a person with an intellectual disability receives “individual funding”, while not totally without its problems, at least enables the person with the support of their family, significant others, and their social worker, locate a service model that will better suit their hopes, dreams and desires. For example, in NSW, Australia, a vacant bed is filled by a government-run committee who peruses an extensive waiting list and the place is allocated based upon priority. Conditionally Sexual recognises this constraint to living.

IMPLICATIONS OF THE STUDY

This is the first known study to explore sexual health needs for men and boys with an intellectual disability which also incorporates exploration of masculinity theory and gendered caring roles. Exploration of the intersection between sexual health, masculinity and gendered care has provided a deeper contextualisation than would have been possible by exploring sexual health isolation. Notwithstanding the significance of the study, there are two important limitations: 1) the absence of the views of males with a moderate to profound intellectual disability on their own sexual health needs and, 2) this study focussed on men and teenage boys with a moderate to profound intellectual disability so without further inquiry the results cannot be generalised to any other group of males. While serious doubts have been raised as to whether the views of people with greater degrees of intellectual impairment can be ascertained (Ware, 2004), the use of ethnography has ensured their preferences were documented, albeit as interpreted by others. In addition to the ethnographic implications of the study, there are both theoretical and practical implications that need to be acknowledged.

Ethnographic Implications

As was discussed in Chapter 4, ethnography has a noteworthy, yet under-used, pedigree in ascertaining the views of people with intellectual disabilities (e.g., Atkins, 1998; De Waele & Van Hove, 2005; Edgerton, 1984, 1993; Klotz, 2004; Löfgren-Mårtenson, 2004). Ethnography, argued Klotz, through observation as a data gathering tool, enables a deeper insight into the lives of people with an intellectual disability through analysis of interactional relatedness: "… [ethnography] allow us to actually enter into intellectually disabled people's worlds and relate to them as people who are already fully human and encultured beings" (p. 101). The present study has managed to elucidate, largely via this methodology, a perspective of male sexual health that is perhaps more "meaningful" than other methods might have produced. It is an ethnographic perspective that recognises the innate humanness of males and their sexual health, irrespective of impairment, but has constructed this meaning through recognition of the role of impairment in the experience of sexual health.

Grbich (1999) argued ethnography can be divided into three categories: classical ethnography, critical ethnography and post-modern/post-structural ethnography. The latter two categories, while slightly different, both seek to explore the distribution and discourse of sociocultural structures of power. While the present study does not claim to strictly adhere to a classical ethnographical orthodoxy, it is situated closer to this paradigm as it did not presuppose the existence of any hegemony. This is an important distinction for several reasons, most of which have been discussed in the context of declaring my *a-priori* perspective, as it enabled any potential power relationships, and in particular gendered power, to emerge naturally and without bias. What emerged were differing situational contexts of power and powerlessness between staff, clients, and the service system, but no direct or tangible evidence of an intellectual, gendered, functional, structural, or racial hegemony.

These seemingly contradictory experiences of power and powerlessness were evident throughout the present study. For example, men and boys with an intellectual disability can hold power over staff, other clients and the service system through behavioural displays of actual and potential strength. A fear of male power was one concern articulated by female staff. On the other hand, some of the men and teenage boys were also powerless in relation to some female staff who might use legitimate restraint in order to gain some perceived control over activities during a shift. The service system holds power over staff and clients through a combination of its lack of guiding policies on human sexuality, and an assumption by staff that the system does not want staff to deal with sexual matters. Male staff were also powerless in the face of stereotypical perspectives that maleness equates to risk. Equally, most people with an intellectual disability, male or female, experience levels of powerlessness because of their intellectual disability and situation as a dependent person. Indeed, by adopting a more classical ethnographic approach, as opposed to looking for evidence of inequality through a critical post-modern perspective, the proposition that no tangible and predictable hegemony exists has some, albeit limited, validity. For example, while paid staff are in a position of power, this does not automatically infer that staff assume that power in their interactions.

Drury et al. (2000) stated not all staff have power, that a professional hierarchy is at play for example between management and other staff. However, there no evidence for this presented within the data, although it must be acknowledged representatives from senior management did not participate in the study. In fact, the data mirrored the findings of N. Wilson, Clegg and Hardy (2008) where even well qualified and experienced staff who faced ethical challenges were inadvertently left vulnerable by a myriad of factors, none of which appeared to be constructed through hegemony. Examples of this include a female staff member unsure what to do about hugging a teenage boy when he expressed a desire for this interaction. His mother had asked the staff to give him a hug, but the official Community Visitor stated it was unacceptable practice, yet most female staff in all settings allowed this form of meaningful interaction to take place. Indeed, my own experience in one of the settings portrayed my own emotional/professional conflict, despite the researcher allegedly holding the power, with a teenage boy who wanted to rumble with me (see Box 8.2).

These are important implications to acknowledge as the ethnographic methodology gave an insight into the complexities of power and powerlessness that are often over-simplified. Future research that employs such a methodology might provide even more revealing insights into how power and powerlessness are practised. The disability, sexuality, and masculinity literature is replete with arguments of hegemony and assertions the attainment of rights will result from a deconstruction of such hegemony. The present study suggests marginalisation, subordination, domination and complicit hegemony is experienced universally by all actors at different times and in different contexts.

Toward a Masculine Ethnography?

The manner with which staff opened up to me during interviews, specifically concerning their gendered perception of each other, leads me to wonder whether a female interviewer would have received the same or a different level of personal reflection. Comments by one of the male staff members about political correctness seemed something that he felt at ease stating because I was also a male:

"… one of the things that I totally laugh at, I put up with it, but I don't really care much about it is this political correctness, I think it is such an unnecessary thing, its like I know it grew from the era of when women's liberation started, and women started asserting their roles [against] dominant males … all it did was scare a lot of guys, you know, out of very worthwhile role playing [caring] careers. A lot of Psych nurses, for example, went and drove taxis and do other things, because who wants to put up with that sort of thing on a daily basis, you can't express your own way, you have to listen to … being called this or that [chauvinist] … instead of competition it should be cooperation, I don't think all males were persecuting the females in the past …. I know there was a patriarchal society that predominated over the centuries but a lot of guys now are easygoing … and now women are complaining men don't have enough assertion to form a [meaningful] relationship [with them]".

Irrespective of the content of this passage, it supports the notion presented in Chapter 4 of a *masculine ethnography*; males researching males. That is, did my role as a male researcher exploring male issues offer a wider contextual validation than would be possible if the researcher was female? As stated in Chapter 4, it is reasonable to assume there are subjects which men do not want to share with women just as there are subjects women don't want to share with men. Data presented in the present study suggest males do have insight into male lives that, while not closed to women, are not as readily open to them. One of the strengths of the present study is not only the inclusion of women's voices, but also the value placed on their critique and perspective of maleness. A masculine ethnography therefore has the potential to offer glimpses into the lives of men at the same time as offering a non-oppressive methodology.

Implications on Practice

The three primary implications of the present study that relate to practice are: 1) the limited guidance for staff on supporting the sexual expression of men and boys with an intellectual disability, 2) the interactional dynamic between staff and these men and boys, and 3) the lack of male-specific health screening. All three practical issues could be efficiently addressed via clear policy and procedural statements to provide staff with an ethical framework within which to practise. A pertinent example relates to penile hygiene for the uncircumcised male (N. J. Wilson, Cumella et al., 2009) where staff need to be aware of the following:

> **1** How to perform adequate penile hygiene; **2** When retraction of a foreskin is not appropriate; **3** How to respond to an erection; **4** How to respond if a tight foreskin will not retract over the glans (head) of the penis (phimosis); **5** How to respond if, once retracted, a tight foreskin gets stuck behind the glans (paraphimosis); **6** Recognising indicators of infection and appropriate responses; and **7** The risks associated with poor penile hygiene.

By identifying simple practice issues, such as these seven points for penile hygiene, the development of clear procedural guidelines is simplified as the focus is directly client centred.

Masturbation provides another very important example where guidance for staff could be made much clearer if the focus was on masturbation for the benefit of the person with an intellectual disability. Drury et al. (2000) recognised the importance of self-exploration pointing to an example of staff providing a specialised bed-sheet for a male with an intellectual disability to enjoy some time without an incontinence pad to masturbate in private. Policy documents on human sexuality reviewed in the present study (see Box 7.2) where they existed, describe what staff can't do but do not offer suggestions on what to do beyond ensuring rights are not denied. The example offered by Drury et al. is simple, gives staff some professional boundaries, but most importantly recognises the valid role of sexual exploration to quality of life. Such a statement might appear in a policy document as a variation of the following:

> All clients should be offered time out of their incontinence pads, in the privacy of their own bedroom, to not only offer the benefits of fresh air to enhance skin integrity, but also for the benefit of any self-exploratory sexual activity they desire. This should be offered at a time convenient to the client and should incorporate appropriate occupational health and safety considerations and aids to minimise any identified risk to both the client and staff.

Cambridge, Carnaby and McCarthy (2003) stated that little attention has been paid to masturbation within the literature, yet it is one of the most common methods of experiencing sexual pleasure. What literature there is, in additional to Cambridge et al.'s contribution, usually relates to masturbation as a problem and offers a range of potential treatments, solutions, or intervention plans (e.g., Kaeser, 1996a; Robison et al., 1992; A. Walsh, 2000). The suggestion by one of the male staff members in the present study that others were reading more into one of the teenage boy's masturbatory repertoire than was necessary is a salient point. That is, masturbation might sometimes only be problematic if it is constructed thus by staff. For example, Cambridge et al. discussed the challenge staff may face trying to understand why a person with an intellectual disability is masturbating. In doing so, Cambridge et al. suggested staff need to reflect upon their own values and beliefs. As it would seem logical that the main reason people masturbate is for its pleasurable effect, drawing staff into the equation by suggesting they question their own values in the process is an invitation to turn masturbation into a staffing/service issue. That is, has masturbation become an ethical issue simply because the discourse constructed by the sector has turned it into one?

The personal gain masturbation offers provides another dimension that has been largely ignored by the literature. Staff stated that one of the young men in this study was much calmer and easier to manage on a shift after masturbating to orgasm. This reflects the known biological and hormonal responses of the arousal – orgasm – resolution cycle defined by Masters and Johnson (Cerver, 2000; Kaeser, 1996a). However, the calmness attributed to the resolution of arousal represents only one point. For example, masturbation has other benefits including alleviating pre-menstrual cramps, inducing sleep, increasing flow of white blood cells and hormones, and stimulating endorphins which enable better oxygen metabolism and more efficient cell functioning (Knowles, 2002). Furthermore, masturbation as a form of regular sexual expression can also decrease the risk of prostate and breast cancer due to the release of hormones, lower the frequency of fatal coronary events, ease pain, and help with muscle relaxation (Gianotten, 2007; Whipple, 2007; Whipple, Knowles, & Davis, 2003).

During her conference presentation describing research on menstruation and girls with an intellectual disability, Krykou (2008) described the experience of her daughter before gynaecological surgery. Apparently, the frequency and duration with which her daughter would masturbate increased in the months prior to the surgical procedure. Krykou, as an insightful mother, physician, and researcher in women’s health, felt this was directly related to pain linked with her gynaecological condition. This sounds highly plausible given the known correlation between masturbation and alleviation of uterine cramps/pain. What of people with an intellectual disability and cerebral palsy who experience varying muscular cramps/pains associated with their spasticity? Does masturbation offer not only a form of release and mood enhancement, but also another method to alleviate specific muscular tensions? Massages, spas, foot rubs, hydrotherapy, and physiotherapy are all embraced for their potential to enhance well-being and muscular release, so should masturbation be viewed any differently? However, while this is being presented as a logical assumption, in practice it would be far from straightforward. In fact, it would more than likely be most contentious, if proposed as part of an overall therapeutic regime, due to the restrictive position of the policy framework reflected in Box 7.2, and the accepted legal position on mental capacity.

The interactional context between staff and the men and teenage boys in this study posed a significant challenge for both male and female staff. A multitude of competing and contradictory issues ensure this is, and will remain, a challenge. One moral question revolves around the type of services created when staff are anxious expressing themselves; it is definitely not okay to construct an interactional context which is devoid of human warmth, but how does human intimacy, and in particular male intimacy, materialize when distrust and fear are the dominant emotions? Male warmth and male banter between male staff and the men and teenage boys in this study have been described as a mutually beneficial interaction on a multitude of levels. However, this issue can only stagnate so long as male staff are reluctant to express themselves naturally, and while female staff reserve the right to be suspicious of their interactional intent.

The following poem by Val French (cited in Biddulph, 2000, p. 2), while about a father - daughter relationship, epitomises my feelings toward this moral question as depicted by staff in this study, and toward my own practice as a specialist male developmental disability nurse:

One delicious memory I have
Imprinted physically and sensually
Which has withstood the years
Was as a five-year-old
Falling asleep on our straight- backed dining chairs.
My father six-foot-three and strong,
So very strong.
Picking me up and putting me to bed.
I can still feel his big arms around me
A loving sensation so wondrously warm
To a little girl
Starved of his touch.

Years later
When he was an old man
He told me he worried about being affectionate
With his three daughters.
He was concerned it may be improper or misconstrued
So he never touched us.
But …
I always had that precious moment.

The data identified that male health screening was a significant omission from both policy and practice. This was further reinforced by the finding that the concept of male sexual health rarely extends beyond the phallus. The older female staff member who mentioned prostate screening raised it as her husband had recently undergone the same screening. The lack of testicular screening was perhaps more worrying, as data from other studies suggest testicular morbidity is more prevent in males with an intellectual disability (McElduff et al., 2003; Patja, Eero et al., 2001; van Schrojenstein Lantman-de Valk, 2005). A publication by the UK Department of Health (1995) concerning health for people with an intellectual disability suggested one way to enhance the rate of breast screening and detection of lumps was through training female carers to offer breast examination. There is no reason why such a strategy should not also be suggested for male staff and testicular examination, during the delivery of personal care for example. Certainly, male staff should not be replacing, but supplementing, the role of an annual health check by their GP. Creating male-specific roles such as this which are inherently positive as opposed to being reflexively perceived via constructs of abuse, might provide one important signal that male staff are valued and needed to work in the sector.

This omission of male health screening leads one to the question the barriers to such screening, presently available in most western countries through a range of primary health services. Data collected in the late 1990s (Emerson et al., 2000; Emerson et al., 2001) show rates of testicular screening vary considerably depending on the type of service received by the male with an intellectual disability. These UK data showed 60% of males living in village communities had received a testicular check in the preceding year compared with only 9% of males living in small group homes, and 24% of males living in supported living schemes. Many social and structural barriers might explain this large disparity, but what these barriers are remain unanswered. For example, what are the differences between models of accommodation that lead to disparity in health screening? As recipients of welfare, people with an intellectual disability are socioeconomically disadvantaged and their location as relatively powerless citizens renders them vulnerable to increased morbidity and mortality (Marmot, 2004; Marmot & Wilkinson, 1999). However, due to this level of vulnerability, the lives of people with an intellectual disability are probably more regulated than any other group in society (e.g. Department of Ageing Disability and Home Care (DADHC), 2007; Department of Health, 1995, 2001b). Data from the present study suggest the role of staff in meeting, or indeed serving as a barrier to, health screening requires further examination.

Implications for Theory

Theoretically, there are a number of implications that can be drawn from this study. Broadly speaking, the data have been interpreted as straddling sociological and biomedical constructs of disability, sexuality and masculinity. What this infers is the importance of a range of perspectives toward an overall construction of the sexual health needs of men and boys with a moderate to profound intellectual disability. However, this declaration needs to be considered alongside the fact that, as the information broker for these data, this interpretation emerged through my biopsychosocial comfort zone. The model Conditionally Sexual (see Figure 6.1) contextualised the data within the health environment, service setting, and a continuum of socio-culturally understood pathogenic and salutogenic masculinity. However, the theoretical implications are greater than this model could depict as it was primarily contextualising the data. Missing were the theoretical perspectives of disability and sexuality presented in Chapters 2 and 3 that also depicted a dichotomy between perspectives.

Furthermore, the model introduced in Figure 6.1 was not able to adequately depict how these dichotomous positions impacted upon the topic of this study, the sexual health needs of men and teenage boys with a moderate to profound intellectual disability. Therefore, a new model was required which incorporated the perspectives described in Chapters 2 and 3, the data, my interpretation of the data, and the implications of the study. A new explanatory model was devised which depicted a biopsychosocial perspective as a pragmatic “middle road” toward male sexual health outcomes. This explanatory model, *The Theoretical Implications of Conditionally Sexual,* are illustrated in Figure 10.1 and translates thus: **male health outcomes for those described as Conditionally Sexual, a theoretical and interactional adaptation of essentialist and constructionist perspectives, are experienced through negotiation of implicit gendered tensions within their health environment.**

Figure 10.1 can be interpreted through three key themes which have been shaded for ease of explanation. The blue shaded area represents the data as described to me by interview participants. The yellow shaded area, Conditionally Sexual, represents my interpretation of the interview data contextualised with observation data. As has been discussed previously, Conditionally Sexual also represents a position of constraint imposed by the fact the men and teenage boys in this study receive a “service’. Therefore, the green shaded area not only represents the future but also represents “supported living” which can only occur if the centralisation of disability services in NSW evolves to allow person-centred accommodation models to emerge. The areas of Figure 10.1 which lie above and below the blue and yellow shaded areas represent the theoretical dichotomies presented within the literature between sociological and bio-medical constructs of disability, sexuality and masculinity.

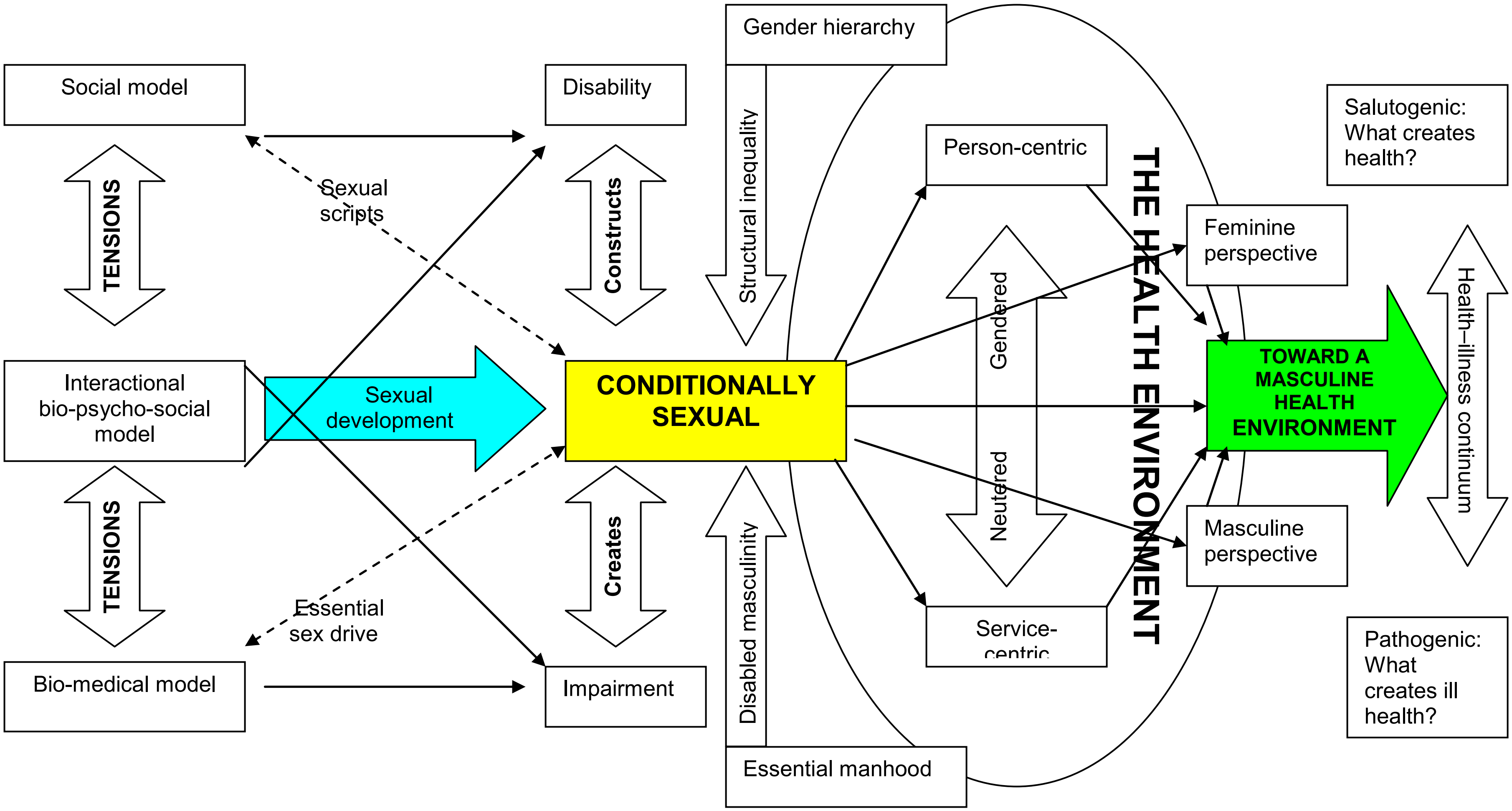


Figure 10.1

Theoretical Implications of Conditionally Sexual

In terms of the implications for disability and sexuality theory, the present study's main contribution to knowledge is to state the importance of appreciating both biomedical and sociological perspectives of disability, sexuality, and masculinity. It is in the areas of masculinity theory and gendered service delivery that this study has made a more significant contribution. Specifically, the intersection of masculinity and intellectual disability has not been recognised by theorists engaged in critical studies on men and masculinities. Regarding gendered service delivery, the present study has highlighted that staff gender is an important feature of service delivery which has an impact on gendered health outcomes.

The formulation of the theoretical construct *Conditionally Masculine* has been argued in N. J. Wilson, Parmenter Stancliffe and Shuttleworth (2009). As the conceptual argument is too extensive to review here, it has been included in Appendix 7 for supplementary perusal. To summarise however, the basis of the argument suggests that a focus on gendered hierarchy, the dominant and widely accepted theoretical position, is unhelpful for men and teenage boys with a moderate to profound intellectual disability. This is because, by viewing their masculinity through a focus on gendered power, with hegemonic masculinity the dominant exemplar, it constructs a **reliant masculinity** from the sum of **cultural stigma** and **individual powerlessness**. Appendix 7 argues such a construction simply reifies gendered power without contextualisation of the myriad factors which contribute to powerlessness due to intellectual impairment. That is, their powerlessness is not wholly gendered; it is socioculturally constructed through layers or structural inequality (Holter, 2005) and the individual experience of impairment.

Therefore, the construct of conditionally masculine challenges the intellectual dominance of hegemonic masculinity as a conceptual framework through which to appreciate gendered relations. The basis of this challenge lies in the assertion that not all gendered experiences are practised through constructs, or continuums, of power. Power and patriarchy does not explain everything, or have meaning to everyone. Appendix 7 then offers a forum to further the theoretical diversification in critical studies on men and masculinities. One specific example from Appendix 7 centres on discussion of using testosterone therapy for men and boys with hypogonadism and how the default position in men and boys with an intellectual disability is to not treat due to fears about masculine "side-effects". This outcome, notwithstanding the denial of therapeutical benefits to overall health, reinforces a neutered being as the preferred state.

Additionally, the present study has made a contribution to the emerging body of work titled "disabled masculinities" which has hitherto been primarily concerned with male physical impairment. Most of this discourse states masculinity is also an embodied construction where bodies are both objects and agents of embodied practice (Connell, 1995). The question arises as to whether masculinity is also a construction that is shaped cognitively for men and boys with an intellectual disability, and indeed for males with acquired brain injury, dementia, and perhaps chronic mental illness? For example, the level of cognitive impairment will shape, on a service level, the nature of supports and accommodation. Data from the present study also showed masculinity is less influenced by sociocultural images and scripts the greater the level of cognitive impairment. Capacity to make decisions and participate in a normatively constructed, rational and liberal society, is more limited the greater the degree of cognitive impairment. This argument is heading toward cognitive differentiation which may affront some, but for want of a better phrase, are masculinities also ***encognified***?

Gendered service delivery also offers a challenge to the intellectual hegemony of gendered sameness. That is, gendered service delivery asserts that gendered differences are an observable fact (Storkey, 2000). Gendered service delivery is also not born from a reaction to the gender equity movement which some argue has created hostile environments for males (Hart, Grand, & Riley, 2006). Storkey stated that you can accept sex differences without buying into biological determinism. That is, we do not need to stereotype differences, but we also do not need to abandon them. This assertion from Storkey was reflected within data from the present study. Staff eloquently and clearly described a plethora of differences between the masculine and feminine carer which were mostly perceived positively. The few negative differences also centred on gendered stereotypes such as males who can't cook or won't do the housework. On the whole, staff described mutuality, cooperation, and a natural healthy gendered balance.

Although framed biblically, Storkey (2000) provided the most congruent explanation for the perspectives of staff in their construction of gendered service delivery. Evidently, the Bible offers no single essentialist answer to understand the relations between males and females, but a more complex narrative analysis. Storkey has summarised these narratives into four broad intertwined paradigms: difference, sameness, complementarity, and union. Difference refers to our biological and historically gendered roles; sameness as an equal part of the human race with the same moral requirements and responsibilities; complementarity that we reciprocate and fulfil one another non-hierarchically; and union that we are a union in humankind. Storkey argued when these four paradigms are taken out of their mutual context, a distortion results. This distortion leads, for example, to perspectives of power and subordination if difference is seen in isolation or in a reinforcement of androgyny if sameness is seen in isolation. Staff described all four paradigms when discussing gendered roles; difference, sameness, complementarity and union. Notwithstanding the importance of female staff to female health needs, the role of male staff as a conduit to positive male outcomes exemplifies the need to better define the role of the masculine carer.

TOWARD A MASCULINE HEALTH ENVIRONMENT

Figure 10.1 has proposed the creation of a masculine health environment, an environment of supported living, a celebration of maleness, and the desire for the creation of healthy masculinity. A propositional masculine health environment, while emphasising the need for a greater number of male staff, is not an environment devoid of females. It is an environment where maleness is valued and sees the masculine carer as every bit as vital as the feminine carer, indeed that without a masculine carer, complementarity is lost. Importantly, a masculine health environment recognises person-centred service delivery, and in turn quality of life, and it cannot exclude consideration of masculinity and femininity. A masculine health environment would focus on the environmental factors which foster male health together with a commitment to create such environments (Macdonald, 2005). Table 10.1 includes a short summary describing what some of these factors may be in order to stimulate a discussion toward understanding and creating a masculine health environment:

Table 10.1
Preliminary factors for a masculine health environment

FEATURE	CLIENT	STAFF	ENVIRONMENT
Self-discovery / Masturbation	Opportunities to masturbate / self-stimulate.	Be able to recognise the health benefits of self-discovery and be confident in supporting clients achieve this benefit.	A policy framework which gives staff the confidence to support clients without fear. Availability of appropriate aids within a legal policy context to support self-discovery.
Physical activity	Opportunities to engage in physical activity and expend male physical energy.	Be able to recognise the health benefits of expressing male energy in a positive and appropriate manner.	The provision of settings and facilities for safe physical activity.
Sexual expression	To be able to sexually express oneself outside of normative ideals and within legal parameters.	To understand that sexual expression is a positive part of humanity and to appreciate the difference between healthy and unhealthy sexualities.	A policy framework focussed on the benefits of sexual expression and human intimacy which outlines to staff what they can do to support their clients.
Male interaction	To express oneself with other people in a manner which recognises the value of a male style of interaction and the nature of the relationship.	To appreciate the differences between male and female interaction and understand the benefits to males of a more physical style of interaction.	Provide a policy context which recognises the difference between physical interaction and heavy handed, or assaultive, actions.
Advocacy	To have available others who will offer male advocacy in an informed manner.	To recognise the importance of their role as male advocates and the uniqueness and value of such advocacy.	To identify the nature of gendered advocacy and the types of specific roles this may entail.
Personal hygiene	To be supported with intimate personal hygiene by people who appreciate the intricacies of male hygiene.	To understand the importance of male hygiene and practise the same competently.	Provide staff with a policy and training / competency context for intimate personal hygiene.

FEATURE	CLIENT	STAFF	ENVIRONMENT
Challenging behaviour	Where challenging behaviour is an identified problem to have the necessary gendered supports to support engagement in positive behavioural expression.	To have the gendered physical and professional capacity to respond reactively and proactively to challenging behaviour.	Provide clients and staff with the necessary skills and environments to minimise the incidence of challenging behaviour and maximise the expression of positive male energy.
Male staff	To have available male staff to support gendered activities.	For male staff to feel confident in their uniquely gendered role. For female staff to appreciate the value male staff offer.	To ensure all male clients have male staff with whom to share their lives and offer the unique gendered supports they require.
Female staff	To have available female staff to provide a gendered balance to support.	For female staff to feel confident in their interactions with male clients and to communicate any fear of male physicality in a positive manner. For male staff to appreciate the value female staff offer.	To ensure all male clients have female staff with whom to share their lives.
Health screening	To have access to age- and gender-specific screening activities.	To understand what screening is required when and know where to access this. For male staff to participate in male health screening activities.	Provide a policy framework for gendered health care and engage male staff in its implementation for male clients.
Family	To maintain positive relationships with their families with access to advocacy and support from fathers and brothers.	To foster family relationships and develop the roles of fathers and brothers in understanding male health needs.	Provide a policy framework for male health care and engage male family members in its implementation.
Relationships	Opportunities to develop meaningful gendered relationships.	To understand the differences in gendered relationships.	Provide a framework for staff to understand gendered relationship formation where communication is limited.

In summary, a masculine health environment focuses on male strengths and not on social pathologies. As a conceptual proposition it requires services to ask what can be done to provide a greater and more positive focus on male sexual health, male sexual expression, male interaction, and male physicality. Furthermore, it also requires services to seek ways to increase the small number of male staff working in a sector which serves a predominantly male clientele. Finally, it requires a philosophy of appreciating the ways in which gender is both the same and different. These differences should be celebrated for the potential they have to enhance the lives of all men and boys with an intellectual disability. Figure 10.2 conceptualises the proposition located in green in Figure 10.1which suggests a movement toward a masculine health environment will provide access to the creation of better male health outcomes and a healthy masculinity.

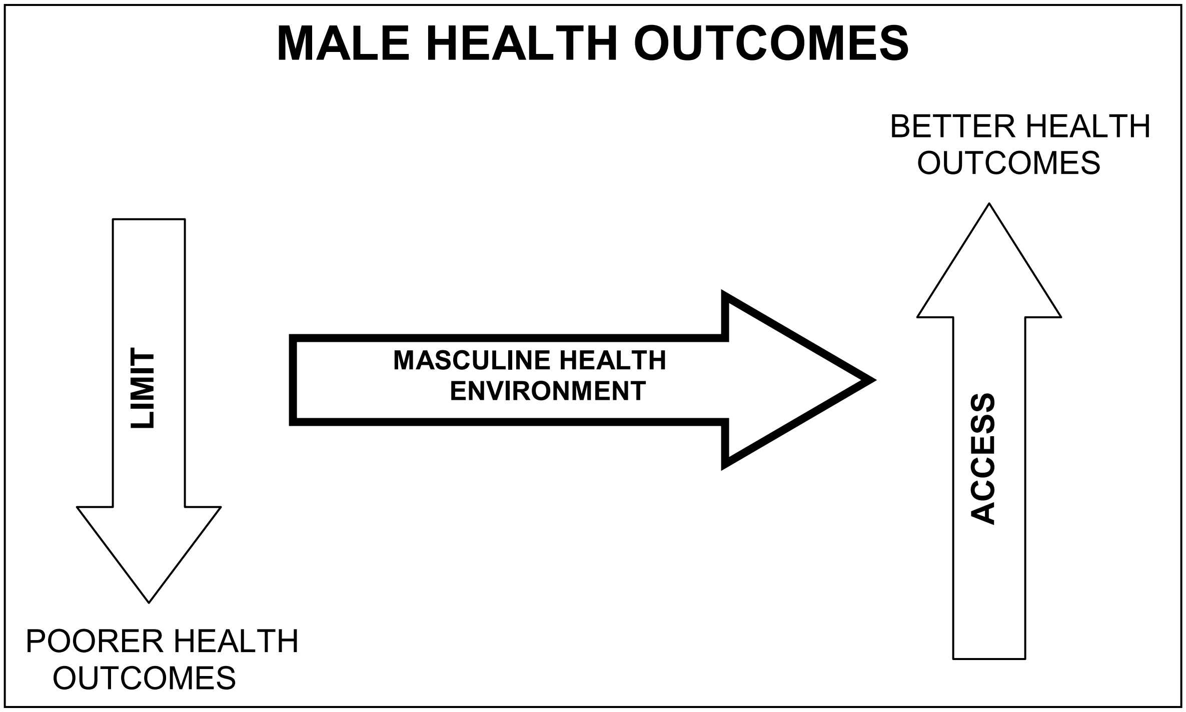


Figure 10.2
Propositional concept for male health outcomes

CONCLUSION

The problematising of the sexual health needs of men and boys with an intellectual disability represents a tacit inequality which has not previously been directly confronted. Despite the focus on the rights of people with an intellectual disability to express their individual and collective sexualities, men and boys with a moderate to profound intellectual disability have restricted sexual rights that are restricted by gender and restricted by intellectual disability. Depending upon a differently gendered appreciation of male sexual health, some males with an intellectual disability are actively neutered, while others are permitted to be sexual beings. Future research needs to test the theoretical suggestions from the present study. Additionally, future research needs to explore further developmental differences in age and capacity, for example between pre-pubescent young boys and older men with an intellectual disability, and the sexual health needs of men and boys with a borderline to mild intellectual disability.

A propositional masculine health environment indicates a way that disability services can actively redress the inequality which some males with an intellectual disability experience. Such a framework will enable the sexual health needs of men and boys with an intellectual disability to be viewed “beyond the genital”, toward a salutogenic understanding of Conditionally Sexual.

REFERENCES

A Group of Women with Disabilities. (1996). *Women with disabilities: Speaking out for ourselves*. Dunedin, NZ: The Donald Beasley Institute.

Abbott, D., & Howarth, J. (2005). *Secret loves, hidden lives? Exploring issues for men and women with learning disabilities who are gay, lesbian, or bisexual*. London: Policy Press.

Adams, R., & Savran, D. (2002). Introduction. In R. Adams & D. Savran (Eds.), *The masculinity studies reader* (pp. 1-8). Malden, MA: Blackwell Publishers.

Allen, J. A. (1992). Frameworks and questions in Australian sexuality research. In R. W. Connell & G. W. Dowsett (Eds.), *Rethinking sex: Social theory and sexuality research* (pp. 5-31). Melbourne: Melbourne University Press.

Allen, R., Lindsay, W. R., MacLeod, F., & Smith, A. H. W. (2001). Treatment of women with intellectual disabilities who have been involved with the criminal justice system for reasons of aggression. *Journal of Applied Research in Intellectual Disabilities, 14*(4), 340-347.

Angrosino, M. V. (2004). Participant observation and research on intellectual disabilities. In E. Emerson, C. Hatton, T. T & T. R. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 161-177). West Sussex: John Wiley & Sons Ltd.

Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International, 11*(1), 11-18.

Arevalo, M. (2003). Influences on health. In J. Thompson & S. Pickering (Eds.), *Meeting the health needs of people who have a learning disability*. London: Bailliere Tindall.

Ashkenazi, M., & Markowitz, F. (1999). Sexuality and prevarication in the praxis of anthropology. In F. Markowitz & M. Ashkenazi (Eds.), *Sex, sexuality and the anthropologist* (pp. 1-21). Urbana: University of Illinois Press.

Atkins, C. (1998). *'Just Little Things': Nurses perceptions of quality of life for people with severe multiple impairments.* Unpublished doctoral thesis, University of Sydney, Sydney.

Aunos, M., & Feldman, M. A. (2002). Attitudes toward sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*, 285-296.

Australian Institute for Health and Welfare (AIHW). (2003). Disability prevalence and trends, disability series. AIHW cat. No. DIS 34: Canberra: AIHW.

Australian Institute for Health and Welfare (AIHW). (2005). Australia's Welfare 2005: AIHW Cat. No. Aus65. Canberra: AIHW.

Australian Institute for Health and Welfare (AIHW). (2008). Unpublished data. Canberra: AIHW.

Australian Society of Sex Educators Researchers and Therapists (ASSERT). (2009). *Professional categories*. Retrieved 22nd January, from http://assertnational.org.au/?page_id=68

Aylott, J. (2001). Developing a positive sexual identity. *Nursing and Residential Care, 3*(6), 254-257.

Azzopardi, M. M. (1975). A breeze of faith and hope. In G. Katz, T. Mutters, D. Norley, P. S. Sporken & F. Stockmann (Eds.), *Mental handicap, human relationships, sexuality* (pp. 71-75). Marburg West Germany: Bundesvereinigung Lebenshilfe.

Bailey, D. B., Hatton, D. D., Tassone, F., Skinner, M., & Taylor, A. K. (2001). Variability in FMRP and early development in males with fragile-X syndrome. *American Journal of Mental Retardation, 106*(1), 16-27.

Balogh, R., Bretherton, K., Whibley, S., Berney, S., Graham, S., Richold, P., et al. (2001). Sexual abuse in children and adolescents with intellectual disability. *Journal of Intellectual Disability Research, 45*(3), 194-201.

Baptista, P. M., Mercadante, M. T., Nacedo, E. C., & Schwartzman, J. S. (2006). Cognitive performance in Rett syndrome girls: A pilot study using eye tracking technology. *Journal of Intellectual Disability Research, 50*(9), 662-666.

Basquill, M. F., Maguth-Nezu, C., Nezu, A. M., & Klein, T. L. (2004). Aggression-related hostility bias and social problem-solving deficits in adult males with mental retardation. *American Journal of Mental Retardation, 109*(3), 255-263.

Bauer, P. E. (2008). "Tell them it's not so bad": Prenatal screening for Down syndrome and bias toward abortion. *Intellectual and Developmental Disabilities, 46*(3), 247-251.

Beange, H., Lennox, N., & Parmenter, T. R. (1999). Health targets for people with an intellectual disability. *Journal of Intellectual and Developmental Disability, 24*(4), 283-297.

Beebee, J. (2003). Improve and Care: How should staff and carers respond when a young man removes his clothes in public when children might be present? *Learning Disability Practice, 6*(10), 10-16.

Berkhan, O. (1912). Hodenverhaltung und verspätetes heabsteigen der hoden bei schwachsinnigen. *Zeitschrift für die erforschung und behandlung des jugendlichen schwachsinns, 4*, 327-329.

Berkson, G. (2006). Mental disabilities in western civilization from ancient Rome to the Prerogativa Regis. *Mental Retardation, 44*(1), 28-40.

Biddulph, S. (1995). *Manhood: An action plan for changing men's lives* (2nd ed.). Sydney: Finch Publishing.

Biddulph, S. (1997). *Raising boys: Why boys are different - and how to help them become happy and well-balanced men*. Sydney: Finch Publishing.

Biddulph, S. (2000). *Stories of manhood: journeys into the hidden hearts of men*. Sydney: Finch Publishing.

Bittles, A., Petterson, B., Sullivan, S., Hussain, R., Glasson, E., & Montgomery, P. (2002). The influence of intellectual disability on life expectancy. *Journal of Gerontology (Series A: Biology Sciences and Medical Sciences), 57*, M470-M472.

Blacher, J., & Tan Mink, I. (2004). Interviewing family members and care providers: Concepts, methodologies, and cultures. In E. Emerson, C. Hatton, T. Thompson & T. R. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 133-159). West Sussex: John Wiley & Sons Ltd.

Boas, K. (1913). Die sexuelle belehrung schwachsinniger. *Zeitschrift für die erforschung und behandlung des jugendlichen schwachsinns, 5*, 373.

Bogle, A. (2007). *Super-crips, disabled anti-heroes and the women who care for them*. Retrieved 1st November, 2008, from http://criticalbogle.blogspot.com/2007/09/super-crips-disabled-anti-heroes-and.html

Booth, T., & Booth, W. (2002). Men in the lives of mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*(3), 187-199.

Boyages, S., Collins, J. K., Maberly, G. F., Morris, J. G., Jupp, J. J., & Eastman, C. J. (1987). Congenital Iodine deficiency disorders (endemic cretinism): History and description. *Journal of Intellectual and Developmental Disability, 13*(1), 3-11.

Braddock, D. L., & Parish, S. L. (2001). An institutional history of disability. In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 11-68). London: Sage.

Bradley, M. (2004, 9th October). Take a shed, add cluey old blokes, and watch boys thrive*. The Sydney Morning Herald*.

Bragg, L. (1997). From mute God to the lesser God: Disability in medieval Celtic and old Norse literature. *Disability and Society, 12*(2), 165-177.

Braun, R. P. (2003). Gender bias: Flaws in the nursing school curriculum. *InterAction, 21*(1), 3.

Bredberg, E. (1999). Writing disability history: Problems, perspectives and sources. *Disability and Society, 14*(2), 189-201.

Brewster, J. (2005). Women's health in Doncaster. *Learning Disability Practice, 8*(1), 29-30.

Brewster, S. J. (2004). Putting words into their mouths? Interviewing people with learning disabilities and little/no speech. *British Journal of Learning Disabilities, 32*, 166-169.

Brooke, S., Collacott, R. A., & Bhaumik, S. (1996). Monosymptomatic hypochondriacal psychosis in a man with learning disabilities. *Journal of Intellectual Disability Research, 41*(1), 71-74.

Brown, H., & Stein, J. (1997). Sexual abuse perpetrated by men with intellectual disabilities: A comparative study. *Journal of Intellectual Disability Research, 41*(3), 215-224.

Brown, H., Stein, J., & Turk, V. (1995). The sexual abuse of adults with learning disabilities: Report of a second two-year incidence survey. *Mental Handicap Research, 8*(1), 3-24.

Butler, P. A. (2004). *Sexual health - a new focus for WHO*. Geneva: World Health Organisation (WHO).

Caesar, D. (1999). Softening them up. In K. Biber, T. Sear & D. Trudinger (Eds.), *Playing the man: New approaches to masculinity* (pp. 19-23). Annandale, NSW: Pluto Press.

Cambridge, P. (1996). Men with learning disabilities who have sex with men in public places: Mapping the needs of services and users in South East London. *Journal of Intellectual Disability Research, 40*, 241-251.

Cambridge, P. (1998). Challenges for safer sex education and HIV prevention in services for people with intellectual disabilities in Britain. *Health Promotion International, 13*(1), 67-74.

Cambridge, P. (2001). Sexuality under scrutiny. *Tizard Learning Disability Review, 6*(1), 2-3.

Cambridge, P., & Carnaby, S. (2000). A personal touch: Managing the risks of abuse during intimate and personal care. *Journal of Adult Protection, 2*(4), 4-16.

Cambridge, P., Carnaby, S., & McCarthy, M. (2003). Responding to masturbation in supporting sexuality and challenging behaviour in services for people with learning disabilities. *Journal of Learning Disabilities, 7*(3), 251-266.

Cambridge, P., & Mellan, B. (2000). Reconstructing the sexuality of men with learning disabilities: Empirical evidence and theoretical interpretations of need. *Disability and Society, 15*(2), 293-311.

Carlson, G., Taylor, M., & Wilson, J. (2000). Sterilisation, drugs which suppress sexual drive and young men who have intellectual disability. *Journal of Intellectual and Developmental Disability, 25*(2), 91-104.

Carlson, G., Wilson, J., & Taylor, M. (1997). Fertility control in young men who have intellectual disability. In Australasian Men's Health Forum (Ed.), *The Second National Men's Health Conference* (pp. 71-85). Fremantle, Western Australia: Australasian Men's Health Forum.

Carlson, L. (2001). Cognitive ableism and disability studies: Feminist reflections on the history of mental retardation. *Hypatia, 16*(4), 124-146.

Carnaby, S., & Cambridge, P. (2002). Getting personal: An exploratory study of intimate and personal care provision for people with profound and multiple intellectual disabilities. *Journal of Intellectual Disability Research, 46*(part 2), 120-132.

Carr, E. G., Smith, C. E., Giacin, T. A., Whelan, B. M., & Pancari, J. (2003). Menstrual discomfort as a biological setting event for severe problem behaviour: Assessment and intervention. *American Journal on Mental Retardation, 108*(4), 117-133.

Carson, D. (1989). The sexuality of people with learning difficulties. *Journal of Social Welfare Law, 11*(6), 355-372.

Cassidy, G. (2006). Epilepsy in people with intellectual disability. In A. Roy, M. Roy & D. Clarke (Eds.), *The psychiatry of intellectual disability* (pp. 51-61). Oxford: Radcliffe Publishing.

Cerver, F. A. (Ed.). (2000). *Sexuality*. Cologne: Könemann.

Chia, Y. H. M., Lee, K. S., & Teo-Kho, S. M. (2002). High intensity cycling performances of boys with and without intellectual disability. *Journal of Intellectual and Developmental Disability, 27*(3), 191-200.

Chilman, C. S. (1990). Promoting healthy adolescent sexuality. *Family Relations, 39*, 123-131.

Chou, Y. C., Lu, Z. Y. J., Wang, F. T. Y., Lan, C. F., & Lin, L. C. (2008). Meanings and experiences of menstruation: Perceptions of institutionalised women with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 21*(6), 578-584.

Clarke, D. (2006). What is intellectual disability? In A. Roy, M. Roy & D. Clarke (Eds.), *The psychiatry of intellectual disability*. Oxford, England: Radcliffe Publishing.

Cochrane, B. (1974). Conception, coercion and control: Symposiums on reproductive rights of the mentally retarded. *Hospital and Community Psychiatry, 25*(5), 283, 287-289, 292-293.

Cocks, E., & Stehlik, D. (1996). History of services. In J. Annison, J. C. Jenkinson, W. A. Sparrow & E. Bethune (Eds.), *Disability: A guide for health professionals* (pp. 8-33). Melbourne: Thomas Nelson.

Coleborne, C. (2006). Families, patients, and emotions: Asylums for the insane in colonial Australia and New Zealand, c. 1880-1910. *Social History of Medicine, 19*(3), 425-442.

Community Services and Health Industry Skills Council. (2005). *Industry skills report*. Canberra: Australian National Training Authority (ANTA; DEST from 2005)

Conahan, F., Robinson, T., & Miller, B. (1993). A case study relating to the sexual expression of a man with developmental disability. *Sexuality and Disability, 11*(4), 309-318.

Connell, R. W. (1995). *Masculinities*. Sydney: Allen and Unwin.

Connell, R. W. (1998). Masculinities and globalization. *Men and Masculinities, 1*(1), 3-23.

Connell, R. W. (2000). *The men and the boys*. Sydney: Allen & Unwin.

Connell, R. W., & Dowsett, G. W. (1992). The unclean motion of the generative parts: Frameworks in western thought on sexuality. In R. W. Connell & G. W. Dowsett (Eds.), *Rethinking sex: Social theory and sexuality research* (pp. 49-75). Melbourne: Melbourne University Press.

Connell, R. W., Hearn, J., & Kimmel, M. S. (2005). Introduction. In M. S. Kimmel, J. Hearn & R. W. Connell (Eds.), *Handbook of studies on men and masculinities*. London: Sage.

Connell, R. W., & Messerschmidt, J. W. (2005). Hegemonic masculinity: Rethinking the concept. *Gender and Society, 19*(6), 829-859.

Coon, D. (1986). *Introduction to psychology: Exploration and application* (4th ed.). St Paul, MN: West Publishing Company.

Cooper, S. A., Morrison, J., Melville, C., Finlayson, J., Allan, L., Martin, G., et al. (2006). Improving the health of people with intellectual disabilities: Outcomes of a health screening programme after 1 year. *Journal of Intellectual Disability Research, 50*(9), 667-677.

Corker, M., & Shakespeare, T. (2002). Mapping the terrain. In M. Corker & T. Shakespeare (Eds.), *Disability / postmodernity: Embodying disability theory* (pp. 1-17). London: Continuum.

Cosgrave, M. P., Tyrell, J., McCarron, M., Gill, M., & Lawlor, B. A. (1999). Age at onset of dementia and age of menopause in women with Down syndrome. *Journal of Intellectual Disability Research, 43*(6), 461-465.

Courtenay, W. H., & Keeling, R. P. (2000). Men, gender and health: Toward an interdisciplinary approach. *Journal of American College Health, 48*(6), 243-246.

Crocker, A. G., Côté, G., Toupin, J., & St-Onge, B. (2007). Rate and characteristics of men with an intellectual disability in pre-trial detention. *Journal of Intellectual and Developmental Disability, 32*(2), 143-153.

Cumella, S. (2001). Finalising a research proposal. In *Module two: M.Sc. in Learning Disability Studies*. Birmingham: The University of Birmingham.

Daly, J., Elliott, D., & Chang, E. (2000). Research in nursing: Concepts and processes. In J. Daly, S. Speedy & D. Jackson (Eds.), *Contexts of nursing: An introduction* (pp. 89-105). Sydney: MacLennan & Petty.

Davies, N., & Duff, M. (2001). Breast cancer screening for older women with intellectual disability living in community group homes. *Journal of Intellectual Disability Research, 45*(3), 253-257.

de la Cruz, F. F., & LaVeck, G. D. (Eds.). (1973). *Human sexuality and the mentally retarded*. New York: Brunner/Mazel.

De Vito, J. A. (1988). *Human communication: The basic course* (4th ed.). New York: Harper Row.

De Waele, I., & Van Hove, G. (2005). Modern times: An ethnographic study on the quality of life of people with a high support need in a Flemish residential facility. *Disability and Society, 20*(6), 625-639.

Dempsey, I., & Arthur, M. (2002). Support staff in a sample of Australian community based services for people with a disability: Career intentions, personal characteristics and professional development needs. *Journal of Intellectual and Developmental Disability, 27*(2), 201-214.

Denzin, N. K., & Lincoln, Y. S. (1998). Introduction: Entering the field of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative enquiry* (pp. 1-34). London: Sage.

Department of Ageing Disability and Home Care (DADHC). (2007). *Health care policy and procedures*. Sydney, NSW: Author.

Department of Health. (1995). *Health of the nation: A strategy for people with learning disabilities*. London: UK Department of Health.

Department of Health. (2001a). *Seeking consent: Working with people with learning disabilities*. London: Department of Health Publications.

Department of Health. (2001b). *Valuing People: A new strategy for Learning Disability in the 21st century*. London: HMSO.

Department of Veterans Affairs. (1999). *Morbidity of Vietnam veterans: A study of the health of Australia's Vietnam veteran community*. Canberra: Author.

Di Giulio, G. (2003). Sexuality and people with physical or developmental disabilities: A review of key issues. *The Canadian Journal of Human Sexuality, 12*(1), 53-68.

Diekema, D. S. (2003). Involuntary sterilization of persons with mental retardation: An ethical analysis. *Mental Retardation and Developmental Disabilities, 9*, 21-26.

Dobson, S., Carey, L., Conyers, I., Upadhyaya, S., & Raghavan, R. (2004). Learning about touch: An exploratory study to identify the learning needs of staff supporting people with complex needs. *Journal of Learning Disabilities (London), 8*(2), 113-129.

Dobson, S., Upadhyaya, S., Conyers, I., & Raghavan, R. (2002). Touch in the care of people with profound and complex needs: A review of the literature. *Journal of Learning Disabilities (London), 6*(4), 351-362.

Donnelly, K. (2005). Is there a crisis in boys' education? In J. Healey (Ed.), *Masculinity: Men and boys* (Vol. 216, pp. 2-3). Thirroul, NSW: The Spinney Press.

Drury, J., Hutchinson, L., & Wright, J. (2000). *Holding on letting go: Sex, sexuality and people with learning disabilities*. London: Souvenir Press.

Dunn, D. (2001). Sexual health. In J. Thompson & S. Pickering (Eds.), *Meeting the health needs of people who have a learning disability* (pp. 211-234). Sydney: Bailliere Tindall.

Dupras, A. (1976). Editorial. *Déficience mentale retardation, 26*(3), 2.

Durvasula, S., Beange, H., & Baker, W. (2002). Mortality of people with intellectual disability in northern Sydney. *Journal of Intellectual and Developmental Disability, 27*(4), 255-264.

Earle, S. (1999). Facilitated sex and the concept of sexual need: Disabled students and their personal assistants. *Disability and Society, 14*(3), 309-323.

Edgerton, R. B. (1984). Anthropology and mental retardation: Research approaches and opportunities. *Culture, Medicine and Psychiatry, 8*, 25-48.

Edgerton, R. B. (1993). *The cloak of competence: Revised and updated*. California: University of California Press.

Edgerton, R. B., & Dingman, H. F. (1964). Good reasons for bad supervision: 'Dating' in a hospital for the mentally retarded. *Psychiatric Quarterly Supplement, 38*, 221-233.

Edwards, S. C. (1998). An anthropological interpretation of nurses' and patients' perceptions of the use of space and touch. *Journal Of Advanced Nursing, 28*(4), 809-817.

Ejskjaer, K., Uldbjerg, N., & Goldstein, H. (2006). Menstrual profile and early menopause in women with Down syndrome aged 26-40 years. *Journal of Intellectual and Developmental Disability, 31*(3), 166-171.

Ellis, L., Hershberger, S., Field, E., Wersinger, S., Pellis, S., Geary, D., et al. (2008). *Sex differences: Summarizing more than a century of scientific research*. New York: Psychology Press.

Emerson, E., & Hatton, C. (2008). Self-reported well-being of women and men with intellectual disabilities in England. *American Journal on Mental Retardation, 113*(2), 143-155.

Emerson, E., Hatton, C., Thompson, T., & Parmenter, T. R. (2004). Preface. In E. Emerson, C. Hatton, T. Thompson & T. R. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. xv-xvi). Chichester, England: John Wiley & Sons Ltd.

Emerson, E., Robertson, J., Gregory, Hatton, C., Kessissoglou, S., Hallam, A., et al. (2000). Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom. *American Journal on Mental Retardation, 105*(2), 81-102.

Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., et al. (2001). Quality and costs of supported living residences and group homes in the United Kingdom. *American Journal on Mental Retardation, 106*(5), 401-415.

Essex, E. L., Seltzer, M. M., & Krauss, M. W. (2005). Fathers as caregivers for adult children with mental retardation. In B. J. Kramer & E. H. Thompson Jr. (Eds.), *Men as caregivers* (pp. 250-268). New York: Prometheus Books.

Fealy, T. (2006). Normalisation / social role valorisation: still relevant or a promise unfulfilled?, *paper presented at the 41st Australasian Society for the Study of Intellectual Disability annual conference*. Canberra: Australia

Fegan, L., Rauch, A., & McCarthy, W. (1993). *Sexuality and people with intellectual disability* (2nd ed.). Sydney: Maclennan Petty.

Feldman, E. J. (1996). The recognition and investigation of X-linked learning disability syndromes. *Journal of Intellectual Disability Research, 40*(5), 400 - 411.

Folkestad, H. (2004). Surrounded by women: Men in care, *paper presented at the 12th World Congress of IASSID*. Montpellier, France.

Foucault, M. (1978). *The history of sexuality, Vol 1: An introduction* (R. Hurley, Trans.). Penguin: Harmondsworth.

Francis, B. (2000). Is gender a social construct or a biological imperative?, *Paper presented at the Seventh Australian Institute of Family Studies Conference*. Sydney: Australia.

Fraser, S., & Sim, J. (2007). *The sexual health needs of young people with learning disabilities*. Edinburgh: Health Scotland.

Fyson, R. (2007). Young people with learning disabilities who sexually harm others: The role of criminal justice within a multi-agency response. *British Journal of Learning Disabilities, 35*, 181-186.

Gagnon, J. H., & Simon, W. (1973). *Sexual conduct: The social sources of human sexuality*. London: Hutchinson.

Gardiner, J. K. (2005). Men, masculinities, and feminist theory. In M. S. Kimmel, J. Hearn & R. W. Connell (Eds.), *Handbook of studies on men and masculinities*. London: Sage.

Garner, C., Callias, M., & Turk, J. (1999). Executive function and theory of mind performance of boys with fragile-X syndrome. *Journal of Intellectual Disability Research, 43*(6), 466-474.

Gerschick, T. J. (2005). Masculinity and degrees of bodily normativity in western culture. In M. S. Kimmel, J. Hearn & R. W. Connell (Eds.), *Handbook of studies on men and masculinities* (pp. 367-378). London: Sage.

Gerson, K., & Horowitz, R. (2002). Observation and interviewing: Options and choices in qualitative research. In T. May (Ed.), *Qualitative research in action* (pp. 199-224). London: Sage.

Ghan-Shyam, L., Tan-Figuero, L., & Kuhler, H. (2000). Aspiration pneumonia and antibiotic resistance in a man with severe developmental disabilities: how much care is enough? *Journal of Intellectual and Developmental Disability, 25*(2), 83-90.

Gianotten, W. (2007). Keynote address: The benefits of sexual expression on physical health, *World Association for Sexual Health 1st World Congress for Sexual Health: Achieving Health, Pleasure and Respect*. Sydney, Australia.

Gillberg, C., Uvebrant, P., Carlsson, G., Hedstrom, A., & Silfenius, H. (1996). Autism and epilepsy (and tuberous sclerosis?) in two pre-adolescent boys: Neuropsychiatric aspects before and after epilepsy surgery. *Journal of Intellectual Disability Research, 41*(1), 75-81.

Gillis, J. R. (1987). Married but not churched: Plebian sexual relations and marital nonconformity in Eighteenth-Century Britain. In R. P. Maccubbin (Ed.), *'Tis natures fault: Unauthorized sexuality during the Enlightenment* (pp. 31-42). Cambridge, UK: Cambridge University Press.

Giz·ewska, M., Cabalska, B., Crytowski, L., Nowacki, P., Z·ekanowski, C., Walczak, M., et al. (2003). Different presentations of late-detected phenylketonuria in two brothers with the same R408W/R111X genotype in the PAH gene. *Journal of Intellectual Disability Research, 47*(2), 146-152.

Glaser, B. G. (1969). The constant comparative method of qualitative analysis. In G. J. McCall & J. L. Simmons (Eds.), *Issues in participant observation: A text and reader* (pp. 216-228). Massachusetts: Addison-Wesley.

Gleeson, B. J. (1997). Disability studies: A historical materialist view. *Disability and Society, 12*, 179-202.

Gold, R. L. (1969). Roles in sociological field observation. In G. J. McCall & J. L. Simmons (Eds.), *Issues in participant observation: A text and reader* (pp. 30-39). Massachusetts: Addison-Wesley.

Gracer, B. L. (2003). What the Rabbis heard: Deafness in the Misnah. *Disability Studies Quarterly, 23*(2), 192-205.

Grant, G., & Whittell, B. (2000). Differentiated coping strategies in families with children or adults with intellectual disabilities: The relevance of gender, family composition and the life span. *Journal of Applied Research in Intellectual Disabilities, 13*, 256-275.

Gray, A. (2003). *Research practice for cultural studies*. London: Sage.

Grbich, C. (1999). *Qualitative research in health: An introduction*. Sydney: Allen and Unwin.

Green, B., & Paul, R. (1974). Parenthood and the mentally retarded. *University of Toronto Law Journal, 24*, 117-125.

Gregg, J., & O'Hara, L. (2007). The red lotus health promotion model: A new model for holistic, ecological, salutogenic health promotion practice. *Health Promotion Journal of Australia, 18*(1), 12-19.

Gregory, A. T., Lowy, M. P., & Zwar, N. A. (2006). Men's health and wellbeing: Taking up the challenge in Australia. *Medical Journal of Australia, 185*(8), 411.

Grieve, A., McLaren, S., & Lindsay, W. R. (2006). An evaluation of research and training resources for the sex education of people with moderate to severe learning disability. *British Journal of Learning Disabilities, 35*, 30-37.

Griffin, T., & Balandin, S. (2004). Ethical research involving people with intellectual disabilities. In E. Emerson, C. Hatton, T. Thompson & T. R. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 61-82). Chichester, England: John Wiley and sons Ltd

Griffiths, D. M. (2007). Sexuality and people who have intellectual disabilities. In I. Brown & M. Percy (Eds.), *A comprehensive guide to intellectual and developmental disabilities* (pp. 573-583). Baltimore: Paul H Brookes.

Griffiths, D. M., Watson, S. L., Lewis, T., & Stoner, K. (2004). Sexuality research and persons with intellectual disabilities. In E. Emerson, C. Hatton, T. Thompson & T. R. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 311-334). Chichester, England: John Wiley & Sons Ltd.

Gunther, D. F., & Diekema, D. S. (2006). Attenuating growth in children with profound developmental delay. *Archives of Pediatrics and Adolescent Medicine, 160*, 1013-1017.

Gust, D. A., Wang, S. A., Grot, J., Ransom, R., & Levine, W. C. (2003). National survey of sexual behaviour and sexual behaviour policies for individuals with mental retardation / developmental disabilities. *Mental Retardation, 41*(5), 365-373.

Haines, C. A., & Wender, R. C. (2006). Preface. In C. A. Haines & R. C. Wender (Eds.), *Primary care, clinics in office practice: Men's health* (pp. xiii-xiv). London: W. B. Saunders.

Haney, L. (2002). Negotiating power and expertise in the field. In T. May (Ed.), *Qualitative research in action* (pp. 286-299). London: Sage.

Hardy, S. (2007). *Men's health education and resource development: National needs assessment*. Melbourne: Foundation 49.

Harris, S. W., Hessl, D., Goodlin-Jones, B., Ferranti, J., Bacalman, S., Barbato, I., et al. (2008). Autism profiles of males with fragile X syndrome. *American Journal on Mental Retardation, 113*(6), 427-438.

Hart, N., Grand, N., & Riley, K. (2006). Making the grade: The gender gap, ADHD, and the medicalization of boyhood. In D. Rosenfeld & C. A. Faircloth (Eds.), *Medicalized masculinities*. Philadelphia: Temple University Press.

Hatton, C., Rose, J., & Rose, D. (2004). Researching staff. In E. Emerson, C. Hatton, T. Thompson & T. R. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 581-605). West Sussex: John Wiley & Sons Ltd.

Hawkes, G. (1996). *A sociology of sex and sexuality*. Buckingham, UK: Open University Press.

Hawkes, G. (2005). Naughty but nice, or never on Sundays? Sex and sin, past and present. In G. Hawkes & J. Scott (Eds.), *Perspectives in human sexuality* (pp. 155-167). Melbourne: Oxford University Press.

Hawkes, G., & Scott, J. (2005a). Sexuality and social theory. In G. Hawkes & J. Scott (Eds.), *Perspectives in human sexuality* (pp. 21-38). Melbourne: Oxford University Press.

Hawkes, G., & Scott, J. (Eds.). (2005b). *Perspectives in human sexuality*. Melbourne: Oxford University Press.

Hayes, S. C. (2005). Diagnosing intellectual disability in a forensic sample: Gender and age effects on the relationship between cognitive and adaptive functioning. *Journal of Intellectual and Developmental Disability, 30*(2), 97-103.

Hayes, S. C. (2009). The relationship between childhood abuse, psychological symptoms and subsequent sex offending. *Journal of Applied Research in Intellectual Disabilities, 22*, 96-101.

Hays, S. J., Murphy, G. H., Langdon, P. E., Rose, D., & Reed, T. (2007). Group treatment for men with intellectual disability and sexually abusive behaviour: Service user views. *Journal of Intellectual and Developmental Disability, 32*(2), 106-116.

Health Canada. (2003). *Canadian guidelines for sexual health education*. Ontario: Author.

Health Scotland. (2004). *Health needs assessment report - summary: People with learning disabilities in Scotland*. Edinburgh: National Health Service, The Stationery Office.

Hearn, J. (1992). *Men in the public eye: Critical studies on men and masculinities*. London: Routledge.

Heath, C., & Hindmarsh, J. (2002). Analysing interaction: Video, ethnography and situated conduct. In T. May (Ed.), *Qualitative research in action* (pp. 99-121). London: Sage.

Heidenhain, A. (1909). Sexuelle belehrung der aus der volksschule entlassenen mädchen. *Zeitschrift für die erforschung und behandlung des jugendlichen schwachsinns, 1*, 63.

Hepper, F. (1999). 'A woman's heaven is at her husbands feet'? The dilemmas for a community learning disability team opposed by the arranged marriage of Bangladeshi client with intellectual disability. *Journal of Intellectual Disability Research, 43*(6), 558-561.

Hess-Röver, J., Crichton, J., Byrne, K., & Holland, A. J. (1999). Diagnosis and treatment of a severe psychotic illness in a man with dual severe sensory impairments caused by the presence of Usher syndrome. *Journal of Intellectual Disability Research, 43*(5), 428-434.

Hickman, T. (1999). *The sexual century*. London: Carlton Books.

Hickson, L., Khemka, I., Golden, H., & Chatzistyli, A. (2008). Profiles of women who have mental retardation with and without a documented history of abuse. *American Journal on Mental Retardation, 113*(2), 133-142.

Highmore, A. (1822). *A treatise on the law and idiocy and lunacy*. Exeter, NH: George Lamson.

Hill, C. A. (2008). *Human sexuality: Personality and social psychological perspectives*. London: Sage.

Hinder, S. A. J., & Perry, D. W. (2000). Sodium-Valporate-induced pancreatitis in a man with profound intellectual disability: The significance of diagnostic difficulties. *Journal of Applied Research in Intellectual Disabilities, 13*(4), 292-297.

Hingsburger, D. (1994). Masturbation: A consultation for those who support individuals with developmental disabilities. *Canadian Journal of Human Sexuality, 3*(3), 278-282.

Hogg, J., Northfield, J., & Turnbull, J. (2001). *Cancer and people with learning disabilities: The evidence from published studies and experiences from cancer services*. Kidderminster UK: British Institute for Learning Disabilities.

Hogg, J., & Tuffrey-Wijne, I. (2008). Cancer and intellectual disability: A review of some key contextual issues. *British Journal of Learning Disabilities, 21*(6), 509-518.

Holland, T., Clare, I. C. H., & Mukhopadhyay, T. (2002). Prevalence of 'criminal offending' by men and women with intellectual disability and the characteristics of 'offenders': Implications for research and service development. *Journal of Intellectual Disability Research, 46*(supplement 1), 6-20.

Hollomotz, A. (2006). *The social creation of vulnerability to sexual violence of people with learning difficulties: An application of feminist theory.* Unpublished masters dissertation, The University of Leeds, Leeds.

Hollomotz, A., & The Speakup Committee. (2009). 'May we please have sex tonight?' - People with learning difficulties pursuing privacy in residential group settings. *British Journal of Learning Disabilities, 37(2), 91-97*.

Holloway, I., & Wheeler, S. (2002). *Qualitative research in nursing* (2nd ed.). Oxford: Blackwell Publishing.

Holter, O. G. (2005). Social theories for researching men and masculinities. In M.S.Kimmel, J.Hearn & R.W.Connell. (Eds.), *Handbook of studies on men and masculinities* (pp. 15-34). London: Sage.

Holyoake, D. D. (2001). *The male nurse: Addressing the myths of maleness in nursing*. Wiltshire, UK: APS Publishing.

Horrocks, R. (1997). *An Introduction to the study of sexuality*. London: Macmillan Press Ltd.

Howe, S. G. (1848). *Report made to the Legislature of Massachusetts upon idiocy*. Boston: Library of the University of Michigan.

Howlett, S., & Danby, J. (2007). Learning disability and sexual abuse: Use of a women-only counselling service by women with a learning disability, a pilot study. *Learning Disability Review, 12*(1), 4-15.

International Association for the Scientific Study of Intellectual Disability (IASSID). (n.d.). *Health guidelines for adults with an intellectual disability*: IASSID.

Jacobs, J. A. (1993). Men in female-dominated fields: Trends and turnover. In C. L. Williams (Ed.), *Doing "women's work": Men in non-traditional occupations* (pp. 49-63). London: Sage.

Janesick, V. J. (1998). The dance of qualitative research design: Metaphor, methodolatry, and meaning. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp. 35-55). London: Sage.

Jansen, D. E. M. C., Krol, B., Groothoff, J. W., & Post, D. (2004). People with intellectual disability and their health problems: A review of comparative studies. *Journal of Intellectual Disability Research, 48*(2), 93-102.

Jeffreys, S. (2008). Disability and the male sex right. *Women's Studies International Forum, 31*, 327-335.

Jenkinson, J. C., Sparrow, W. A., & Shinkfield, A. J. (1996). Cognitive and motor functions. In J. Annison, J. Jenkinson, W. Sparrow & E. Bethune (Eds.), *Disability: A guide for health professionals* (pp. 114-137). Melbourne: Nelson.

Jenkinson, J. C., & Wilson, L. J. (1996). Causes and prevention of disability. In J. Annison, J. C. Jenkinson, W. A. Sparrow & E. Bethune (Eds.), *Disability: A Guide for health professionals* (pp. 90-113). Melbourne: Thomas Nelson.

John, S., & Ovsiew, F. (1996). Erotomania in a brain-damaged male. *Journal of Intellectual Disability Research, 40*(3), 279-283.

Johnson, A. (1900). The self-supporting imbecile. *Journal of Psycho-Asthenics, IV*(March), 91-100.

Jones, C. (2007). More than one victim: When people with learning disabilities make false allegations of sexual abuse. *Learning Disability Review, 12*(1), 28-35.

Joseph, R. (1991). A case analysis in human sexuality: Counselling to a man with severe cerebral palsy. *Sexuality and Disability, 9*(2), 149-159.

Judge, C. (1987). *Civilization and mental retardation: A history of the care and treatment of mentally retarded people*. Melbourne: Cliff Judge.

Kaeser, F. (1992). Can people with severe mental retardation consent to mutual sex? *Sexuality and Disability, 10*(1), 33-42.

Kaeser, F. (1996a). Developing a philosophy of masturbation training for persons with severe or profound mental retardation. *Sexuality and Disability, 14*(4), 295-308.

Kaeser, F. (1996b). A survey of the perceptions of twenty three service providing agencies on the sexual behaviours of persons with severe or profound mental retardation. *Sexuality and Disability, 14*(4), 309-320.

Kakakios, M. (2001). Men's health - the way forward. *NSW public health bulletin, 12*(12), 315-317.

Kanner, L. (1964). *A history of the care and study of the mentally retarded*. Illinois: Charles C. Thomas Publisher.

Katz, G., Mutters, T., Norley, D., Sporken, P. S., & Stockmann, F. (Eds.). (1975). *Mental handicap, human relationships, sexuality*. Marburg, West Germany: Bundesvereinigung Lebenshilfe.

Kaur, A., Dhillon, S., Garg, P. D., & Singh, J. R. (2008). Ring chromosome 7 in an Indian woman. *Journal of Intellectual and Developmental Disability, 33*(1), 87-94.

Kempton, W., & Kahn, E. (1991). Sexuality and people with intellectual disabilities: A historical perspective. *Sexuality and Disability, 9*(2), 93-111.

Kennedy, C. H., & Niederbuhl, J. (2001). Establishing criteria for sexual consent capacity. *American Journal on Mental Retardation, 106*(6), 503-510.

Kerr, M. (2002). Men's health: The female of the species is more healthy than the male. In P. Noonan-Walsh & T. Heller (Eds.), *Health of women with intellectual disabilities* (pp. 219-227). Oxford: Blackwell Science.

Khemka, I. (2000). Increasing independent decision-making skills of women with mental retardation in simulated situations of abuse. *American Journal of Mental Retardation, 105*(5), 387-401.

Kickbusch, I. (1996). Tribute to Aaron Antonovsky - 'what creates health'. *Health Promotion International, 11*(1), 5-6.

King, A. (2007). *New resources for dads and families: Hey, Dad! for fathers who have a child with a disability.* Paper presented at the 7th National Men's Health Conference; Debate and invigorate: challenges in men's health, Adelaide Convention Centre.

Kittler, P., Krinsky-McHale, S. J., & Devenny, D. A. (2004). Sex differences in performance over 7 years on the Wechsler Intelligence Scale for children - revised among adults with intellectual disability. *Journal of Intellectual Disability Research, 48*(2), 114-122.

Klotz, J. (2004). Sociocultural study of intellectual disability: Moving beyond labelling and social constructionist perspectives. *British Journal of Learning Disabilities, 32*, 93-104.

Knowles, J. (2002). *Masturbation: from stigma to sexual health*. Retrieved 17th December, 2008, from http://www.plannedparenthood.org/resources/research-papers/masturbation-6360.htm

Kramer, B. J. (2005). Epilogue: Implications for practice and future research. In B. J. Kramer & E. H. Thompson Jr. (Eds.), *Men as caregivers* (pp. 379-385). New York: Prometheus Books.

Kuo, A. Y., Reiss, A. L., Freund, L. S., & Huffman, L. C. (2002). Family environment and cognitive abilities in girls with fragile-X syndrome. *Journal of Intellectual Disability Research, 46*(4), 328-339.

Kyrkou, M. R. (2005). Health issues and quality of life in women with intellectual disability. *Journal of Intellectual Disability Research, 49*(10), 770-772.

Kyrkou, M. R. (2008). Puberty to menopause in females with disability, *Paper presented at the 43rd Australasian Society for the Study of Intellectual Disability (ASSID) conference: Principles, policies and practices; the search for evidence*. University of Melbourne

Laberge, S., & Albert, M. (2000). Conceptions of masculinity and gender transgressions in sport among adolescent boys. In J. McKay, M. A. Messner & D. Sabo (Eds.), *Masculinities, gender relations, and sport* (pp. 195-221). Thousand Oaks, Ca: Sage.

Lancioni, G. E., Singh, N. N., O'Reilly, M. F., Sigafoos, J., Didden, R., Smaldone, A., et al. (2008). Helping a man with multiple disabilities increase object-contact responses and reduce hand stereotypy via a microswitch cluster program. *Journal of Intellectual and Developmental Disability, 33*(4), 349-353.

Lee, C., & Glynn-Owens, R. (2002). Issues for a psychology of men's health. *Journal of Health Psychology, 7*(3), 209-217.

Leeder, S. R., & Dominello, A. (2005). Health, equity and intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 18*, 97-100.

Leedy, P. D. (1997). *Practical research: Planning and design* (6th ed.). New Jersey: Merrill Prentice Hall.

Lehman, K. (2005). The provision of sexual health care for adult women with learning disabilities. *Journal of Community Nursing, 19*(9), 10-14.

Lennox, N. (Ed.). (2005). *Management guidelines: Developmental disability* (2nd ed.). Melbourne: Therapeutic Guidelines Limited.

Lennox, N. G., & Kerr, M. P. (1997). Primary health care and people with an intellectual disability: The evidence base. *Journal of Intellectual Disability Research, 41*(5), 365-372.

LeRoy, B. W., Noonan-Walsh, P., Kulik, N., & Rooney, M. (2004). Retreat and resilience: Life experiences of older women with intellectual disabilities. *American Journal of Mental Retardation, 109*(5), 429-441.

Liamputtong, P. (2007). *Researching the vulnerable*. London: Sage.

Lindsay, W. R. (2002). Research and literature on sex offenders with intellectual and developmental disabilities. *Journal of Intellectual Disability Research, 46*(supplement 1), 74-85.

Lindsay, W. R., Olley, S., Jack, C., Morrison, F., & Smith, A. H. W. (1998). The treatment of two stalkers with intellectual disabilities using a cognitive approach. *Journal of Applied Research in Intellectual Disabilities, 11*(4), 333-344.

Lindsay, W. R., & Smith, A. H. W. (1998). Responses to treatment for sex offenders with intellectual disability: a comparison of men with 1 and 2 year probation sentences. *Journal of Intellectual Disability Research, 42*(5), 346-353.

Lindsay, W. R., Smith, A. H. W., Quinn, K., A, A., Smith, A., Allan, R., et al. (2004). Women with intellectual disability who have offended: Characteristics and outcome. *Journal of Intellectual Disability Research, 48*(6), 580-590.

Little, D. T. (2009). Prenatal diagnosis - benefit or betrayal? *Quadrant, LIII*(1-2), 74-76.

Löfgren-Mårtenson, L. (2004). "May I?" About sexuality and love in the new generation with intellectual disabilities. *Sexuality and Disability, 22*(3), 197-207.

Lohan, M. (2007). How might we understand men's health better? Integrating explanations from critical studies on men and inequalities in health. *Social Science and Medicine, 65*, 493-504.

Long, K., & Holmes, N. (2001). Helping adults with a learning disability keep safe in the local community: Report of a group design, development and evaluation. *British Journal of Learning Disabilities, 29*(4), 139-144.

López-Sosa, C., & Tévar, R. R. (2005). The human sexual system in the context of the health sciences. *Sexuality and Disability, 23*(3), 145-154.

Lunsky, Y. (2003). Depressive symptoms in intellectual disability: Does gender play a role? *Journal of Intellectual Disability Research, 47*(6), 417-427.

Lunsky, Y., Frijters, J., Griffiths, D. M., Watson, S. L., & Williston, S. (2007). Sexual knowledge and attitudes of men with intellectual disability who sexually offend. *Journal of Intellectual and Developmental Disability, 32*(2), 74-81.

Lunsky, Y., Straiko, A., & Armstrong, S. (2003). Women be healthy: Evaluation of a women's health curriculum for women with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 16*(4), 247-253.

Lyons, G. (2005). The life satisfaction matrix: An instrument and procedure for assessing the subjective quality of life of individuals with profound multiple disabilities. *Journal of Intellectual Disability Research, 49*(10), 766-769.

Macdonald, J. J. (1998). *A salutogenic approach to men's health.* Paper presented at the 2nd national men's health conference, Fremantle: Western Australia.

Macdonald, J. J. (2005). *Environments for health: A salutogenic approach*. London: Earthscan.

Macdonald, J. J. (2006). Shifting paradigms: a social determinants approach to solving problems in men's health policy and practice. *Medical Journal of Australia, 185*(8), 456-458.

Macdonald, J. J., McDermott, D., & Di Campli, C. (2001). Making it OK to be male: The role of a positive approach to the health and well being of boys and men, *Paper presented at the 8th national conference, Suicide Prevention Australia*. Sydney.

Macdonald, J. J., McDermott, D., Woods, M., Brown, A., & Sliwka, G. (2000). A salutogenic approach to men's health: Challenging the stereotypes, *Paper presented at the 12th Australian National Health Promotion Conference*. Melbourne: Victoria.

MacInnes, J. (1998). *The end of masculinity*. Buckingham: Open University Press.

Macnamara, J. R. (2006). *Media and male Identity: The making and remaking of men*. New York: Palgrave Macmillan.

Maher, W. B., & Maher, B. (1982). The ship of fools: Stultifera navis or ignis fatuus? *American Psychologist, 37*(7), 756-761.

Mann, J., & Foreman, D. M. (1996). Homo-erotomania for a delusional parent: Erotomania with Capgras and Fregoli syndromes in a young male with learning difficulties. *Journal of Intellectual Disability Research, 40*(3), 275-278.

Manning, C. (2008). *Bye-bye Charlie: Stories from the vanishing world of Kew Cottages*. Sydney: University of New South Wales Press.

Marmot, M. (2004). *Status syndrome: How your social standing directly affects your health*. London: Bloomsbury Publishing.

Marmot, M., & Wilkinson, R. G. (Eds.). (1999). *Social determinants of health*. Oxford, UK: Oxford University Press.

Marsh, W., & Andresen, G. (2008). Men and fathers health forum '08, *Men and fathers health forum '08: Parliament house Canberra*. Unanderra, NSW: The Fatherhood Foundation.

Mason, J. (2002). Qualitative interviewing: Asking, listening and interpreting. In T. May (Ed.), *Qualitative research in action* (pp. 225-241). London: Sage.

Mason, L., & Cunningham, C. (2008). An exploration of issues around menstruation for women with Down syndrome and their carers. *Journal of Applied Research in Intellectual Disabilities, 21*(3), 257-267.

Matsuishi, T., Yamada, Y., Endo, K., Sakai, H., & Fukushima, Y. (1996). Ring chromosome 15 syndrome in an adult female. *Journal of Intellectual Disability Research, 40*(5), 478-481.

Mays, J. M. (2006). Feminist disability theory: Domestic violence against women with a disability. *Disability and Society, 21*(2), 147-158.

McCall, G. J., & Simmons, J. L. (1969). The nature of participant observation. In G. J. McCall & J. L. Simmons (Eds.), *Issues in participant observation: A text and reader* (pp. 1-5). Massachusetts: Addison-Wesley.

McCarthy, M. (1996). The sexual support needs of people with learning disabilities: A profile of those referred for sex education. *Sexuality and Disability, 14*(4), 265-279.

McCarthy, M. (1999). *Sexuality and women with learning disabilities*. London: Jessica Kingsley.

McCarthy, M. (2002). Going through the menopause: perceptions and experiences of women with intellectual disability. *Journal of Intellectual and Developmental Disability, 27*(4), 281-295.

McCarthy, M., & Thompson, D. (1996). Sexual abuse by design: An examination of issues in learning disability services. *Disability and Society, 11*(2), 205-217.

McCarthy, M., & Thompson, D. (1997). A prevalence study of sexual abuse of adults with intellectual disabilities referred for sex education. *Journal of Applied Research in Intellectual Disabilities, 10*(2), 105-124.

McConkey, R., McAuley, P., Simpson, L., & Collins, S. (2007). The male workforce in intellectual disability services. *Journal of Policy and Practice in Intellectual Disabilities, 4*(3), 186-193.

McConkey, R., & Ryan, D. (2001). Experiences of staff in dealing with client sexuality in services for teenagers and adults with intellectual disability. *Journal of Intellectual Disability Research, 45*(1), 83-87.

McConnell, D., Mayes, R., & Llewellyn, G. (2008a). Pre-partum distress in women with intellectual disabilities. *Journal of Intellectual and Developmental Disability, 33*(2), 177-183.

McConnell, D., Mayes, R., & Llewellyn, G. (2008b). Women with intellectual disability at risk of adverse pregnancy and birth outcomes. *Journal of Intellectual Disability Research, 52*(6), 529-535.

McCormack, B., Kavanagh, D., Caffrey, S., & Power, A. (2005). Investigating sexual abuse: Findings of a 15-year longitudinal study. *Journal of Applied Research in Intellectual Disabilities, 18*, 217-227.

McCutchen, W. H. (2000). *Lycurgus; father of Spartica*. Retrieved 27th August 2007, from www.e-classics.com/lycurgus.htm

McDonagh, P. (2000). Diminished men and dangerous women: Representations of gender and learning disability in early and mid-nineteenth-century Britain. *British Journal of Learning Disabilities, 28*, 49-53.

McElduff, A., & Beange, H. (2003). Men's health and well-being: Testosterone deficiency. *Journal of Intellectual and Developmental Disability, 28*(2), 211-213.

McElduff, A., Center, J., & Beange, H. (2003). Hypogonadism in men with intellectual disabilities: A population study. *Journal of Intellectual and Developmental Disability, 28*(2), 163-170.

McVilly, K. R. (2000). Sorry, I'm a support worker, not you're friend. *Intellectual Disability Australasia, 21*(4), 6-7, 19.

McVilly, K. R. (2004). *'I get by with a little help from my friends': Adults with intellectual disability discuss friendship.* Unpublished Doctoral thesis, University of Sydney, Sydney.

McVilly, K. R. (Ed.). (2007). *Australasian code of ethics for direct support professionals* (1st ed.). Victoria: Australasian Society for the Study of Intellectual Disability (ASSID) Inc.

McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. M. (2008). Remaining open to quantitative, qualitative and mixed-method designs: An unscientific compromise, or good research practice? *International Review of Research in Mental Retardation, 35*, 151-203.

Medicare Australia. (2008). Medicare Item 718 processed from July 2007 to December 2007: Canberra: Author.

Melberg-Schwier, K., & Hingsburger, D. (2000). *Sexuality: your sons and daughters with intellectual disabilities*. Baltimore: Paul H Brookes.

Metzler, I. (2006). *Disability in medieval Europe: Thinking about physical impairment during the high Middle Ages, c. 1100-1400*. Oxford: Routledge.

Millberger, S., LeRoy, B. W., Lachance, L., & Edelson, G. (2002). Osteoporosis and women with Down syndrome. *Journal of Intellectual and Developmental Disability, 27*(4), 273-280.

Miller, B., & Cafasso, B. S. (1992). Gender differences in caregiving: Fact or artifact? *The Gerontologist, 32*(4), 498-507.

Moore, S. (2005). Sexuality: Psychological perspectives. In M. Temple-Smith & S. Gifford (Eds.), *Sexual health: An Australian perspective* (pp. 81-99). Melbourne: IP Communications.

Morrow, R. (2005). Sexual dysfunction and sex therapy. In G. Hawkes & J. Scott (Eds.), *Perspectives in human sexuality* (pp. 187-202). Melbourne: Oxford University Press.

Morse, J. M. (1998). Designing funded qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp. 56-85). London: Sage.

Mosier, H. D., Grossman, H. J., & Dingman, H. F. (1962). Secondary sex development in mentally deficient individuals. *Child Development, 33*, 273-286.

Mount, R. H., Hastings, R. P., Reilly, S., Cass, H., & Charman, T. (2002). Behaviour problems in adult women with Rett syndrome. *Journal of Intellectual Disability Research, 46*(8), 619-624.

Murphy, C., Yeargin-Allsopp, M., Decoufle, P., & Drews, C. D. (1993). Prevalence of cerebral palsy among ten-year-old children in metropolitan Atlanta, 1985 through 1987. *Journal of Pediatrics, 123*(5), S13-S20.

Murphy, G., & Fernando, S. (1999). Services for people with challenging behaviour and mental health needs. *Tizard Learning Disability Review, 4*(3), 31-39.

Murphy, G., Powell, S., Guzman, A. M., & Hays, S. J. (2007). Cognitive-behavioural treatment for men with intellectual disabilities and sexually abusive behaviour: A pilot study. *Journal of Intellectual Disability Research, 51*(11), 902-912.

Murphy, M. M., & Abbeduto, L. (2007). Gender differences in repetitive language in fragile-X syndrome. *Journal of Intellectual Disability Research, 51*(5), 387-400.

Nakamura, M., Hara, K., Watamaki, T., Nishimura, B., Kumagai, T., Matsumoto, A., et al. (1999). Difficulty in writing Japanese semantic characters in a 9-year old boy with Williams syndrome. *Journal of Intellectual Disability Research, 43*(6), 562-567.

Nathanson, P., & Young, K. (2001). *Spreading misandry: The teaching of contempt for men in popular culture*. Quebec: McGill-Queen's University Press.

Nehring, W. M. (Ed.). (2005). *Health promotion for people with intellectual and developmental disabilities: The state of scientific evidence*. Washington, DC: American Association on Mental Retardation.

New South Wales Ombudsman. (2007). *Report of reviewable deaths in 2006:Deaths of people with disabilities in care*. Sydney: Author.

O'Lynn, C. E. (2007a). History of men in nursing: A review. In C. E. O'Lynn & R. E. Tranbarger (Eds.), *Men in nursing: History, challenges and opportunities* (pp. 5-42). New York: Springer Publishing Company.

O'Lynn, C. E. (2007b). Men, caring, and touch. In C. E. O'Lynn & R. E. Tranbarger (Eds.), *Men in nursing: history, challenges and opportunities* (pp. 121-141). New York: Springer Publishing Company.

O'Lynn, C. E., & Tranbarger, R. E. (Eds.). (2007). *Men in nursing: History challenges and opportunities*. New York: Springer Publishing Company.

Olesen, V. L. (2000). Feminisms and qualitative research at and into the millennium. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 215-255). London: Sage.

Ornstein, P. A., Schaaf, J. M., Hooper, S. R., Hatton, D. D., Mirrett, P., & Bailey, D. B., Jr. (2008). Memory skills of boys with Fragile X syndrome. *American Journal on Mental Retardation, 113*(6), 453-465.

Ouellette-Kuntz, H. (2005). Understanding health disparities and inequities faced by individuals with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 18*, 113-121.

Pan American Health Organisation, & World Health Organisation. (2000). *Promotion of sexual health: recommendations for action*. Antigua, Guatemala: World Health Organisation.

Parents defend growth-stunt operation. (2007, January 5th). *Sydney Morning Herald*.

Parker, D. (2008). Sexual Health and Relationships Training and the Disability Worker, *Paper presented at the 19th annual conference of the Professional Association of Nurses in Developmental Disability Areas (PANDDA)*. Sydney.

Parkes, N., & Keoghan, S. (2007). Erectile dysfunction: Meeting the needs of men with learning disabilities. *Nursing Standard, 21*(31), 35-41.

Parmenter, T. R. (2001). Intellectual disabilities - Quo Vadis? In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 267-296). London: Sage.

Paterson, B. L., Tschikota, S., Crawford, M., Saydak, M., Venkatesh, P., & Aronowitz, T. (1996). Learning to care: Gender issues for male nursing students. *Canadian Journal of Nursing Research, 28*(1), 25-39.

Patja, K., Eero, P., & Iivanainen, M. (2001). Cancer incidence among people with intellectual disability. *Journal of Intellectual Disability Research, 45*(4), 300-307.

Patja, K., Mölsä, P., & Iivanainen, M. (2001). Cause-specific mortality of people with intellectual disability in a population-based, 35 year follow up study. *Journal of Intellectual Disability Research, 45*(1), 30-40.

Peate, I. (2003). *Men's sexual health*. London: Whurr Publishers Ltd.

Peckham, N. G., Howlett, S., & Corbett, A. (2007). Evaluating a survivors group pilot for women with significant intellectual disabilities who have been sexually abused. *Journal of Applied Research in Intellectual Disabilities, 20*(4), 308-322.

Peterson, C. (1989). *Looking forward through the lifespan: Developmental psychology* (2nd ed.). Sydney: Prentice Hall.

Popenoe, P. (1928). Marriage after sterilization. *Sessions, Proceedings, and Addresses of the Annual Session of the American Association on Mental Deficiency, xxxiii*, 62-76.

Porter, C. L., Christian, L., & Poling, A. (2003). Research brief: Some data concerning the reporting of participants gender in the mental retardation literature. *Mental Retardation, 41*(2), 75-77.

Porter, R. (1987). "The secrets of generations display'd": Aristotles master-piece in eighteenth-century England. In R. P. Maccubbin (Ed.), *'Tis nature's fault: Unauthorized sexuality during the Enlightenment* (pp. 1-21). Cambridge, UK: Cambridge University Press.

Porter, S. (2002). Critical realist ethnography. In T. May (Ed.), *Qualitative research in action* (pp. 53-72). London: Sage.

Potts, M., & Short, R. (1999). *Ever since Adam and Eve: The evolution of human sexuality*. Cambridge: Cambridge University Press.

Price, J., Roberts, J. E., Vandergrift, N., & Martin, G. (2007). Language comprehension in boys with fragile-X syndrome and boys with Down syndrome. *Journal of Intellectual Disability Research, 51*(4), 318-326.

Pringle, K. (1995). *Men, masculinities and social welfare*. London: UCL Press.

Quinsey, V. L., Book, A., & Skilling, T. A. (2004). A follow-up of deinstitutionalised men with intellectual disabilities and histories of antisocial behaviour. *Journal of Applied Research in Intellectual Disabilities, 17*, 243-253.

Rhodes, R. (1993). Mental retardation and sexual expression: An historical perspective. *Journal of Social Work and Human Sexuality, 8*(2), 1-27.

Ricci, L. A., & Hodapp, R. M. (2003). Fathers of children with Down's syndrome versus other types of intellectual disability: Perceptions, stress and involvement. *Journal of Intellectual Disability Research, 47*(4-5), 273-284.

Richards, B. W. (Ed.). (1967). *Proceedings of the first congress of the International Association for the Scientific Study of Mental Deficiency*. Surrey, UK: Michael Jackson Publishing Company.

Roberts, J. E., Hennon, E. A., Price, J. R., Dear, E., Anderson, K., & Vandergrift, N. A. (2007). Expressive language during conversational speech in boys with fragile-X syndrome. *American Journal of Mental Retardation, 112*(1), 1-17.

Roberts, J. E., Mirrett, P., & Burchinal, M. (2001). Receptive and expressive communication development of young males with fragile-X syndrome. *Journal of Intellectual and Developmental Disability, 106*(3), 216-230.

Roberts, J. E., Price, J., Barnes, E., Nelson, L., Burchinal, M., Hennon, E. A., et al. (2007). Receptive vocabulary, expressive vocabulary, and speech production of boys with fragile-X syndrome in comparison to boys with Down syndrome. *American Journal of Mental Retardation, 112*(3), 177-193.

Roberts, J. E., Schaaf, J. M., Skinner, M., Wheeler, A., Hooper, S. R., Hatton, D. D., et al. (2005). Academic skills of boys with fragile-X syndrome: Profiles and predictors. *American Journal of Mental Retardation, 110*(2), 107-120.

Roberts, J. E., Symons, F. J., Johnson, A. M., Hatton, D. D., & Boccia, M. L. (2005). Blink rate in boys with fragile-X syndrome: Preliminary evidence for altered dopamine function. *Journal of Intellectual Disability Research, 49*(9), 647-656.

Robertson, S. (2007). *Understanding men and health: Masculinities, identity and well-being*. Berkshire: Open University Press.

Robison, C. P., Conahan, F., & Brady, W. (1992). Reducing self-injurious masturbation using a least intrusive model and adaptive equipment. *Sexuality and Disability, 10*(1), 43-55.

Rogers, A. C. (1897). Editorial: Desexualization. *Journal of Psycho-Asthenics, II*(September), 50-51.

Rogers, J., & Lipscombe, J. (2005). The nature and extent of help given to women with intellectual disabilities to manage menstruation. *Journal of Intellectual and Developmental Disability, 30*(1), 45-52.

Rogers, J., Lipscombe, J., & Santer, M. (2006). Menstrual problems experienced by women with learning disabilities. *Journal of Applied Research in Intellectual Disabilities, 19*(4), 364-373.

Rose, J., Jenkins, R., O'Connor, C., Jones, C., & Felce, D. (2002). A group treatment for men with intellectual disabilities who sexually offend or abuse. *Journal of Applied Research in Intellectual Disabilities, 15*(2), 138-150.

Rose, M. L. (2003). *The staff of Oedipus: Transforming disability in ancient Greece*. Michigan: University of Michigan Press.

Rosenfeld, D., & Faircloth, C. A. (Eds.). (2006). *Medicalized masculinities*. Philadelphia: Temple University Press.

Roy, M. (2006). Sexuality and people with intellectual disability. In A. Roy, M. Roy & D. Clarke (Eds.), *The psychiatry of intellectual disability* (pp. 121-131). Oxford: Radcliffe Publishing.

Rubio-Aurioles, E. (2005). Presidential address: Closing ceremony of the XVII World Congress of Sexology, *Montreal Sexo 2005*. Montreal: Canada.

Russell, C., & Schofield, T. (1986). *Where it hurts: An introduction to sociology for health workers*. North Sydney: Allen and Unwin.

Sabaratnam, M. (2000). Pathological and neuropathological findings in two males with fragile-X syndrome. *Journal of Intellectual Disability Research, 44*(1), 81-85.

Sabo, D. (2005). The study of masculinities and men’s health, an overview. In M.S.Kimmel, J.Hearn & R.W.Connell (Eds.), *Handbook of studies on men and masculinities* (pp. 326-352). London: Sage.

Sajith, S. G., Morgan, C., & Clarke, D. (2008). Pharmacological management of inappropriate sexual behaviours: A review of its evidence, rationale, and scope in relation to men with intellectual disabilities. *Journal of Intellectual Disability Research, 52*(12), 1078-1090.

Saloviita, T. (2002). Behavioural treatment of improper eating by an institutionalised woman with profound intellectual disability - a description of a successful intervention. *Journal of Intellectual and Developmental Disability, 27*(1), 15-20.

Salzman, B. E., & Wender, R. C. (2006). Male sex: A major health disparity. In C. A. Haines & R. C. Wender (Eds.), *Primary care: Clinics in office practice - men's health* (Vol. 33 (1), pp. 1-16). Philadelphia: W.B. Saunders.

Sánchez-Jankowski, M. (2002). Representation, responsibility and reliability in participant-observation. In T. May (Ed.), *Qualitative research in action* (pp. 144-160). London: Sage.

Saunders, E. J. (1981). The mental health professional, the mentally retarded, and sex. *Hospital and Community Psychiatry, 32*(10), 717-721.

Savarimuthu, D., & Bunnell, T. (2003). Sexuality and learning disabilities. *Nursing Standard, 17*(39), 33-35.

Schehr, L. R. (1997). *Parts of an andrology: On representations of men's bodies*. Stanford, CA: Stanford University Press.

Schofield, T., Connell, R. W., Walker, L., Wood, J. F., & Butland, D. L. (2000). Understanding men's health and illness: A gender-relations approach to policy, research, and practice. *Journal of American College Health, 48*(6), 247-256.

Schrager, S., Kloss, C., & Ju, A. W. (2007). Prevalence of fractures in women with intellectual disabilities: A chart review. *Journal of Intellectual Disability Research, 51*(4), 253-259.

Schupf, N., Zigman, W., Kapell, D., Lee, J. H., Kline, J., & Levin, B. (1997). Early menopause in women with Down syndrome. *Journal of Intellectual Disability Research, 41*(3), 215-224.

Segal, L. (2007). *Slow motion: Changing masculinities, changing men* (3rd ed.). New York: Palgrave Macmillan.

Seltzer, G. B., Schupf, N., & Wu, H. S. (2001). A prospective study of menopause in women with Down's syndrome. *Journal of Intellectual Disability Research, 45*(1), 1-7.

Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 12*, 48-56.

Servais, L., Hoyois, P., & Roussaux, J. P. (2000). Sterilising people with learning disabilities: A problem belonging to the past? *European Journal on Mental Disability, 21*, 4-16.

Servais, L., Leach, J. R., Conod, L., Hoyois, P., Dan, B., & Roussaux, J. P. (2002). Contraception of women with intellectual disability: Prevalence and determinants. *Journal of Intellectual Disability Research, 46*(2), 108-119.

Sexual Health and Wellbeing Network. (2008). *Sexual health and relationships: A review of resources for people with learning disabilities*. Edinburgh: Health Scotland.

Shakespeare, T. (2006). *Disability rights and wrongs*. London: Routledge.

Shanahan, M., Roberts, J., Hatton, D., Reznick, J., & Goldsmith, H. (2008). Early temperament and negative reactivity in boys with fragile-X syndrome. *Journal of Intellectual Disability Research, 52*(12), 842-854.

Shavelle, R., & Strauss, D. (1999). Mortality of persons with developmental disabilities after transfer to community care: A 1996 update. *American Journal on Mental Retardation, 104*(2), 143-147.

Shelton, D. (1992). Client sexual behaviour and staff attitudes: Shaping masturbation in an individual with a profound mental and secondary sensory handicap. *Mental Handicap, 20*(June), 81-84.

Shorter, E. (1997). *A history of psychiatry: From the era of the asylum to the age of Prozac*. London: John Wiley and Sons.

Shuttleworth, R. P. (2000). The search for sexual intimacy for men with cerebral palsy. *Sexuality and Disability, 18*(4), 263-282.

Shuttleworth, R. P. (2003). The case for a focus on sexual access in a critical approach to disability and sexuality research, *Paper presented at the 1st Annual Disability Studies Association*. Lancaster, England.

Shuttleworth, R. P. (2006). Toward a constructionist focus on access and the inclusion of disabled people in the sexual rights movement. In T. Teunis & G. Herdt (Eds.), *Sexual inequalities and social justice* (pp. 174-208). Berkeley: University of California Press.

Silverman, D. (2005). *Doing qualitative research* (2nd ed.). London: Sage Publications.

SkillsConnection Colac. (2008). Colac: SkillsConnection.

Smeltzer, S. C. (2007). Improving the health and wellness of persons with disabilities: A call to action too important for nursing to ignore. *Nursing Outlook, 55*(July/August), 189-195.

Smith, D. E. (2002). Institutional ethnography. In T. May (Ed.), *Qualitative research in action* (pp. 17-52). London: Sage.

Smith, J. A. (2007). Beyond masculine stereotypes: Moving men's health promotion forward in Australia. *Health Promotion Journal of Australia, 18*(1), 20-25.

Smith, M., & Willner, P. (2004). Psychological factors in risk assessment and management of inappropriate sexual behaviour by men with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*(4), 285-297.

Stake, R. E. (1998). Case studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp. 86-109). London: Sage.

Stancliffe, R. J., Emerson, E., & Lakin, K. C. (2004). Residential supports. In E. Emerson, C. Hatton, T. Thompson & T. R. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 459-478). West Sussex: John Wiley & sons Ltd.

Stancliffe, R. J., & Keane, S. (2000). Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. *Journal of Intellectual and Developmental Disability, 25*(4), 281-305.

Stansfield, A. J., Holland, A. J., & Clare, I. C. H. (2007). The sterilisation of people with intellectual disabilities in England and Wales during the period 1988 to 1999. *Journal of Intellectual Disability Research, 51*(8), 569-579.

Stibbe, A. (2004). Health and the social construction of masculinity in Men's Health magazine. *Men and Masculinities, 7*(1), 31-51.

Stiker, H. J. (1999). *A history of disability* (W. Sayers, Trans.). Michigan: The University of Michigan Press.

Stinson, J. (2004). *A systems approach to the development of a model of sexuality for adults with developmental disabilities.* Unpublished doctoral dissertation, Alliant International University, Los Angeles.

Storkey, E. (2000). *Created or constructed? The great gender debate*. Carlisle, UK: Paternoster Press.

Stratham, M., & Timblick, D. (2001). Self-concept and people who have learning disabilities. In J. Thompson & S. Pickering (Eds.), *Meeting the health needs of people who have a learning disability* (pp. 179-194). London: Baillere Tindall.

Strauss, A., & Corbin, J. (1998). Grounded theory methodology: An overview. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative enquiry* (pp. 158-183). London: Sage.

Strauss, D., Shavelle, R., Baumeister, A., & Anderson, T. W. (1998). Mortality in persons with developmental disabilities after transfer into community care. *American Journal on Mental Retardation, 102*(6), 569-581.

Sullivan, E. J. (2007). Foreward. In C. E. O'Lynn & R. E. Tranbarger (Eds.), *Men in nursing: History, challenges and opportunities* (pp. xxi-xxii). New York: Springer Publishing Company.

Tauber, E. S. (1940). Effects of castration upon the sexuality of the adult male. *Psychosomatic Medicine, 11*(1), 74-87.

Taylor, J. M. (1898). Hints to the officers of institutions for the feeble-minded. *Journal of Psycho-Asthenics, 3*(2), 76-81.

Tedlock, B. (2000). Ethnography and ethnographic representation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 455-486). London: Sage.

Tewari, S. (2006). Intellectual disability and the law. In A. Roy, M. Roy & D. Clarke (Eds.), *The psychiatry of intellectual disability* (pp. 133-152). Oxford: Radcliffe Publishing.

The Donald Beasley Institute. (2001). *Taking more control of my health: A health guide for women*. Dunedin, NZ: The Donald Beasley Institute.

The Kinsey Institute. (2007). *Origin of the institute*. Retrieved 21st September, 2007, from http://www.kinseyinstitute.org/about/origins.html

Thompson, A. R., & Beail, N. (2002). The treatment of auto-erotic asphyxiation in a man with severe intellectual disabilities: The effectiveness of a behavioural and educational programme. *Journal of Applied Research in Intellectual Disabilities, 15*(1), 36-47.

Thompson, D. (1998). *The sexual experiences and sexual identity of men with learning disabilities.* Unpublished doctoral thesis, The University of Kent, Canterbury.

Thompson, D. (2001). Is sex a good thing for men with learning disabilities? *Tizard Learning Disability Review, 6*(1), 4-12.

Thompson, D., Clare, I., & Brown, H. (1997). Not such an ordinary relationship: The role of women support staff in relation to men with learning disabilities who have difficult sexual behaviour. *Disability and Society, 12*(4), 573-592.

Thompson, E. H., Jr. (2005). What's unique about men's caregiving? In B. J. Kramer & E. H. Thompson Jr. (Eds.), *Men as caregivers* (pp. 20-47). New York: Prometheus Books.

Thompson, T., Caruso, M., & Ellerbeck, K. (2003). Sex matters in autism and other developmental disabilities. *Journal of Learning Disabilities (London), 7*(4), 345-362.

Traustadottir, R., & Johnson, K. (Eds.). (2000). *Women with intellectual disabilities: Finding a place in the world*. London: Jessica Kingsley Publishers Ltd.

Tsakanikos, E., Bouras, N., Sturney, P., & Holt, G. (2006). Psychiatric co-morbidity and gender differences in intellectual disability. *Journal of Intellectual Disability Research, 50*(8), 582-587.

Turk, J., & Cornish, K. (1998). Face recognition and emotion perception in boys with fragile-X syndrome. *Journal of Intellectual Disability Research, 42*(6), 490-499.

Tyler, G., & Parker, M. (2001). Men's talk. *Learning Disability Practice, 3*(6), 22-25.

Tyrer, F., Smith, L. K., & McGrother, C. W. (2007). Mortality in adults with moderate to profound intellectual disability: A population-based study. *Journal of Intellectual Disability Research, 51*(7), 520-527.

U.S. Department of Health and Human Services. (2005). *The Surgeon General's call to action to improve the health and wellness of persons with disabilities*. Office of the Surgeon General: Author.

Umb-Carlsson, Õ., & Sonnander, K. (2006). Living conditions of adults with intellectual disabilities from a gender perspective. *Journal of Intellectual Disability Research, 50*(5), 326-334.

United Kingdom General Social Care Council. (2002). *Code of practice for social care workers and code of practice for employers of social care workers*. London: Author.

van Schrojenstein Lantman-de Valk, H. M. J. (2005). Health in people with intellectual disabilities: Current knowledge and gaps in knowledge. *Journal of Applied Research in Intellectual Disabilities, 18*, 325-333.

Vidich, A. J., & Lyman, M. (2000). Qualitative methods: Their history in sociology and anthropology. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 37-84). London: Sage.

Wales, L., Charman, T., & Mount, R. H. (2004). An analogue assessment of repetitive hand behaviours in girls and young women with Rett syndrome. *Journal of Intellectual Disability Research, 48*(7), 672-678.

Walford, G. (2001). *Doing qualitative educational research: A personal guide to the research process*. London: Continuum.

Wallace, R. A., & Beange, H. (2008). On the need for a specialist service within the generic hospital setting for the adult patient with intellectual disability and physical health problems. *Journal of Intellectual and Developmental Disability, 33*(4), 354-361.

Walsh, A. (2000). IMPROVE and CARE: Responding to inappropriate masturbation in people with severe intellectual disabilities. *Sexuality and Disability, 18*(1), 27-39.

Walsh, P. N. (2000). Rights of passage: Life course transitions for women with intellectual disabilities. In D. May (Ed.), *Transition and change in the lives of people with intellectual disabilities* (pp. 135-156). London: Jessica Kingsley Publishers.

Walsh, P. N. (2007). A gendered approach to intellectual and developmental disabilities. In I. Brown & M. Percy (Eds.), *A comprehensive guide to intellectual and developmental disabilities* (pp. 585-593). Baltimore: Paul H. Brookes.

Walsh, P. N., & Heller, T. (2002). *Health of women with intellectual disabilities*. Oxford: Blackwell Science.

Walsh, P. N., Heller, T., Schupf, N., & van Schrojenstein Lantman-de Valk, H. M. J. (2001). Healthy ageing-adults with intellectual disabilities: Women's health and related issues. *Journal of Applied Research in Intellectual Disabilities, 14*(3), 195-217.

Walsh, P. N., & LeRoy, B. (2004). *Women with disabilities ageing well*. Oxford, UK: Blackwell Publishing.

Ware, J. (2004). Ascertaining the views of people with profound and multiple learning disabilities. *British Journal of Learning Disabilities, 32*, 175-179.

Watters, G., & Carroll, S. (2001). *Your penis: A users guide*. Port Macquarie, NSW: Urology Publications.

Webb, J. (1998). *Junk male*. Sydney: Harper Collins Publishers.

Weeks, J. (1986). *Sexuality* (2nd ed.). London: Routledge.

Weeks, J. (1991). *Against nature: Essays on history, sexuality and identity*. London: Rivers Oram Press.

West, P. (2004). "Lets play a game of footy, Sir": Boy's difficulties and the link with male teachers, *Paper presented to the Senate Committee inquiring into the Sex Discrimination Bill in Australia*. Canberra.

Westheimer, R. K., & Lopater, S. (2005). *Human sexuality: A psychosocial perspective* (2nd ed.). Baltimore, MD: Lippincott Williams & Wilkins.

Wheeler, P. (2001). Sexuality: Meaning and relevance to learning disability nurses. *British Journal of Nursing, 10*(14), 920-927.

Wheeler, P. (2004). Sex, the person with a learning disability and the changing legal framework. *Learning Disability Practice, 7*(3), 32-39.

Wheeler, P. (2007). 'I count myself as normal, well, not normal but normal enough': Men with learning disabilities tell their stories about sexuality and sexual identity. *Learning Disability Review, 12*(1), 16-27.

Wheeler, P., & Jenkins, R. (2004). The management of challenging sexual behaviour. *Learning Disability Practice, 7*(5), 28-37.

Whipple, B. (2007). Keynote address: The benefits of sexual expression on reproductive health and on sexuality itself, *World Association for Sexual Health 1st World Congress for Sexual Health: Achieving Health, Pleasure and Respect*. Sydney, Australia.

Whipple, B., Knowles, J., & Davis, J. (2003). *The health benefits of sexual expression*. Retrieved 17th December, 2008, from http://www.plannedparenthood.org/resources/research-papers/sexual-expression-6358.htm

White, J., & Chiarella, M. (2000). So, you want to be a nurse. In J. Daly, S. Speedy & D. Jackson (Eds.), *Contexts of nursing*. Sydney: MacLennan & Petty.

Wilcox, E., Finlay, W. M., & Edmonds, J. (2006). 'His brain is totally different': An analysis of care-staff explanations of aggressive challenging behaviour and the impact of gendered discourses. *British Journal of Social Psychology, 45*, 197-216.

Wilkins, D., & Baker, P. (2004). *Getting it sorted: A policy programme for men's health*. London: The Men's Health Forum

Williams, R., & Robertson, S. (2006). Masculinities, men and promoting health through primary care. *Primary Health Care, 16*(8), 25-28.

Willner, P., & Smith, M. (2008). Can attribution theory explain carers' propensity to help men with intellectual disabilities who display inappropriate sexual behaviour? *Journal of Intellectual Disability Research, 52*(1), 79-88.

Wilson, N., Clegg, J., & Hardy, G. (2008). What informs and shapes ethical practice in intellectual disability services? *Journal of Intellectual Disability Research, 52*(7), 608-617.

Wilson, N. J. (2005). Men, health and intellectual disability: The current status. *The Journal of the Association for Practitioners in Learning Disabilities, 21*(3), 6-13.

Wilson, N. J. (2007a). Constructing a salutogenic framework for the sexual health needs of men with an intellectual disability, *Paper presented at the Annual conference for the Association of Psychologists in Developmental Disability Services (PSYCHDD)*. Mercure Hotel, Parramatta: NSW.

Wilson, N. J. (2007b). Defining the sexual health needs of men with an intellectual disability: A salutogenic approach, *Paper presented at the 42nd annual conference of the Australasian Society for the Study of Intellectual Disability (ASSID): Active citizenship, community engagement.* Fremantle: Western Australia.

Wilson, N. J. (2007c). *A forgotten and vulnerable population: men with profound and severe intellectual disabilities.* Paper presented at the 7th National Men's Health Conference; Debate and invigorate: challenges in men's health, Adelaide convention centre.

Wilson, N. J. (2007d). Sexual health and men with an intellectual disability: A population health approach drawing upon masculinity theory, *Oral poster presented at the World Association for Sexual Health 1st World Congress for Sexual Health: Achieving Health, Pleasure and Respect*. Sydney: NSW.

Wilson, N. J., Cumella, S., Parmenter, T. R., Stancliffe, R. J., & Shuttleworth, R. P. (2009). Penile hygiene: Puberty, paraphimosis, and personal care for men and boys with an intellectual disability. *Journal of Intellectual Disability Research, 53*(2), 106-114.

Wilson, N. J., Parmenter, T. R., Stancliffe, R. J., & Shuttleworth, R. P. (2009). From diminished men to conditionally masculine: toward a salutogenic construct of masculinity for men and boys with an intellectual disability. *Manuscript submitted for publication*.

Wilton, T. (2000). *Sexualities in health and social care: A textbook*. Buckingham: Open University Press.

Withers, P., Ensum, I., Howarth, D., Krall, P., Thomas, D., Weekes, D., et al. (2001). A psychoeducational group for men with intellectual disabilities who have sex with men. *Journal of Applied Research in Intellectual Disabilities, 14*(2), 327-339.

Wolfensberger, W. (2008). The fiftieth anniversary of what appears to be the world's first doctoral degree program in mental retardation: Some reminiscences of an early graduate. *Intellectual and Developmental Disabilities, 46*(1), 64-79.

Women's Health Goulburn North East. (2002). *There's no disability in women's hearts. Count me two: a project about sexual health for women with an intellectual disability*. Wangaratta, Victoria: Author.

Wood, R. (2007). Cervical screening for women with learning disability: Current practice and attitudes within primary care in Edinburgh. *British Journal of Learning Disabilities, 35*, 84-92.

Woods, M. (2002a). A brief word on 'discourse', *Men's health information and resource centre*. University of Western Sydney.

Woods, M. (2002b). *Killing them subtly - social determinants in men's health*. Retrieved April, 2006, from http://menshealth.uws.edu.au/documents/Which%20men%20are%20sick.html

Woods, M. (2007). The rhetoric and reality of violence against men, *Paper presented at the 7th National Men's Health Conference; Debate and invigorate: challenges in men's health*. Adelaide convention centre: The Australasian Men's Health Forum.

Woodyatt, G. C., & Murdoch, B. E. (1996). The effect of the presentation of visual and auditory stimuli on the breathing patterns of two girls with Rett syndrome. *Journal of Intellectual Disability Research, 40*(3), 252-259.

World Association for Sexual Health. (2007). *The sexual health for the millennium declaration*: Author.

World Health Organisation (WHO). (2001). *International classification of functioning, disability and health* (10th ed.). Geneva, Switzerland: Author.

Wright, G., Herzog, D., & Seymour, J. (1992). Treatment of a constellation of inappropriate sexual and social behaviours in a 20 year old man with Down's syndrome. *Sexuality and Disability, 10*(1), 57-61.

Yacoub, E., & Hall, I. (2009). The sexual lives of men with mild learning disability: A qualitative study *British Journal of Learning Disabilities, 37*(1), 5-11.

Young, J. (1996). Paving the way to discrimination. *Kaitiaki: Nursing New Zealand*(May), 29.

APPENDICES

Appendix 1. **322**

Ethics approval

Appendix 2. **324**

Consent form

Appendix 3. **325**

Participant information sheet

Appendix 4. **326**

Recruitment letter

Appendix 5. **327**

Interview Schedule

Appendix 6. **328**

Additional consent form for photograph

Appendix 7. **329**

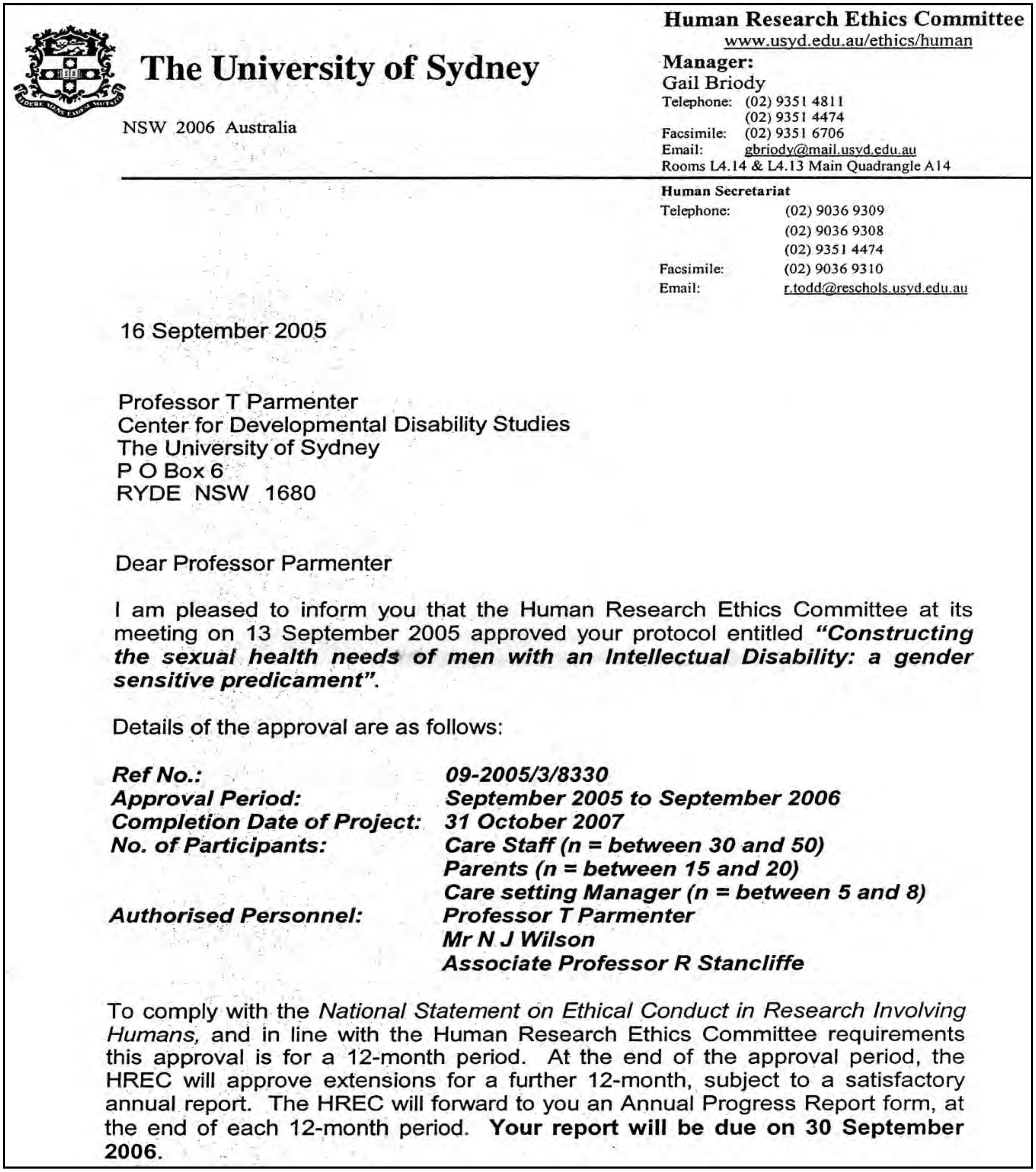
Conditionally Masculine book chapter submitted for review with Vanderbilt Press

Appendix 8. **358**

Tabular example of codes using constant comparative method

Appendix 1

ETHICS APPROVAL, PAGE 1.



The University of Sydney
NSW 2006 Australia

Human Research Ethics Committee
www.usyd.edu.au/ethics/human
Manager:
Gail Briody
Telephone: (02) 9351 4811
(02) 9351 4474
Facsimile: (02) 9351 6706
Email: gbriody@mail.usyd.edu.au
Rooms L4.14 & L4.13 Main Quadrangle A14

Human Secretariat
Telephone: (02) 9036 9309
(02) 9036 9308
(02) 9351 4474
Facsimile: (02) 9036 9310
Email: r.todd@reschols.usyd.edu.au

16 September 2005

Professor T Parmenter
Center for Developmental Disability Studies
The University of Sydney
P O Box 6
RYDE NSW 1680

Dear Professor Parmenter

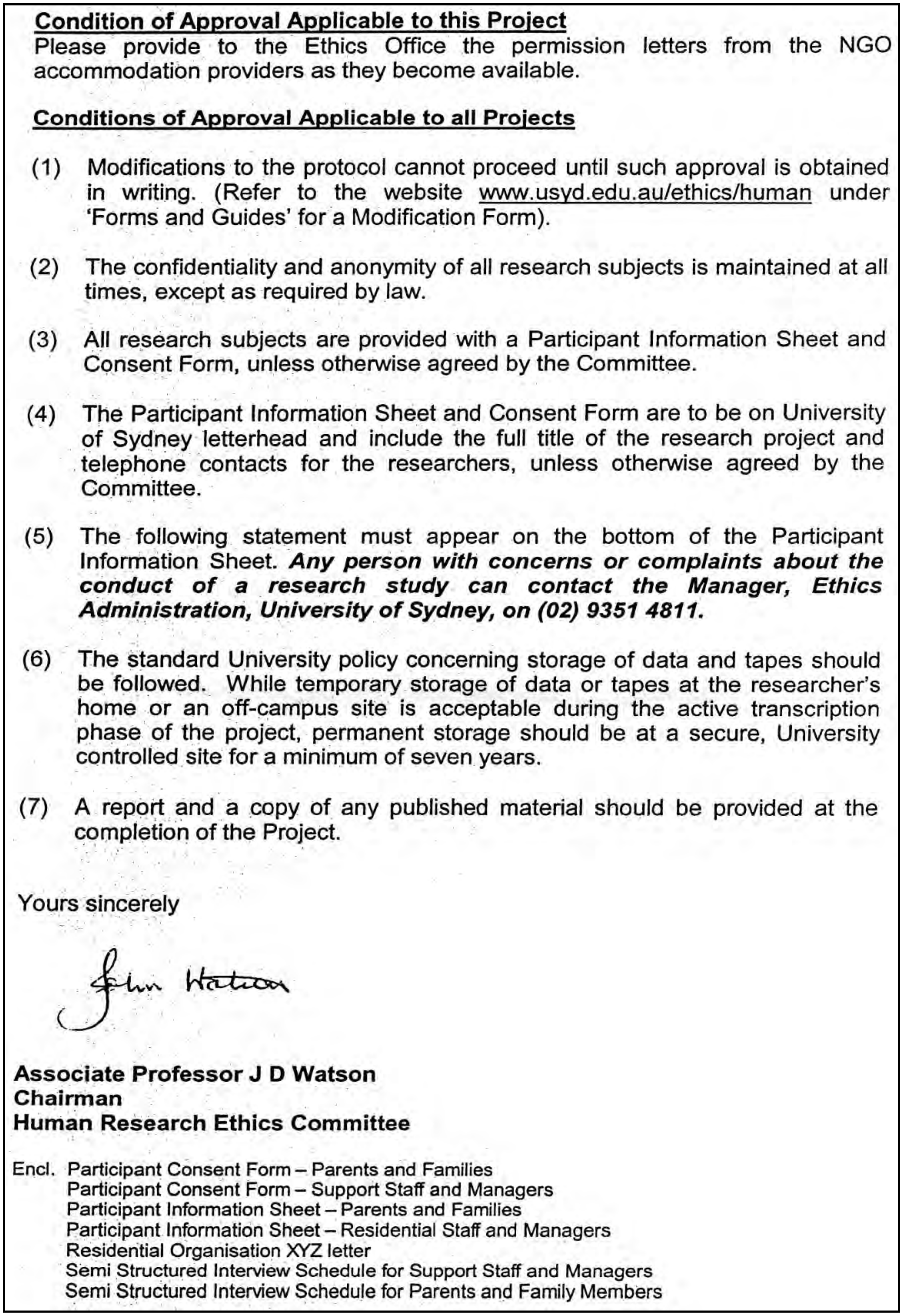
I am pleased to inform you that the Human Research Ethics Committee at its meeting on 13 September 2005 approved your protocol entitled ***"Constructing the sexual health needs of men with an Intellectual Disability: a gender sensitive predicament"***.

Details of the approval are as follows:

Ref No.:	***09-2005/3/8330***
Approval Period:	***September 2005 to September 2006***
Completion Date of Project:	***31 October 2007***
No. of Participants:	***Care Staff (n = between 30 and 50)*** ***Parents (n = between 15 and 20)*** ***Care setting Manager (n = between 5 and 8)***
Authorised Personnel:	***Professor T Parmenter*** ***Mr N J Wilson*** ***Associate Professor R Stancliffe***

To comply with the *National Statement on Ethical Conduct in Research Involving Humans,* and in line with the Human Research Ethics Committee requirements this approval is for a 12-month period. At the end of the approval period, the HREC will approve extensions for a further 12-month, subject to a satisfactory annual report. The HREC will forward to you an Annual Progress Report form, at the end of each 12-month period. **Your report will be due on 30 September 2006.**

ETHICS APPROVAL, page 2



Condition of Approval Applicable to this Project

Please provide to the Ethics Office the permission letters from the NGO accommodation providers as they become available.

Conditions of Approval Applicable to all Projects

(1) Modifications to the protocol cannot proceed until such approval is obtained in writing. (Refer to the website www.usyd.edu.au/ethics/human under 'Forms and Guides' for a Modification Form).

(2) The confidentiality and anonymity of all research subjects is maintained at all times, except as required by law.

(3) All research subjects are provided with a Participant Information Sheet and Consent Form, unless otherwise agreed by the Committee.

(4) The Participant Information Sheet and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee.

(5) The following statement must appear on the bottom of the Participant Information Sheet. ***Any person with concerns or complaints about the conduct of a research study can contact the Manager, Ethics Administration, University of Sydney, on (02) 9351 4811.***

(6) The standard University policy concerning storage of data and tapes should be followed. While temporary storage of data or tapes at the researcher's home or an off-campus site is acceptable during the active transcription phase of the project, permanent storage should be at a secure, University controlled site for a minimum of seven years.

(7) A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely

John Watson

Associate Professor J D Watson
Chairman
Human Research Ethics Committee

Encl. Participant Consent Form – Parents and Families
Participant Consent Form – Support Staff and Managers
Participant Information Sheet – Parents and Families
Participant Information Sheet – Residential Staff and Managers
Residential Organisation XYZ letter
Semi Structured Interview Schedule for Support Staff and Managers
Semi Structured Interview Schedule for Parents and Family Members

Appendix 2

CONSENT FORM

The University of Sydney

Trevor R. Parmenter Ph.D
Director of CDDS
Foundation Professor of Developmental Disabilities
Faculty of Medicine

CDDS
Centre for
Developmental
Disability
Studies
ABN: 69 082 298 575

PARTICIPANT CONSENT FORM: SUPPORT STAFF AND MANAGERS

DEFINING THE SEXUAL HEALTH NEEDS OF MEN WITH AN INTELLECTUAL DISABILITY

I, ...
[name]

have read and understood the information for participants on the above named research study and have discussed it with the researcher/s.

I am aware of the procedures involved in the study, including any inconvenience, risk, discomfort and their potential implications.

I freely choose to participate in this study and understand that I can withdraw without compromise at any time.

I also understand that the research study is strictly confidential.

I hereby agree to participate in this research study.

UNIVERSITY OF SYDNEY
HUMAN ETHICS COMMITTEE
APPROVED
DATE: 13-9-03

Signature:..

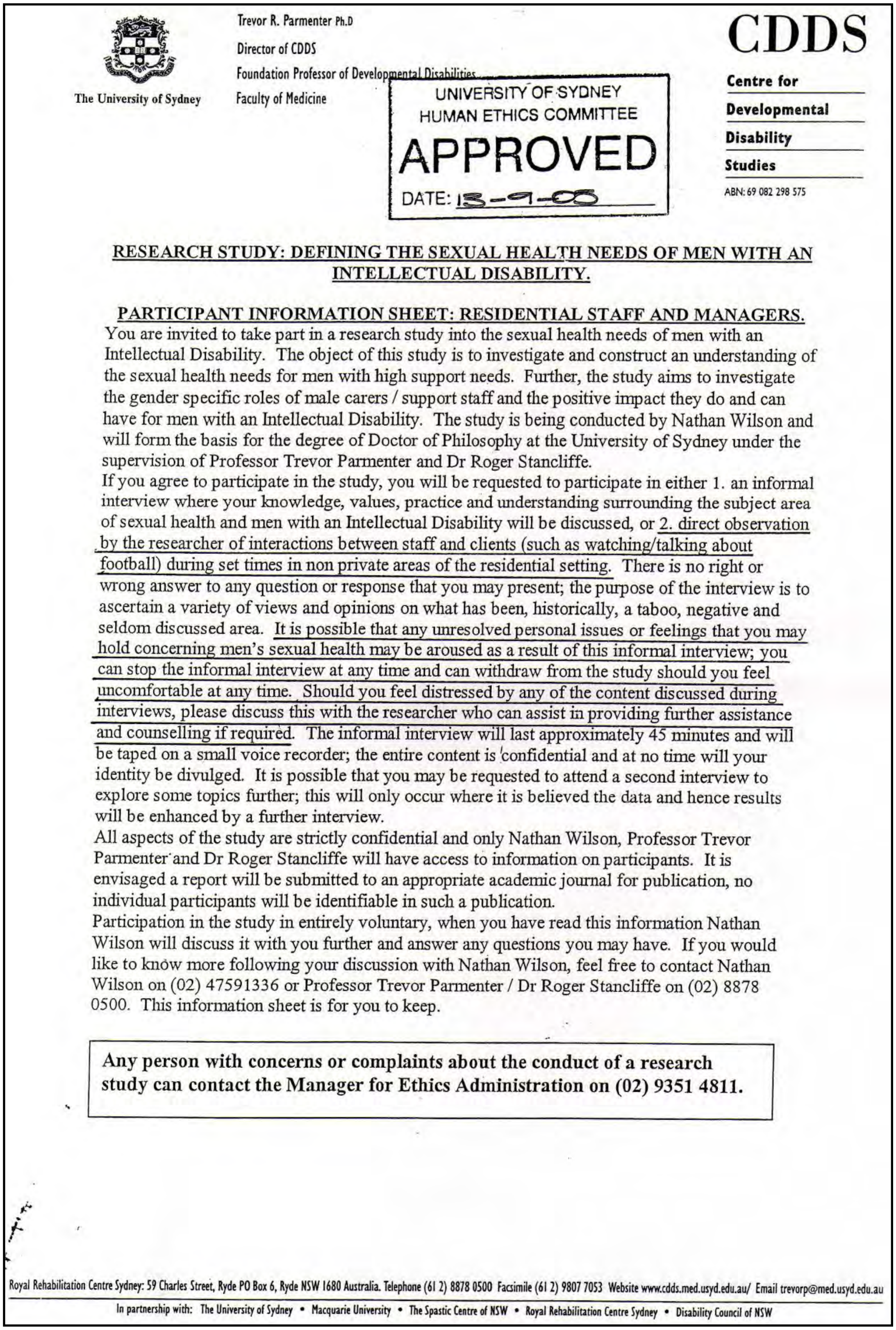
Name:..

Date:...

Royal Rehabilitation Centre Sydney: 59 Charles Street, Ryde PO Box 6, Ryde NSW 1680 Australia. Telephone (61 2) 8878 0500 Facsimile (61 2) 9807 7053 Website www.cdds.med.usyd.edu.au/ Email trevorp@med.usyd.edu.au
In partnership with: The University of Sydney • Macquarie University • The Spastic Centre of NSW • Royal Rehabilitation Centre Sydney • Disability Council of NSW

Appendix 3

PARTICIPANT INFORMATION SHEET



The University of Sydney

Trevor R. Parmenter Ph.D
Director of CDDS
Foundation Professor of Developmental Disabilities
Faculty of Medicine

CDDS
Centre for
Developmental
Disability
Studies
ABN: 69 082 298 575

UNIVERSITY OF SYDNEY
HUMAN ETHICS COMMITTEE
APPROVED
DATE: 13-9-05

RESEARCH STUDY: DEFINING THE SEXUAL HEALTH NEEDS OF MEN WITH AN INTELLECTUAL DISABILITY.

PARTICIPANT INFORMATION SHEET: RESIDENTIAL STAFF AND MANAGERS.

You are invited to take part in a research study into the sexual health needs of men with an Intellectual Disability. The object of this study is to investigate and construct an understanding of the sexual health needs for men with high support needs. Further, the study aims to investigate the gender specific roles of male carers / support staff and the positive impact they do and can have for men with an Intellectual Disability. The study is being conducted by Nathan Wilson and will form the basis for the degree of Doctor of Philosophy at the University of Sydney under the supervision of Professor Trevor Parmenter and Dr Roger Stancliffe.

If you agree to participate in the study, you will be requested to participate in either 1. an informal interview where your knowledge, values, practice and understanding surrounding the subject area of sexual health and men with an Intellectual Disability will be discussed, or 2. direct observation by the researcher of interactions between staff and clients (such as watching/talking about football) during set times in non private areas of the residential setting. There is no right or wrong answer to any question or response that you may present; the purpose of the interview is to ascertain a variety of views and opinions on what has been, historically, a taboo, negative and seldom discussed area. It is possible that any unresolved personal issues or feelings that you may hold concerning men's sexual health may be aroused as a result of this informal interview; you can stop the informal interview at any time and can withdraw from the study should you feel uncomfortable at any time. Should you feel distressed by any of the content discussed during interviews, please discuss this with the researcher who can assist in providing further assistance and counselling if required. The informal interview will last approximately 45 minutes and will be taped on a small voice recorder; the entire content is confidential and at no time will your identity be divulged. It is possible that you may be requested to attend a second interview to explore some topics further; this will only occur where it is believed the data and hence results will be enhanced by a further interview.

All aspects of the study are strictly confidential and only Nathan Wilson, Professor Trevor Parmenter and Dr Roger Stancliffe will have access to information on participants. It is envisaged a report will be submitted to an appropriate academic journal for publication, no individual participants will be identifiable in such a publication.

Participation in the study in entirely voluntary, when you have read this information Nathan Wilson will discuss it with you further and answer any questions you may have. If you would like to know more following your discussion with Nathan Wilson, feel free to contact Nathan Wilson on (02) 47591336 or Professor Trevor Parmenter / Dr Roger Stancliffe on (02) 8878 0500. This information sheet is for you to keep.

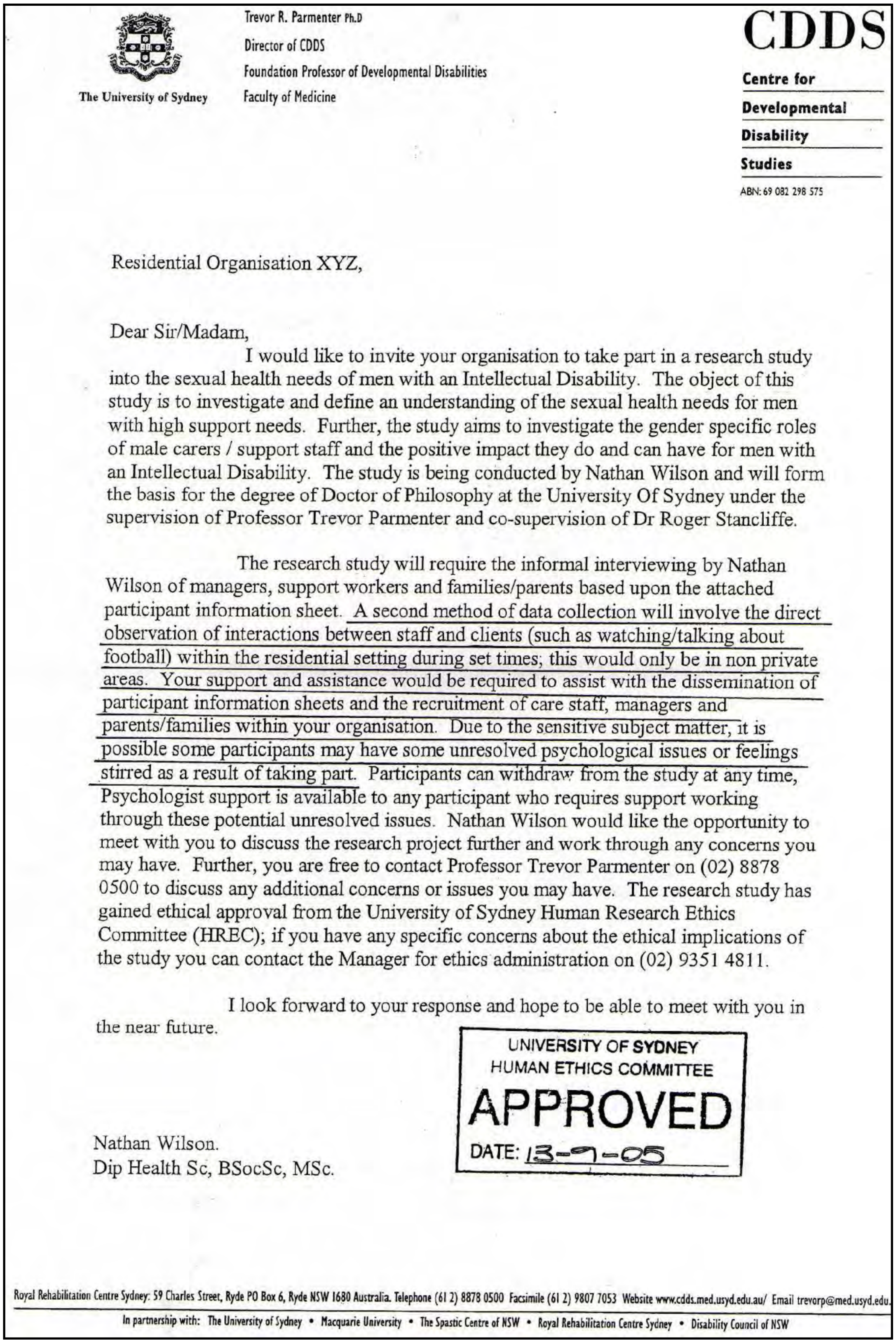
Any person with concerns or complaints about the conduct of a research study can contact the Manager for Ethics Administration on (02) 9351 4811.

Royal Rehabilitation Centre Sydney: 59 Charles Street, Ryde PO Box 6, Ryde NSW 1680 Australia. Telephone (61 2) 8878 0500 Facsimile (61 2) 9807 7053 Website www.cdds.med.usyd.edu.au/ Email trevorp@med.usyd.edu.au

In partnership with: The University of Sydney • Macquarie University • The Spastic Centre of NSW • Royal Rehabilitation Centre Sydney • Disability Council of NSW

Appendix 4

RECRUITMENT LETTER



The University of Sydney

Trevor R. Parmenter Ph.D
Director of CDDS
Foundation Professor of Developmental Disabilities
Faculty of Medicine

CDDS
Centre for
Developmental
Disability
Studies
ABN: 69 082 298 575

Residential Organisation XYZ,

Dear Sir/Madam,

I would like to invite your organisation to take part in a research study into the sexual health needs of men with an Intellectual Disability. The object of this study is to investigate and define an understanding of the sexual health needs for men with high support needs. Further, the study aims to investigate the gender specific roles of male carers / support staff and the positive impact they do and can have for men with an Intellectual Disability. The study is being conducted by Nathan Wilson and will form the basis for the degree of Doctor of Philosophy at the University Of Sydney under the supervision of Professor Trevor Parmenter and co-supervision of Dr Roger Stancliffe.

The research study will require the informal interviewing by Nathan Wilson of managers, support workers and families/parents based upon the attached participant information sheet. A second method of data collection will involve the direct observation of interactions between staff and clients (such as watching/talking about football) within the residential setting during set times; this would only be in non private areas. Your support and assistance would be required to assist with the dissemination of participant information sheets and the recruitment of care staff, managers and parents/families within your organisation. Due to the sensitive subject matter, it is possible some participants may have some unresolved psychological issues or feelings stirred as a result of taking part. Participants can withdraw from the study at any time, Psychologist support is available to any participant who requires support working through these potential unresolved issues. Nathan Wilson would like the opportunity to meet with you to discuss the research project further and work through any concerns you may have. Further, you are free to contact Professor Trevor Parmenter on (02) 8878 0500 to discuss any additional concerns or issues you may have. The research study has gained ethical approval from the University of Sydney Human Research Ethics Committee (HREC); if you have any specific concerns about the ethical implications of the study you can contact the Manager for ethics administration on (02) 9351 4811.

I look forward to your response and hope to be able to meet with you in the near future.

UNIVERSITY OF SYDNEY
HUMAN ETHICS COMMITTEE
APPROVED
DATE: 13-9-05

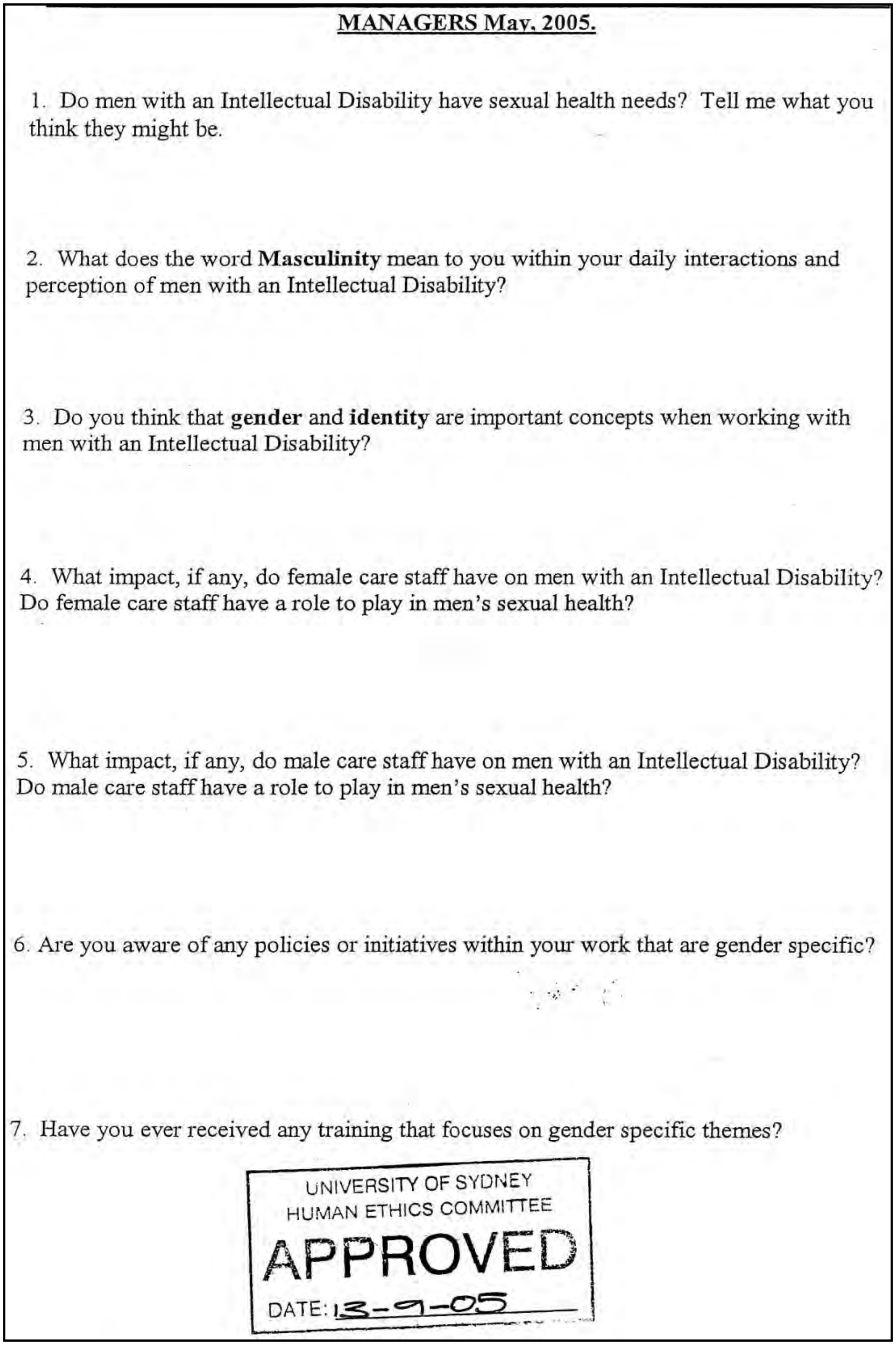
Nathan Wilson.
Dip Health Sc, BSocSc, MSc.

Royal Rehabilitation Centre Sydney: 59 Charles Street, Ryde PO Box 6, Ryde NSW 1680 Australia. Telephone (61 2) 8878 0500 Facsimile (61 2) 9807 7053 Website www.cdds.med.usyd.edu.au/ Email trevorp@med.usyd.edu

In partnership with: The University of Sydney • Macquarie University • The Spastic Centre of NSW • Royal Rehabilitation Centre Sydney • Disability Council of NSW

Appendix 5

INTERVIEW SCHEDULE



MANAGERS May, 2005.

1. Do men with an Intellectual Disability have sexual health needs? Tell me what you think they might be.

2. What does the word **Masculinity** mean to you within your daily interactions and perception of men with an Intellectual Disability?

3. Do you think that **gender** and **identity** are important concepts when working with men with an Intellectual Disability?

4. What impact, if any, do female care staff have on men with an Intellectual Disability? Do female care staff have a role to play in men's sexual health?

5. What impact, if any, do male care staff have on men with an Intellectual Disability? Do male care staff have a role to play in men's sexual health?

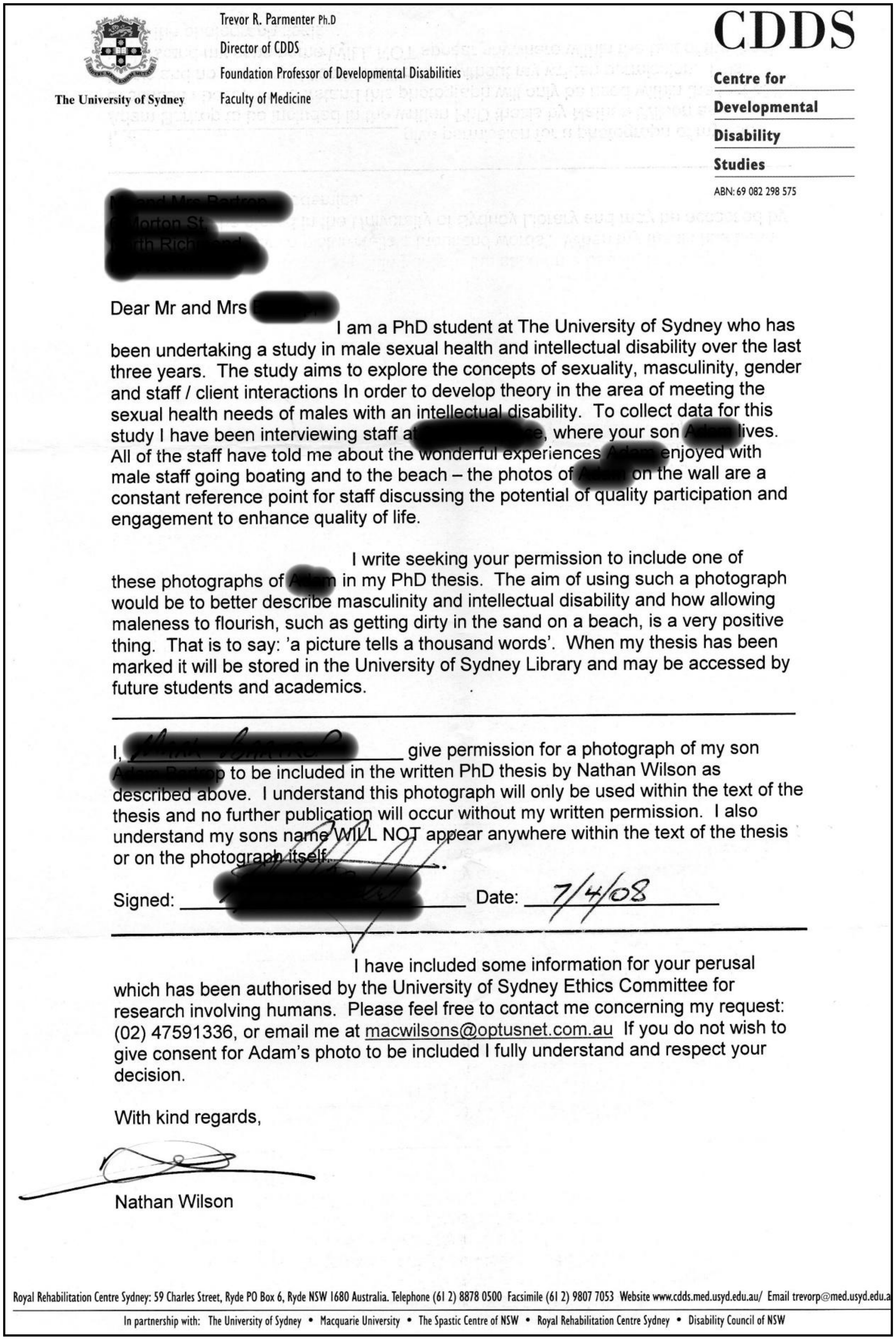
6. Are you aware of any policies or initiatives within your work that are gender specific?

7. Have you ever received any training that focuses on gender specific themes?

UNIVERSITY OF SYDNEY
HUMAN ETHICS COMMITTEE
APPROVED
DATE: 13-9-05

Appendix 6

ADDITIONAL CONSENT FOR PHOTOGRAPH



The University of Sydney
Trevor R. Parmenter Ph.D
Director of CDDS
Foundation Professor of Developmental Disabilities
Faculty of Medicine

CDDS
Centre for
Developmental
Disability
Studies
ABN: 69 082 298 575

[redacted]

Dear Mr and Mrs [redacted]

I am a PhD student at The University of Sydney who has been undertaking a study in male sexual health and intellectual disability over the last three years. The study aims to explore the concepts of sexuality, masculinity, gender and staff / client interactions In order to develop theory in the area of meeting the sexual health needs of males with an intellectual disability. To collect data for this study I have been interviewing staff a[redacted]e, where your son [redacted] lives. All of the staff have told me about the wonderful experiences [redacted] enjoyed with male staff going boating and to the beach – the photos of [redacted] on the wall are a constant reference point for staff discussing the potential of quality participation and engagement to enhance quality of life.

I write seeking your permission to include one of these photographs of [redacted] in my PhD thesis. The aim of using such a photograph would be to better describe masculinity and intellectual disability and how allowing maleness to flourish, such as getting dirty in the sand on a beach, is a very positive thing. That is to say: 'a picture tells a thousand words'. When my thesis has been marked it will be stored in the University of Sydney Library and may be accessed by future students and academics.

I, [redacted]________ give permission for a photograph of my son [redacted] to be included in the written PhD thesis by Nathan Wilson as described above. I understand this photograph will only be used within the text of the thesis and no further publication will occur without my written permission. I also understand my sons name WILL NOT appear anywhere within the text of the thesis or on the photograph itself.

Signed: [redacted] Date: 7/4/08

I have included some information for your perusal which has been authorised by the University of Sydney Ethics Committee for research involving humans. Please feel free to contact me concerning my request: (02) 47591336, or email me at macwilsons@optusnet.com.au If you do not wish to give consent for Adam's photo to be included I fully understand and respect your decision.

With kind regards,

Nathan Wilson

Royal Rehabilitation Centre Sydney: 59 Charles Street, Ryde PO Box 6, Ryde NSW 1680 Australia. Telephone (61 2) 8878 0500 Facsimile (61 2) 9807 7053 Website www.cdds.med.usyd.edu.au/ Email trevorp@med.usyd.edu.a
In partnership with: The University of Sydney • Macquarie University • The Spastic Centre of NSW • Royal Rehabilitation Centre Sydney • Disability Council of NSW

Appendix 7

Draft book chapter submitted for review

FROM ‘DIMINISHED MEN[1]’ TO ‘CONDITIONALLY MASCULINE’:

Toward a salutogenic construct of masculinity for men and adolescent boys with an intellectual disability.[2]

Nathan J. Wilson, M.Sc. [3]
PhD student, Centre for Developmental Disability Studies (CDDS), Faculty of Medicine, University of Sydney

Prof. Trevor R. Parmenter, PhD
CDDS, Faculty of Medicine, University of Sydney

Assoc. Prof. Roger J. Stancliffe, PhD
Disability studies, Faculty of Health Sciences, University of Sydney

Russell P. Shuttleworth, PhD
Lecturer in Sexual Health, Faculty of Health Sciences, University of Sydney

---

[1] Diminished men is a direct reference from a published article by McDonagh (2000)

[2] This chapter is based on the Doctoral Research of Nathan J Wilson which was partly funded by a University Postgraduate Award (UPA) in the Faculty of Medicine, University of Sydney, plus a small grant from the Blue Mountains Health Trust, NSW Australia.

[3] Corresponding author: CDDS, The University of Sydney, PO Box 6, Ryde, NSW 1680 Australia

INTRODUCTION

How do constructs of masculinity intersect with the lives of men and boys with an intellectual disability[4]? One barrier to answering this question may be the limited expressive and receptive repertoire of communication that is often intrinsic with intellectual disability. In the study which underpins this chapter, this barrier has been described thus: *"It's limited … a limited sphere of participation"*. The historical lack of legitimacy afforded to the views of people with an intellectual disability may present another barrier. It is also possible academics and policy-makers who are primarily concerned with improving the lives of people with an intellectual disability, have become somewhat insulated from the theoretical challenges offered by some mainstream[5] thinking, such as that offered in critical studies on men and masculinities. The preponderance of female carers in the lives of men and boys with an intellectual disability; described as a tacit and unique gender imbalance (Folkestad, 2004), may also be a contributing factor. Irrespective, the lives, experiences, challenges, citizenship, rights, and choices of men and boys with an intellectual disability are unique and therefore demand some scrutiny within the emerging speciality of critical studies on men and masculinities.

An ethnographic study was conducted with the intention of exploring sexual health for men and adolescent boys with a moderate to profound intellectual disability. Research themes included not only sexuality and sexual health, but also the influence of

---

[4] The use of the term „intellectual disability' is accepted terminology in Australia. Use of the term „men and adolescent boys with an intellectual disability' instead of the widely accepted „person with an intellectual disability' is used to not only provide greater clarity throughout the chapter, but also in recognition of unique sex differences.

[5] „Mainstream' refers to research, philosophy and policy outside the sphere of intellectual disabilities.

masculinities, and the gendered care environment. The aim was to construct[6] the sexual health needs of this population from a salutogenic, or strengths-based, position. While approximately 60% of all people with an intellectual disability are male (Australian Institute for Health and Welfare (AIHW), 2003), they do not represent an homogenous group. The study sought to explore the situation of one sub-group who were least able: men and adolescent boys with a moderate to profound intellectual disability residing in community-based group homes[7] and provided with 24-hour support by paid staff. Data included the perspectives of care staff, perspectives of male clients via participant observation, and review of key policy and staff training documents. Selected data from this study will be presented to illuminate some of the key conceptual issues to the lives of men and adolescent boys with an intellectual disability[8].

BACKGROUND

People with an intellectual disability have been defined by a variety of terms (Parmenter, 2001a, 2001b) which may have started off as taxonomic categories, or medico-legal terms to aid therapy, but often evolved into negative labels and/or derogatory slurs which implied an undesirable difference (Craig, Craig, Withers, Hatton, & Limb, 2002). These include, but are not limited to: cretin, moron, idiot, imbecile, feeble-minded, sub-normal, mental-defective, and retard. In addition to labels, historical imagery of people with an intellectual disability from freak shows reinforced mockery, difference,

---

[6] Use of the word „construct' does not imply a research or theoretical process derived solely from, or to, a social constructionist stance: „construct' simply means, for example, to build, create, or erect. However, any conceptual construction naturally incorporates the influence of social factors.

[7] This model of accommodation has been defined by Stancliffe and Keane (2000) as „… a household of 3 – 7 people with full time support (at least during waking hours) by paid staff from an accommodation support agency for people with a disability. There may be times on weekdays when all residents are away from the house attending their day programmes and no other staff are on duty. Night support may be provided by awake shift staff of sleepover staffing, or there may be no staff present when residents are asleep. Staff are present at all other times' (p. 284).

[8] The use of *italics* throughout the chapter represents direct quotes from care staff.

animalistic traits, sub-human characteristics, and defined some people with an intellectual disability as contemptuous specimens, or freaks (Bogdan, 1986). The advent of IQ scores which categorized mental age from the beginning of the 20th century saw the emergence of new categories of intellectual disability defined as mild, moderate, severe or profound (Kanner, 1964). More recently, the widespread use of the person first principle expresses for example “people with an intellectual disability”, or “person with mental retardation”.

Using the person first principle may have satisfied those seeking to move beyond labelling, stigma and in/competence, but such a focus still detracts from appreciating the heterogeneous nature of humanity; our unique differences. Klotz (2004) argues that embracing unique human differences allows socio-cultural meaning, interaction and intimacy to exist outside normative social practices and behaviours, a significant factor for those least able. The innate nature of sex (gender) differences is one vital part of humanness, however its exploration in the intellectual disability literature has been limited. For example, key conceptual issues in intellectual disability research range from social relationships, family issues, sexuality, quality of life, behavioural issues, mental health, and residential supports (Emerson, Hatton, Thompson, & Parmenter, 2004). Yet, the key variables used to explore these issues only occasionally extend to examining data as a function of sex-difference (Porter, Christian, & Poling, 2003). Failing to examine sex-difference represents a flaw in the literature limiting a deeper appreciation of human meaning, interaction and intimacy.

Male and female intellectually disabled stereotypes, which symbolically shape cultural understanding of this group, further limit understanding. For example, representations of intellectual disability in early- and mid-19th century literature portrays „diminished men' and „dangerous women' (McDonagh, 2000). Diminished men, or the diminished man, can be best characterised by Mr Dick in Charles Dickens' David Copperfield;

> „…Copperfield's aunt, looked after him and allowed him to carry change which he jingled impressively in his pocket, thereby passing in society as a man of some resources, but the coins he played with in his pocket were only a surrogate phallus ….. his illusory manhood rests in the hands of [his aunt]' (p.28).

The diminished man metaphorically reflects Edgerton's (1993) depiction of the „cloak of competence'; struggling to independently exist post-deinstitutionalisation without the generosity of a benefactor. The diminished man is partly humoured and partly supported into assuming a veneer of masculinity; constructed thus, their masculinity remains a chimera.

More recently however, a more pervasive and problematised stereotype has emerged. A pathological male discourse has been reified, not only by broader sexuality research and practice in the intellectual disability field (e.g. Cambridge & Mellan, 2000), but also by centralising other male pathologies, namely physical aggression (e.g. Thompson, Clare, & Brown, 1997) and challenging sexual behaviour (e.g. Wheeler & Jenkins, 2004). Furthermore, a feminist narrative which has focussed on the unique needs of women and girls with an intellectual disability (e.g., Hollomotz, 2006; McCarthy, 1999) has rightly sought the empowerment of women and girls but at the same time has problematised the oppressive male role, further reinforcing the pathological discourse. For example: „…the sexual abuse of people with intellectual disabilities is overwhelmingly a problem caused by men, as it is with all other victim groups' (McCarthy & Thompson, 1997, p. 112). Although it is known only some, not all, males display such pathological behaviour, the discourse unfortunately does other males a disservice.

Up to this point, four main ideas have been presented: the intersection of intellectual disability and masculinity is under-explored, negative labels and stereotypes have persisted, analysis of sex differences in the literature is limited, and, a problematised male discourse pervades. A narrative on masculinity and intellectual disability is proposed which extends beyond labelling, stigma, and the social pathologies which behaviourally reduce males to stereotypical maleness. This narrative however will vary from the narrative of other masculinities as the epistemological and ontological perspective of those without an intellectual disability will have influence over how it is constructed and communicated[9]. The emerging narrative should therefore be treated with caution, but should also be considered in the absence of any alternative. Critical studies on men and masculinities provides the first step.

CRITICAL STUDIES ON MEN AND MASCULINITIES

Social theories

Critical studies on men and masculinities have fostered new masculinities which have emerged from the critical analysis of gender undertaken by feminism over many decades (Connell, Hearn, & Kimmel, 2005). Different masculinities are uniquely constructed and hence have, for example, different needs, requirements, and desires:

> „The fact is not all men are alike, and various male groups face different conditions in the gender order. At any given historical moment, there are

---

[9] It is important to note this statement is made with reference to the population under study; males with milder intellectual disabilities will be able to better articulate their own narrative of masculinity. Furthermore, males with an autistic spectrum disorder or an acquired brain injury may experience masculinity differently again.

> competing masculinities – some dominant, some marginalised, and some stigmatised' (Sabo, 2005, p. 336).

However, different masculinities have usually been constructed through the lens of a socio-cultural perspective where a gendered power–oppression continuum, or hierarchy, is central. The notion of a hierarchy of masculinities emanated from the historical oppression of homosexual males by other non-homosexual males (Connell & Messerschmidt, 2005). Formulated by Connell (1995), the framework for understanding masculinities recognises configurations, or patterns, of practice between hegemonic, complicit, subordinate and marginalised masculinities. Importantly, Connell and Messerschmidt urge the interpretation of this framework not be based on a set of specific identities and/or role expectations but on patterns of things that are done, such as violence toward homosexual males. This approach emphasis gendered-power and gender-relations as the fulcrum to understanding, meaning and interpretation, and has been defined by Holter (2005) as the Direct Gender Hierarchy perspective.

It is likely that this perspective however does not resonate with the experience of men and boys with a moderate to profound intellectual disability where power and powerlessness is not wholly gendered. Their powerlessness comes more from their degree of cognitive impairment and limited opportunities for independent decision making. They often face restrictions as recipients of welfare, are reliant upon families and/or support staff, are relatively powerless within the disability service system, and exist within the controls of the dominant ideology of the day. Their masculinity through the lens of gendered-power is a „reliant masculinity'; the antonym of „hegemonic masculinity'. If hegemonic masculinity as Connell (1995) suggests, is the most dominant and desired masculinity constructed by the sum of „cultural ideal' and „institutional power,' then „reliant masculinity' is the sum of „cultural stigma' and „individual powerlessness'. Such a construction is both intolerable and perhaps unhelpful[10] but, against the theoretical parameters of gendered-power and gender-relations, it is one logical and hierarchical conclusion.

One problem of masculinity viewed through gendered-power is that it confirms the existence of a gendered hierarchy but does little toward explaining the context, causes, dynamics and possibilities for behaviour change; it is a static notion held together by sociocultural stereotypes (Holter, 2005). However, viewing masculinity as a wider system of meaning, which Holter has called the Structural Inequality Perspective, opens up other possibilities. It allows other masculinities to emerge which are not dependent upon power. Power is but one part of a wider framework; it helps provide meaning but is not **the** meaning. It is possible, although not certain[11], that room can be made for men and boys with an intellectual disability to have access to masculinity unencumbered by constructs of power or lack of power. The key difference in a structural inequality perspective is its view that male societal roles are responsible for gender discrimination, not men and masculinities. This argument allows for the social gradient to be better explored as a structural facet of society rather than the hegemonic aspect of power relations.

The two theoretical views which diverge at this point; either gender is seen within the context of power and patriarchy (direct gender hierarchy), or gender is seen as a

---

[10] It is both intolerable and unhelpful as such a construction emphasis a difference and powerlessness that is both negative and judgemental; reminiscent of notions of past stigma and derogatory slurs. That is, it reinforces powerlessness and progresses the intellectual debate toward a dead end.

[11] This equivocation is used in recognition of the dearth of empirical research exploring the intersection of masculinity and intellectual disability and the hitherto emergence of any considered theoretical ideas.

system of contextual meaning (structural inequality) are illustrated in Figure 1. Gender as contextual meaning is distinguished from patriarchy as a system of power (Holter, 2005).

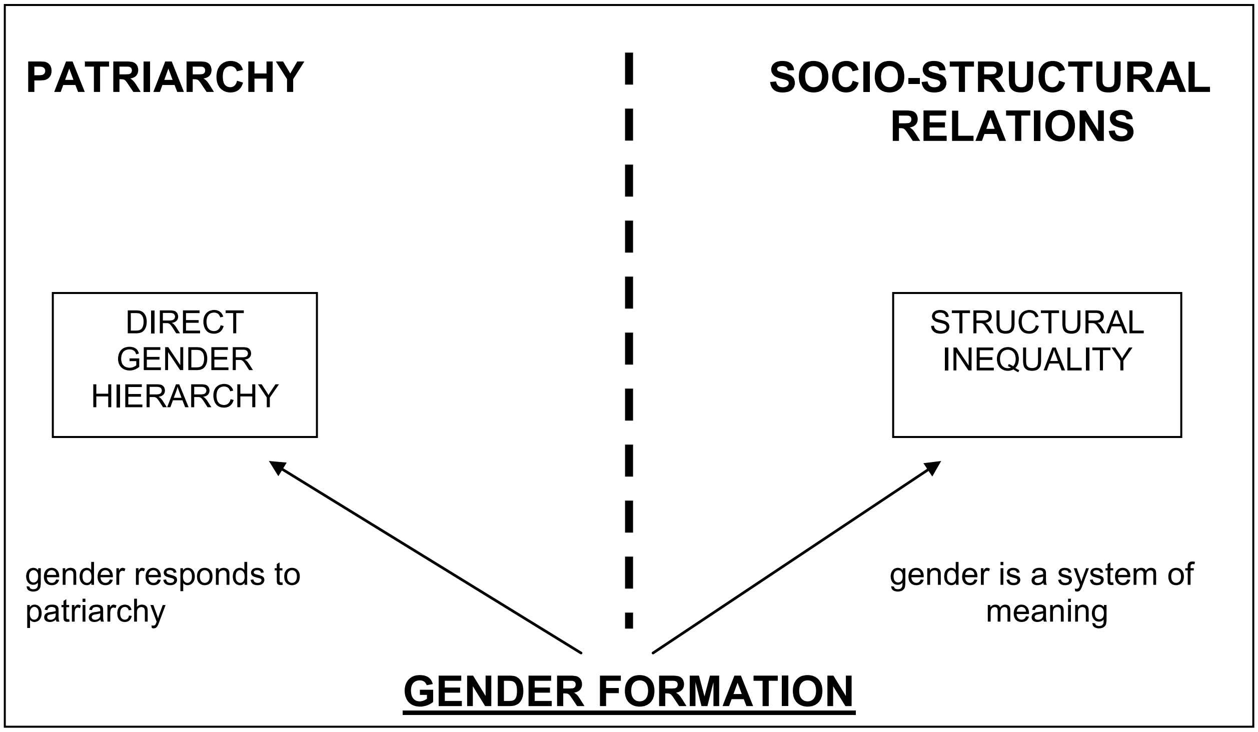


Figure1:
Two perspectives of gender formation, adapted from Holter (2005)

Shaping masculinities

Masculinities are also shaped, or constructed, by global, institutional, structural, practices, and political factors (Connell et al., 2005). Herein lay a further set of differences to the lives of men and boys with an intellectual disability. Globally, deinstitutionalisation[12] programs in Western countries represent a very significant change to the lives of many people with an intellectual disability. Edgerton's (1993) pioneering anthropological work in the 1960s explored the lives of former institution residents who faced the problem of denying their difference and having to pass as normal, for example:

---

[12] Deinstitutionalisation refers to government policy across North America, Europe, and Australia to close, or partly devolve, large-scale institutions for people with intellectual disabilities toward a move to more normative community-based residential supports (Stancliffe, Emerson, & Lakin, 2004).

> „Yeah, I was in there because of the robberies I was doing when I was a kid. Cops caught me, so I was sent up to that place. I was never supposed to be there with those mental patients. I was there because of those robberies, you know' (p.135).

Life in the community exposed a residents difference measured against normative masculine ideals: getting a job, finding a mate, managing material possessions, displaying interpersonal competence. Being released exposed the diminished man:

> „When you have been out of work so long and can't seem to get no job you really worry: is there something wrong with me or something? A man's got a right to work. Besides, you're better off when you're doing something. it puts your mind at ease, makes you feel like you're as good as everybody else' (p.138).

Likewise, due to the pressure to conform, people with physical disabilities may go to great lengths to appear more normatively masculine; changes may be induced for example by body building, tattoos, cosmetic surgery, or penile surgery (Gerschick, 2005). The body represents the male identity; hence a more normative body represents a more normative, and in turn positive, masculine identity (Robertson, 2007). The point of Gershick's argument is that bodies, and in turn masculinity, is both mutable and malleable. However, the experience of our bodies and masculinity is simultaneously a cognitive and physical experience. While work such as Gershick's and Robertson's have helped to understand how masculinity is embodied, there remains little understanding how degrees of less-normative cognition and masculinity interrelate and are experienced.

The diversity of less-normative cognition can be encapsulated by the image of the illusory manhood of the diminished man. This language describes the degrees of cognitive normativeness and, just as masculinities change over time and historical context, so too has this language. For example, where once cretin described characteristics, capacity and expectation in earlier centuries, profound intellectual disability does this in the modern world. Just as it is logical to discuss degrees of bodily normativity in critical studies of men and masculinities; it is also logical to discuss degrees of cognitive normativity. However, history reminds us how language can become a symbolic and stereotypical label so caution in the discussion of cognitive difference, which may lead to further derogatory labelling, must be exercised.

Another feature unique to men and boys with a moderate to profound intellectual disability is the influence of others in shaping, and reinforcing, a less-normative masculinity. McElduff and Beange (2003) highlight how the default position of pubertal failure, not reaching sexual maturity, in men and boys with an intellectual disability is to not treat with testosterone therapy, the opposite of the approach for males without an intellectual disability. The likely explanation for this position rests in a fear of stereotypical masculine expression; increased aggression supposedly related to testosterone therapy. Despite the adverse health consequences of hypogonadism, which men and boys with an intellectual disability experience at a greater rate than their non-disabled peers (McElduff, Center, & Beange, 2003), the diminished man remains. Conversely, a treatment option for some males with an intellectual disability who display sexually inappropriate behaviour can be anti-libidinal medication, or even orchidectomy (removal of the testes) (Carlson, Taylor, & Wilson, 2000; Carlson, Wilson, & Taylor, 1997). Again, masculinity is shaped to reinforce the diminished man; the asexual, manageable and safe image synonymous with low testosterone.

The mythological rise of testosterone as the antecedent for pathological maleness misses the point of the major health benefits testosterone for the male body. These include increased bone density, healthier body mass index (BMI), and normal male haemoglobin levels (McElduff & Beange, 2003; McElduff et al., 2003). Secondly, there is no direct correlation between testosterone and male behavioural pathologies (Clare, 2000; Pool, 1993, chap. 8). Clare argues despite the human body accommodating many other hormones, the focus on testosterone, as a uniquely sex-linked hormone, by „…those who most loudly trumpet its alleged causal role in aggression and dominance do so in support of an ideological position' (p.35). It is therefore unjust that some males with an intellectual disability are denied testosterone therapy with its clear health benefits. Effects such as penile growth, facial hair, sperm production, muscle bulk, and a deepened voice, the developmental epitome of normative maleness, are instead characterised as undesirable based on this pathological myth. This leads to the inevitable question of whether men and boys with an intellectual disability are excluded from experiencing a more normative masculinity.

CONDITIONALLY MASCULINE

Conditionally masculine is a concept which emerged from the ethnographic study described earlier. The concept was drawn from data gathered during interviews with group home care staff and participant observation in the group home; data were analysed using the constant comparative technique from the grounded theory method (Strauss & Corbin, 1998). It is neither the diminished man nor does it approximate a more normative masculinity. Conditionally masculine is less a purely social construction but more a biopsychosocial perspective; a perspective which appreciates the intrinsic disadvantage when capacity, function and communication is limited, as well as location on the social gradient. Importantly, it is an empirically based concept which contrasts from the stereotype of the diminished man and the theoretical basis of the hegemonic masculine ideal. Furthermore, conditionally masculine does not represent the „other' as described by Shakespeare (1994); a reminder of the vulnerability of disability, a threat to normative bodily and cognitive masculine invincibility. The following quote from one of the care staff illuminates how conditionally masculine as a concept started to evolve:

> *"I see both of them as young men … they're adults … but I also see them as their child-side… because they're not … in their brains they haven't formed to an adult … they can still do the things that a grown man could do but their capacity in their brains, when they talk to you, are as children"*.

It is also a construct which appreciates the structural inequality described by Holter (2005). That is, it appreciates the structural inequality of masculinity being conditional upon the interpretation of masculinity by those providing the support; communicated and experienced by dress, grooming, hygiene, choice, activity, relaxation, health, socialisation and so on. Conditionally masculine reflects the perspective of staff who work in the community group home; their gender, skills, communication, training, and values. It is also a reproduction of organisational culture, the philosophy of participation, integration, choice, and inclusion, as well as imitating the geography and architecture of that care and support. Figure 2 illustrates the construction of conditionally masculine as described by the data. Explicit within this construction is the role of a gendered care environment as a unique feature of the structural inequality people reliant on 24-hour support face: female staff are *"…a bit more motherly with clients compared with male staff … females are softer in their approach"*. Female staff typically outnumber male staff in the care sector, a feature supported by this study; numbers of female staff in the disability sector have been reported as high as 95% of the total (McConky, McAuley, Simpson, & Collins, 2007).

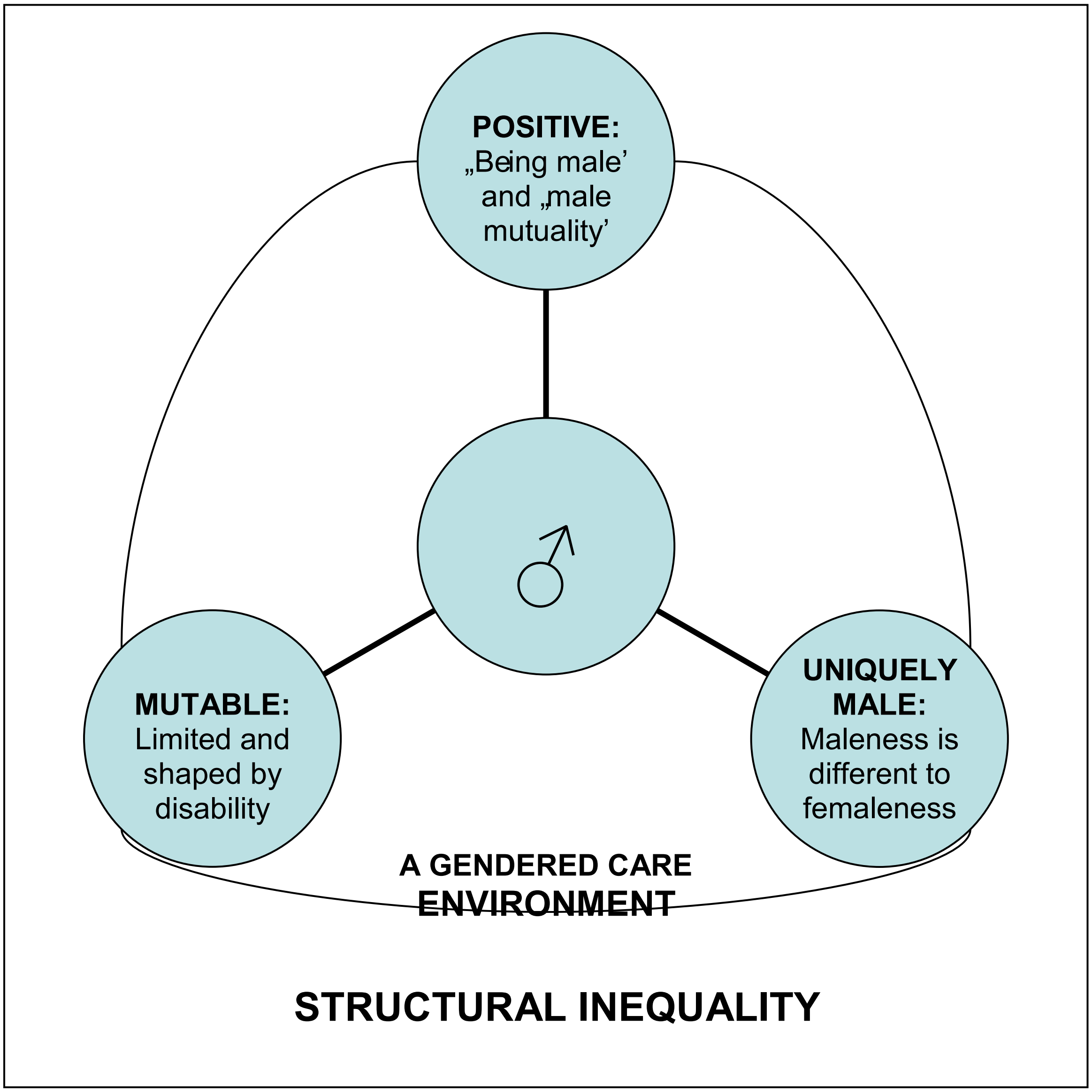


Figure 2:
The construction of conditionally masculine

A positive construct

Positive masculinity was described by care staff as two broad themes: a combination of the intrinsic qualities of being male plus the importance of male mutuality. Being male included doing, expressing, and feeling maleness; it included expressing femaleness; looking male was important; as was having positive male role models. Maleness is expressed by a rougher, more physical, more active disposition; femaleness by a softer, gentler, temperament; yet both formed a part of being male. That is, an implicit male physical drive of energy that needs to be expressed: *"… a young energetic boy who likes to run around and I like to give him the freedom to do what he likes [express that energy] … he will tell you he wants to run around as he might start to push chairs over"*.

Maleness sounds and acts differently; it is assembled from pride, appearance, sport, strength, and dominance. One example from the data was a young man whom strove to be active, despite his limited mobility, by rambling about the house on all fours unaided by staff; care staff defined part of his maleness via male strength because he would regularly topple over and get straight back up without showing any pain or distress. Box 1 represents an excerpt from field notes which illustrate the physicality of conditionally male.

Box 1
The release of male energy

Once out of his chair Client C ran around on all fours up and down the corridor, into his room, climbing all over the bed and bean bags in his room, banging on the lounge room door where one of the female client's family were visiting. Very energetic stuff. At one point he stood erect by leaning back on the table and banged his chest and grunted just like Tarzan in the movies; one of the care staff called it his silverback gorilla routine. Great description and one that appears valid. He started to annoy a second female client by throwing her toys away and so on. He also climbed over the female staff wanting hugs for comfort as well as a „physical' joust. Laughing all the time.

Another male client loved to rollerblade and kick a soccer ball around the yard but with full staff support due to a significant visual impairment; care staff described part of his maleness through supported sport and physicality. While sport was articulated as one way to do maleness, it was not a metaphor for the way normative male bodies are often commoditised in mass media to promote the „vast merchandise of manliness' (Segal, 2007). Being male through sport were constructed not through a dichotomy of physical (maleness) / not physical (femaleness), but more via a continuum of physicality; being male operated anywhere on the continuum. In contrast to hegemonic exemplars such as the male sporting hero, the different possibilities for physicality were not defined hierarchically; they were positively constructed individually with incorporated supports.

Male mutuality was described by the data as a combination of male warmth, banter, and belonging; the positive construct was built from the presence of other males. Care staff suggested males offer a different kind of interaction than females; a part of being accepted as *"… one of the boys"*. One example given by a female staff member was the discussion of sexual exploits between males; a discussion not tarnished by smut but a part of normative male development. The female staff member did not really want to hear about such exploits from male clients which she felt was a discussion better had between males. Several of the care staff referred to the visible excitement some male clients expressed when a male staff member came on shift. This excitement was described as a combination of mutual male warmth and a shared understanding of maleness. All of the care staff asserted the positive notion that males promote maleness; the presence of male staff had a positive impact upon some male clients: *"… when [male staff member] comes in he gets excited, you know another male around …. [male staff will] interact with him …. men sort of bond and protect each other"*. This finding has been reported in other research: McConky et al. (2007) found some male clients in their study „…expressed a wish to have men as support staff and they reportedly responded better to them' (p.190). One younger male client reportedly *"… blossomed"* from the 1:1 support he received from a male staff member over a period of time. Their relationship was described by an older female staff member as *"…a beautiful male bond"*.

A mutable construct

Mutable masculinity recognised that masculinity was both shaped and limited by the effect of intellectual disability on function and capacity. That is, disability as a disadvantage to doing maleness: *"… [He] is not less of a male … I don't know how, I just think it's more difficult for him to express [masculinity] … there is something less going on in that area [masculinity]"*. The greater the physical dependency on others the harder it is to express maleness; physicality, energy, power, strength, independence. However, while disability was a disadvantage to expressing maleness, maleness was still possible. For example, care staff compared two adolescent male clients who shared a house, one far more able than the other. Both liked to masturbate regularly (some female care staff felt masturbation was more common in males than females), yet due to an additional physical disability one male client only had access to his penis during nappy changes and bath time. The physical act of masturbation for this male was conditional upon care staff not only providing access, but also conditional upon access for a duration greater than a routine nappy change. Care staff acknowledged the sexual health needs of both clients were normatively male, but the personal context was limited by disability and shaped by the interpretation of the carer.

Care staff who worked with a man with Down syndrome also perceived his masculinity as being additionally shaped by his syndrome; short stature and an affectionate and cuddly *"… Downs"* (sic) disposition. This man was described as a *"…soft and gentle person"* as a consequence of Down syndrome. That is, he was perceived as being less masculine because of his syndrome and its attributed traits; traits such as actively seeking cuddles and related intimacy was expressing femaleness as a way to do maleness. One staff member stated *"… I don't see him [male client with Down syndrome] as being as that much of an issue [masculinity] with him as it is with some of the younger clients … and older ones who are more able to [develop a] rapport with me, and to do things together … because of the Down syndrome, I don't see him as masculine, to tell you the truth, as other [male] clients"*. The notion of a syndrome shaping masculinity points to another potential area of development in studies on men and masculinities. For example, exploring any links between so-called syndrome specific traits to hypogonadism and low testosterone levels, which is very common in males with Down syndrome (McElduff et al., 2003). There are possible correlations here, albeit hypothetical, between the preferential myths suggesting lower testosterone equates to a more manageable and controlled maleness.

A uniquely male construct

Maleness was defined by participants as uniquely different to femaleness. In addition to the physicality of maleness already described, interactions between care staff and male clients were described as rougher than they are between care staff and female clients; „…rough but gentle at the same time'. One participant described being gentler with a particular male client, who was relatively frail compared with other male clients, but still not as gentle as she was with female clients: *"… I don't think I'd respond to [client B]* *in nearly the same way as I would with [client C] because [client C] is so much more boisterous … but I'd adopt a more gentle tone when I'm talking to a female [client]"*. That is, greater levels of disability reflected a softer, or more feminine, approach to the interaction. Stimulating oneself sexually was also defined as being a predominantly male activity. For example, according to one female staff member, more private time should be afforded as males mature: *"They're getting older ... they're different to the females and they have different needs, like the independent time [to masturbate] that the girls don't necessarily need … these young men are … getting to an age when it does need to be addressed". Interviewer: "So, is masturbation more of a male thing?" "Yes, men think about sex more often, women think about sex when they have to but men think about sex a lot more"*. Significantly, one male staff member felt masturbation for males *"…was more a sensory and normal thing so some females should just try not to read into it"*.

Gendered care environment

Participants described a gendered care environment where maleness and femaleness interacted with each other within defined characteristics of the feminine carer and masculine carer. A feminine perspective was firmly based in representations of mothering: gentle, loving, nurturing, soft, and being motherly. That is, the role of the feminine carer was performed through constructs of mothering. One female participant described *"…as parents yourself, and you are, sort of, in that caring [motherly] role, looking after kids"*. Data showed how mothering was an easier practice to assume the more disabled a person was; in turn mothering was more conducive to lesser states of masculinity. The practice of mothering supported the diminished man. The diminished man does not resist femaleness; he is compliant to dressing, grooming, activities, routine; he does not argue for maleness.

Mothering also had another side where the desire to control, and organise male clients potentially limited maleness. Mothering also reflected different values toward the interactions between male and female clients. Research exploring the concept of love between young males and females with an intellectual disability echoed these findings where female staff were perceived as more controlling and limiting the sorts of permissible interactions between clients at discos (Löfgren-Mårtenson, 2004). This sense of worrying about interactions, practised by control and boundaries, was illustrated by an example of a male client who was intimately fussed over by two female clients. The two female clients would regularly compete to shower him with kisses and affection which he reportedly tolerated up to a point, when he could take no more he often required support from staff to fend off the unwanted interest. When participants were asked hypothetically what they would do if two male clients showed the same interest in a single female client, the suggested response was, comparatively, aversive. This included suggested measures such as separation, reactive and proactive behaviour intervention plans, and counselling. The single male client was deemed lucky to warrant such feminine interest, a hypothetical single female client in the same situation deemed vulnerable to overt male interest.

The masculine carer was based in representations of physicality: supporting clients with swimming and other sports, going on outings, managing and responding to aggressive behaviour, and exhibiting a rougher style of interaction (a style compared as a unique and required balance to motherly affection). Female participants gave some examples of activities they would neither initiate nor enthusiastically volunteer for such as kicking a soccer ball around the garden with a young male client who was also visually impaired and required support with physical activities. This group home was staffed wholly by females: *"we've had male staff coming out and kick the ball around outside with [him] which is something that we could do, but being girls we don't do that, because it's socially not acceptable for us to do that"*. The absence of a masculine carer for this male client was limiting possibilities for physical activity which inadvertently meant male physicality may have been otherwise expressed in more behaviourally challenging ways.

The masculine carer also held more relaxed attitudes toward male clients, in particular toward masculine sexual expression. For example, a male staff member was reported to have a more relaxed attitude toward a male client masturbating in his room whenever he chose; participants believed under such a relaxed approach, the male client displayed far fewer challenging behaviours during the shift. In contrast, female staff communicated they felt threatened by this male client's physicality and managed this by a more restriction of access to masturbation which often resulted in an increase in behavioural incidents. This same theme was also identified by Löfgren-Mårtenson (2004); male staff were perceived as being easy going with physical intimacy and allowed the progression of intimacy to go further than female staff would permit.

What does all this mean?

The concept of conditionally masculine is a representation for some males with an intellectual disability where access to masculinity can be conditional upon a number of factors. On a broader level, these data have supported some of the accepted wider themes in critical studies of men and masculinities. These are that there is no single masculinity, but masculinity-ies; that masculinity is a changeable construct geographically, culturally and historically; and that masculinity is embodied (Adams & Savran, 2002; Connell, 1995; Connell & Messerschmidt, 2005; Gerschick, 2005). Significantly, data has been presented which illuminates how degrees of cognition can contribute to changes in masculinity. It is in these data the construct of conditionally masculine starts to emerge; the notion that masculinity is not only conditional upon cognition but also the role of surrogates in performing conditionally masculine.

Conditionally masculine recognises the limitations of disability upon expressing maleness but not upon being male. It allows for an underlying unique difference between males and females and that masculinity operates more on a conditional continuum. Furthermore, conditionally masculine was open to the interpretation by care staff of masculinity which also shaped the practice and expression of maleness. This interpretation is influenced primarily by issues of gender, but not purely a gendered hierarchy, with unique feminine and masculine perspectives at play. However, problems remain with the construct of conditionally masculine, mainly in the gendered care environment. While the gendered environment is not male unfriendly, it is certainly not male friendly. The environment errs more toward a feminised environment where the diminished man belongs as opposed to a masculine environment where masculine physicality and interaction is valued.

A SALUTOGENIC CONSTRUCT

An environment where conditionally masculine may progress toward a more wholly valued notion is required. Such an environment has been described by mainstream health writers as a salutogenic construct (Macdonald, 1998, 2005; Macdonald, McDermott, Woods, Brown, & Sliwka, 2000) which asks: what are the factors which create health and well-being? (Kickbusch, 1996). It suggests a focus away from oppositional dichotomies such as health / ill-health, risk / no risk, masculine / un-masculine, by accepting as humans we are all inherently flawed (Antonovsky, 1996). Applied to masculinity and a masculine environment it argues for seeing „…what is positive and life-enhancing in male characteristics and behaviour and to applaud and foster the positive elements' (Macdonald, 1998, p. 261).

That is, while male health has been described through the lens of socio-culturally constructed masculinity (Robertson, 2007; Schofield, Connell, Walker, Wood, & Butland, 2000) the notion of masculinity being viewed through the lens of a salutogenic model for health is potentially contentious. Salutogenic masculinity is less about social issues of access to normative masculinity than a biopsychosocial construct of access which recognises masculinity outside of normative social practices and behaviours. It directly acknowledges a power imbalance different from gendered power as described by gender hierarchy perspectives (Holter, 2005). It takes on board the social gradient, the intrinsic disadvantage of impairment, and the mutable nature of masculinity, and recognises an individualised construct of masculinity that may, at times, be conditional but equally as vital as any normative or hegemonic ideal.

An example from the data of a salutogenic construct was found in a wall of photos inside one of the group homes. Two adolescent male clients had recently been on a holiday to the seaside with paid male staff support. These two male clients had intellectual and physically disabilities, limited communication skills, were totally dependent on staff for care and support, and experienced multiple health problems. Photographs of the male clients rolling in and covered head to foot in sand, playing in the shore breaks, and enjoying a boat trip were described by all participants as an example of *being male* forged by a unique understanding of male mutuality. It was a salutogenic, life-enhancing, risk-taking, masculine and healthy exchange for the controlled confines of the diminished man and conditionally masculine. What stood out perhaps most of all in the photographs were the facial expressions of sheer joy. Participants highlighted these prominent photographs as evidence of a possible masculinity uninhibited by notions of gendered power or normative comparison.

CONCLUSIONS

This chapter has highlighted that the intersection of intellectual disability and masculinity represents a gap in critical studies on men and masculinities. Data from an emerging ethnographic research project has been presented to initiate analysis of this intersection. To contextualise the data, historical background was provided to better describe how the lives of people with an intellectual disability can differ greatly from the lives of those without such disability. A brief overview of social theories has been offered to position males with an intellectual disability into the narrative of social theories of masculinity. It was proposed that a perspective based upon gendered power is not as relevant as one based upon structural inequality.

The argument presented has moved from stigmatising historical labels toward the stereotypical and dominant notion of the diminished man. It has been argued the diminished man remains a state that can be deliberately shaped from a more vibrant masculinity. The notion of conditionally masculine, as described by care staff, was introduced to acknowledge the disadvantage intrinsic to significant levels of intellectual disability. That is, their disability was not valued, nor was it devalued; their cognitive impairment was simply an intrinsic part of who they are. Their disability was viewed in the same way their maleness was understood; unique and NOT framed against normative ideals. Conditionally masculine is not a dichotomous proposition, it is a recognition of masculinity on a continuum. This chapter has acknowledged the restriction which arises from a gendered care environment. Finally we proposed a salutogenic framework as the starting point for a masculinity not dependent upon power and/or normative comparison; a construct that recognises masculinity in its many varied and conditional, but vibrant, life-enhancing guises.

There are some significant limitations with the research reported in this chapter along with limitations in the theoretical development to critical studies on men and masculinities offered. The research project only concerned males with a moderate to profound intellectual disability residing in 24-hour staffed group homes. Therefore, the data cannot be generalised to all males with an intellectual disability. For example, many males with an intellectual disability live with their parents or other non-paid carers in the family home. Furthermore, these data do not reflect the lives of males with a borderline to mild intellectual disability who will usually experience a more independent lifestyle and may relate more to constructs of gendered hierarchy.

This group of men have hitherto not been acknowledged by the field of critical studies on men and masculinities and therefore our ideas are emerging like the field itself. In addition, it is acknowledged the notion of conditionally masculine may affront some readers who are firmly opposed to a theoretical focus on impairment that recognises that this difference carries with it disadvantages in human functioning, a notion attributed to the so-called medical model of disability. Even so, this chapter has presented some new ideas which deserve a balanced critique.

REFERENCES

Adams, R., & Savran, D. (2002). Introduction. In R. Adams & D. Savran (Eds.), *The masculinity studies reader* (pp. 1-8). Malden, MA: Blackwell Publishers.

Antonovsky, A. (1996). The salutogenic model as a theory to guide health promotion. *Health Promotion International, 11*(1), 11-18.

Australian Institute for Health and Welfare (AIHW). (2003). Disability prevalence and trends, disability series. AIHW cat. No. DIS 34: Canberra: AIHW.

Bogdan, R. (1986). Exhibiting mentally retarded people for amusement and profit, 1850-1940. *American Journal of Mental Deficiency, 91*(2), 120-126.

Cambridge, P., & Mellan, B. (2000). Reconstructing the sexuality of men with learning disabilities: Empirical evidence and theoretical interpretations of need. *Disability and Society, 15*(2), 293-311.

Carlson, G., Taylor, M., & Wilson, J. (2000). Sterilisation, drugs which suppress sexual drive and young men who have intellectual disability. *Journal of Intellectual and Developmental Disability, 25*(2), 91-104.

Carlson, G., Wilson, J., & Taylor, M. (1997). Fertility control in young men who have intellectual disability. In Australasian Men's Health Forum (Ed.), *The Second National Men's Health Conference* (pp. 71-85). Fremantle, Western Australia: Australasian Men's Health Forum.

Clare, A. (2000). *On men and masculinity in crisis*. London: Arrow Books.

Connell, R. W. (1995). *Masculinities*. Sydney: Allen and Unwin.

Connell, R. W., Hearn, J., & Kimmel, M. S. (2005). Introduction. In M. S. Kimmel, J. Hearn & R. W. Connell (Eds.), *Handbook of studies on men and masculinities*. London: Sage.

Connell, R. W., & Messerschmidt, J. W. (2005). Hegemonic masculinity: Rethinking the concept. *Gender and Society, 19*(6), 829-859.

Craig, J., Craig, F., Withers, P., Hatton, C., & Limb, K. (2002). Identity conflict in people with intellectual disabilities: What role do service-providers play in mediating stigma? *Journal of Applied Research in Intellectual Disabilities, 15*, 61-72.

Edgerton, R. B. (1993). *The cloak of competence: Revised and updated*. California: University of California Press.

Emerson, E., Hatton, C., Thompson, T., & Parmenter, T. R. (Eds.). (2004). *The international handbook of applied research in intellectual disabilities*. West Sussex, UK: John Wiley and Sons.

Folkestad, H. (2004). Surrounded by women: Men in care, *paper presented at the 12th World Congress of IASSID*. Montpellier, France.

Gerschick, T. J. (2005). Masculinity and degrees of bodily normativity in western culture. In M. S. Kimmel, J. Hearn & R. W. Connell (Eds.), *Handbook of studies on men and masculinities* (pp. 367-378). London: Sage.

Hollomotz, A. (2006). *The social creation of vulnerability to sexual violence of people with learning difficulties: An application of feminist theory.* Unpublished masters dissertation, The University of Leeds, Leeds.

Holter, O. G. (2005). Social theories for researching men and masculinities. In M.S.Kimmel, J.Hearn & R.W.Connell. (Eds.), *Handbook of studies on men and masculinities* (pp. 15-34). London: Sage.

Kanner, L. (1964). *A history of the care and study of the mentally retarded*. Illinois: Charles C. Thomas Publisher.

Kickbusch, I. (1996). Tribute to Aaron Antonovsky - 'what creates health'. *Health Promotion International, 11*(1), 5-6.

Klotz, J. (2004). Sociocultural study of intellectual disability: Moving beyond labelling and social constructionist perspectives. *British Journal of Learning Disabilities, 32*, 93-104.

Löfgren-Mårtenson, L. (2004). "May I?" About sexuality and love in the new generation with intellectual disabilities. *Sexuality and Disability, 22*(3), 197-207.

Macdonald, J. J. (1998). *A salutogenic approach to men's health.* Paper presented at the 2nd national men's health conference, Fremantle: Western Australia.

Macdonald, J. J. (2005). *Environments for health: A salutogenic approach*. London: Earthscan.

Macdonald, J. J., McDermott, D., Woods, M., Brown, A., & Sliwka, G. (2000). A salutogenic approach to men's health: Challenging the stereotypes, *Paper presented at the 12th Australian National Health Promotion Conference*. Melbourne: Victoria.

McCarthy, M. (1999). *Sexuality and women with learning disabilities*. London: Jessica Kingsley.

McCarthy, M., & Thompson, D. (1997). A prevalence study of sexual abuse of adults with intellectual disabilities referred for sex education. *Journal of Applied Research in Intellectual Disabilities, 10*(2), 105-124.

McConky, R., McAuley, P., Simpson, L., & Collins, S. (2007). The male workforce in intellectual disability services. *Journal of Policy and Practice in Intellectual Disabilities, 4*(3), 186-193.

McDonagh, P. (2000). Diminished men and dangerous women: Representations of gender and learning disability in early and mid-nineteenth-century Britain. *British Journal of Learning Disabilities, 28*, 49-53.

McElduff, A., & Beange, H. (2003). Men's health and well-being: Testosterone deficiency. *Journal of Intellectual and Developmental Disability, 28*(2), 211-213.

McElduff, A., Center, J., & Beange, H. (2003). Hypogonadism in men with intellectual disabilities: A population study. *Journal of Intellectual and Developmental Disability, 28*(2), 163-170.

Parmenter, T. R. (2001a). The contribution of science in facilitating the inclusion of people with intellectual disability into the community. *Journal of Intellectual Disability Research, 45*(3), 183-193.

Parmenter, T. R. (2001b). Intellectual disabilities - Quo Vadis? In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 267-296). London: Sage.

Pool, R. (1993). *The new sexual revolution*. London: Hodder and Stoughton.

Porter, C. L., Christian, L., & Poling, A. (2003). Research brief: Some data concerning the reporting of participants gender in the mental retardation literature. *Mental Retardation, 41*(2), 75-77.

Robertson, S. (2007). *Understanding men and health: Masculinities, identity and well-being*. Berkshire: Open University Press.

Sabo, D. (2005). The study of masculinities and men’s health, an overview. In M.S.Kimmel, J.Hearn & R.W.Connell (Eds.), *Handbook of studies on men and masculinities* (pp. 326-352). London: Sage.

Schofield, T., Connell, R. W., Walker, L., Wood, J. F., & Butland, D. L. (2000). Understanding men's health and illness: A gender-relations approach to policy, research, and practice. *Journal of American College Health, 48*(6), 247-256.

Segal, L. (2007). *Slow motion: Changing masculinities, changing men* (3rd ed.). New York: Palgrave Macmillan.

Shakespeare, T. (1994). Cultural representation of disabled people: Dustbins for disavowal? *Disability and Society, 9*(3), 283-299.

Stancliffe, R. J., Emerson, E., & Lakin, C. K. (2004). Residential supports. In E. Emerson, C. Hatton, T. Thompson & T. R. Parmenter (Eds.), *The international handbook of applied research in intellectual disabilities* (pp. 459-478). West Sussex: John Wiley & sons Ltd.

Stancliffe, R. J., & Keane, S. (2000). Outcomes and costs of community living: A matched comparison of group homes and semi-independent living. *Journal of Intellectual and Developmental Disability, 25*(4), 281-305.

Strauss, A., & Corbin, J. (1998). Grounded theory methodology: An overview. In N. K. Denzin & Y. S. Lincoln (Eds.), *Strategies of qualitative enquiry* (pp. 158-183). London: Sage.

Thompson, D., Clare, I., & Brown, H. (1997). Not such an ordinary relationship: The role of women support staff in relation to men with learning disabilities who have difficult sexual behaviour. *Disability and Society, 12*(4), 573-592.

Wheeler, P., & Jenkins, R. (2004). The management of challenging sexual behaviour. *Learning Disability Practice, 7*(5), 28-37.

Appendix 8

TABULAR EXAMPLE OF CODING FRAMEWORK

Table App.1 *Male staff in the care setting*

the data	open code	axial code	selective code
Male staff will do physical activities, Swimming, physical stuff, outings, running around.	Physical maleness	**MALENESS DIFFERENT TO FEMALENESS**	**THE MASCULINE CARER**
Being a man is another world, Males more relaxed than females, Males change their behaviour around certain females to avoid scrutiny, Men need to chat and let off steam without fear of political correctness,	unique maleness		
Female client wants a boyfriend therefore males should not work nights, All of us worry about male staff working alone with female client, Scrutiny of male staff by female peers, male staff less likely to give cuddles.	Maleness as a risk		
Male staff good at supporting with challenging behaviours, Better to have males around in case sex comes up, Male staff to help with male appointments, More attention to male genital hygiene, Good role models	Positive qualities as a carer	**MALES AS CARERS**	
Not good with housework; lazy, Males not interested in domestic side of the job, Good at taking out but not good at the housework	Negative qualities as a carer		
Care work not highly paid; you cant support a family on it, Males are in the job short term before moving on to professional roles,	Attributes of a carer		

Political correctness and feminism has scared a lot of males away from care work, A lot of male staff are gay; socially feminine, Care work a female job. - not macho.			
A allowed to masturbate in his room whenever he wants; negative behaviours are less, A enjoys the extra time in the bath he gets from male staff, TD will only kick a ball with male staff, Male staff make him feel like a man, Male staff more understanding of male sexual needs, More relaxed and easygoing, Rough but gentle at the same time, More likely to speak up on behalf of male sexual needs, Males understand the importance of masturbation to males, Males provide better supervision when masturbating, Male needs more likely to be met in all male house, Male clients need the different male stimulation – touch, feel smell. More tolerant to male sexual discussion	Males promoting maleness	**MALES AS A CONDUIT TO MALE-WELL BEING**	
A has blossomed with the support of male staff, A and J have a beautiful male bond, Male staff improve D's mood, Younger male staff good for younger male client – look on his face, he gets excited, Males are rougher which they respond to well.	Results of promoting maleness		